

## Dementia

In Issue 9 of 'Generation' we looked at dementia: the different types, increasing awareness, implications for sufferers and some of the practical issues for carers. In this issue we will look more closely at diagnosis and, to the extent it exists, treatment.

### Diagnosis

Unfortunately there is no single test for the diagnosis of dementia. A memory test alone is insufficient and the cognitive tests available, more often than not, lead to high false positive rates. A brain scan is also not sufficient and in practice a diagnosis can only be made after combining a medical assessment, cognitive tests and a careful history of the patient. A full medical examination and blood testing will also be required to rule out or identify underlying illnesses. Questioning the person about recent events, their past memories and investigating their thinking skills is a further diagnostic method available, along with talking with family members to identify clues as to changes in the patient's health over time. Fundamentally it takes time to confirm a dementia diagnosis once symptoms begin to be recognised and even here this will vary depending on the attitudes of the person with dementia and his or her family. Barriers to early diagnosis from both the patient

and care perspective have commonly been identified as:

- lack of knowledge about the closeness of dementia symptoms to ageing
- gradual manifestation and inability to treat problems
- fear and denial of the disease and its implications
- lack of trust in the health system, and
- lack of support from family, friends and professionals.

Diagnosis is further complicated by the fact that different forms of dementia have different symptom profiles. In Alzheimer's disease (AD), the most common form of dementia, the development of symptoms are broadly as the result of abnormal proteins which interfere with the patient's brain cells, ability to communicate and ultimately cause brain cell death. It is likely that these changes are present in the brain

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many years before the onset of any symptoms. Finding biological tests that identify these changes has been the focus of much current research effort. Other forms of dementia have different mechanisms of destroying the communications between cells and as a result the onset of symptoms and their manifestation is different.

### Treatment

Drug therapy cannot cure AD. None deal with the fundamental pathological processes involved although they can slow the effects. Currently there are five drugs available, although they fall into two classes, Acetylcholinesterase, Inhibitors (ACIs) and N-Methyl-D-Aspartate (NMDA) receptor antagonist. These are however supportive and palliative therapies rather than a cure or disease modifying treatments. There is little to offer medically for dementias other than AD although dementia with lewy bodies (DLB) can respond well to ACIs.

Sadly no new treatments have become available to treat AD or any other form of dementia for more than a decade and although some progress has been made in neuro imaging, genetics and blood testing, they remain some way from having clinical utility.



## Improving Wellbeing through Care at Home\*

There are almost 15 million people over 60 in the UK, a number which is expected to rise to 20 million by 2030<sup>1</sup>, and of these, 426,000 are currently in residential care<sup>2</sup>, the majority of which are suffering with a form of dementia. But this represents less than half of all people suffering with the illness. In autumn 2014, The Alzheimer's Society released a report showing that there are more than 800,000 people in the UK living with dementia<sup>3</sup>, a figure which is expected to grow to over one million by 2025 and over two million by 2051.

Behavioural challenges, such as agitation, aggression and psychosis are common in people suffering with dementia; up to 90% of all people living with the condition experience difficult behaviour patterns at some point, and are seen as indicating unmet needs. But despite this, these behavioural challenges are frequently a precursor to hospitalisation and admission to a care home.

Despite large residential care home populations, research confirms a huge majority, 97%, of older people would prefer to stay at home rather than moving into residential care<sup>4</sup>.

A move into a care home is too often not through choice, but rather forced by circumstance, often leading to feelings of loneliness and insignificance, or even to a more severe emotional state described as 'move trauma'.

Recent studies and evidence of care for older people, (including those with dementia and examining the case for live-in care as opposed to residential care in a care home) have revealed the significant positive impact that person-centred home care can have on health outcomes and increased independence with activities of daily living compared to those in care homes.

One of the most comprehensive pieces of research<sup>5</sup> into this area considered a cross-sectional study of people with dementia, comparing those who were cared for at home with those in a care home, and reviewed a number of



indicators for quality of life including social content and physical functioning. The key findings of the study suggested that older adults with mild dementia living at home and maintaining contact with the community, rather than in a nursing home, experienced:

- improved quality of life and wellbeing
- greater social connection
- higher levels of happiness and satisfaction with care received
- fewer hospital admissions
- reduction in falls
- reduced decline in function.

There is growing support for a person-centred approach to care in the community. The World Health Organisation's 'Health 2020' mandate highlights the need to do more to create better people-centred health systems for older people, and the Ready for Ageing Report (2013) prepared for Parliament also recommends personalised care at home wherever possible, advocating that older people

only go into hospitals or care homes when essential, and the home remains the core of care and support.

Depending on the level of care required, the cost of care at home can be comparable to a residential care home, with the added benefit of one-to-one care based around individual needs, rather than the less personalised structure of a care home. Overall, the evidence strongly supports the belief that home care delivers a number of benefits for older people, allowing them to maintain consistency and familiarity, which is an especially important factor for those with dementia, as well as providing the added benefit of maintaining asset appreciation.

*\*Report and statistics provided by The Good Care Group, November 2015*

<sup>1</sup> *Age UK Later Life in the UK, 2015*

<sup>2</sup> *Care of Elderly People Market Survey, Laing and Buisson, 2014*

<sup>3</sup> *Alzheimer's Society Dementia Update, 2015*

<sup>4</sup> *One Poll, 2014*

<sup>5</sup> *Nikmat, Hawthorne, Al-Mashoor, 2011*

## What happens when a trustee loses mental capacity?

Being a trustee is often an important way to help a friend or a family member. The trustee takes responsibility for money that's been set aside in a trust for someone else, and must make decisions regarding the use of the money in the best interest of the beneficiary and obey the rules of the trust.

But what happens if the trustee loses mental capacity? If this situation arises it will have an impact, even if other trustees are in place. For this reason, the consequences and options should be understood by all interested parties. Of course, it is possible for a trustee to lose their mental capacity suddenly, following a stroke or accident, for example. However, it tends to happen more gradually, perhaps as a result of dementia.

### **In England, Wales and Northern Ireland**

If possible, it is best to take action to avoid any difficulties. Early action using provisions included in trusts can help; for example, it is possible to use specific

trust provision to dismiss a trustee. Alternatively, a trustee who is developing dementia can usually resign. In either case, however, dismissal or resignation must happen before the trustee has lost the mental capacity to act.

### *Is dismissal or resignation possible?*

Dismissing a trustee can be a delicate issue and needs to be handled with sensitivity. There may also be occasions where it is not appropriate, or possible, to dismiss a trustee. For example, two individual trustees must remain in place after dismissing the trustee who is losing capacity. Should a trustee wish to resign, two must remain, or one if a replacement is appointed at the same time.

### *What happens if a trustee has already lost the mental capacity to act?*

When a trustee has already lost mental capacity, it is generally relatively straightforward to appoint a replacement, and it's normally possible without

needing to apply to the courts. However, the person nominated will need to arrange for their own legal adviser to draft a deed of removal and replacement of trustees. If no one is nominated to appoint new trustees or the nominated person is unable to act, the power falls to the continuing trustees.

However, it's not possible to do this if the mentally incapable trustee is also a beneficiary of the trust. In this case, the remaining trustees would have to apply to the court.

### **In Scotland**

While it is possible for a trustee to resign under Scottish law prior to losing mental capacity, there is no legislative provisions enabling a trustee to be removed in these circumstances. Although the courts can remove one if mentally incompetent, the remaining trustees will need to arrange for their own legal advice to make the application to the court.



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## **What happens if there is a power of attorney in place?**

Many individuals plan for the possibility of losing their mental capacity by creating a power of attorney. This can be a lasting power of attorney (LPA) in England and Wales, an enduring power of attorney (EPA) in Northern Ireland, or a continuing power of attorney (CPA) in Scotland.

While EPAs continue to apply in Northern Ireland, on 1 October 2007, LPAs replaced EPAs in England and Wales. EPAs created in England and Wales prior to 1 October 2007

continue to be valid, but can only be used once registered. (An EPA can only be registered when the donor has lost mental capacity.) The individual creating the power of attorney is known as the 'donor' (or 'granter' in Scotland). In all cases, the attorney usually has wide powers to deal with the donor's or granter's personal financial affairs and investments. However, the attorney cannot act on behalf of the donor or granter when the donor or granter is acting as a trustee. The question of mental capacity is straightforward when considering an EPA, but the same cannot be said when considering LPAs or CPAs.

LPAs and CPAs can be registered at any time and, consequently, registration does not provide evidence that the donor is no longer mentally competent to act. In addition, LPAs reflect the position taken on the degree of an individual's mental competence and imposes a requirement for the attorney to involve the donor as much as possible in decisions that will affect them.

This view of LPAs and mental capacity can create ambiguities if the donor is also a trustee. For example, the donor might continue to make decisions for themselves, with some assistance from their power of attorney. But this raises the question as to whether they have sufficient mental capacity to continue to act as a trustee.



### **Summary**

If there is any doubt about whether a trustee does have the mental capacity to continue to act, it is preferable, if they have sufficient understanding, for them to resign or be dismissed.

If the trustee has lost capacity, they can be replaced as explained earlier, unless Scottish law applies. If you would like to discuss arranging a power of attorney, contact your St. James's Place Partner who will be happy to help you.

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