

Executive summary

There are over 750,000 people living with dementia in the UK today, with numbers set to rise over 1 million by 2021 (Alzheimer's Society, 2010). Meanwhile, the way that we deal with money is rapidly changing, with financial transactions becoming more personalised yet differentiated. This poses serious challenges to people with dementia, who require support to manage their money and stay safe from financial abuse. Most work on this subject to date has focused on older people in general, overlooking the particular circumstances of people with dementia.

These circumstances vary considerably. People with dementia who have wealth and resources may attract those keen to exploit them through fraud or theft. At the other end of the scale, those with few assets are less likely to make future plans; as their cognitive abilities decline, they may find themselves struggling to manage their finances.

Financial planning is particularly important for people with dementia, because they are likely to face the highest long-term care costs. The increasing prevalence of dementia means growing numbers of people will need support to manage their finances over the coming years.

Cognitive impairment can have a huge impact on someone's ability to look after their finances. However, we know that people with dementia, even in the later stages, want to stay involved with their money wherever possible. For people to do so while protecting themselves from abuse, they must feel comfortable and empowered to talk about financial issues openly, before and after diagnosis.

Having dementia puts many people at greater risk of financial abuse for many reasons. For example, people with dementia may be less able to judge risk, while living alone might make them more vulnerable. Moreover, the fact that someone has dementia can, in itself, make it difficult to detect when financial abuse is happening.

Currently there are too many loopholes and problems in the systems which should be protecting individuals from financial abuse. In particular, the services offered by banks and other providers are not meeting the needs of people with dementia and carers. Those who support people with dementia need greater understanding of financial abuse, so they can spot the signs or prevent it happening. At the moment, too many people are being let down, leaving them more open to financial abuse.

Purpose of the report

The purpose of this report is to gather new evidence about the issues that people with dementia and carers face when managing their money. It also explores what they consider to be financial abuse. The aim is to use this evidence to raise awareness among the public, and those working with people with dementia, about the issues raised by money management and financial abuse in the context of dementia. The report makes recommendations for helping people with dementia and carers to manage their money as well as possible, for as long as possible, while minimising the risks of financial abuse.

Methodology

This report is based on quantitative and qualitative evidence collected from people with dementia, carers, Alzheimer's Society staff, and adult safeguarding co-ordinators from local authorities. This information was collected in 2011.

The quantitative information was collected from the following groups:

- 1 A survey of people with dementia – 47 people with dementia responded to a survey on how they managed money and their perceptions of financial abuse, distributed through Alzheimer's Society services.
- 2 A survey of carers – 104 carers responded to a survey on how they managed money and their perceptions of financial abuse, distributed through Alzheimer's Society services.
- 3 A survey for Alzheimer's Society staff – 86 staff who support people with dementia responded to an online survey on their experiences of money management and financial abuse.²

The qualitative information was based on focus groups, interviews and case studies:

- two focus groups with people with dementia
- three focus groups with carers
- two mixed focus groups were held of people with dementia and their carers
- a focus group of professionals which included nursing staff and social workers
- interviews with 12 adult safeguarding co-ordinators working for local authorities, carried out by researchers at King's College London
- case studies drawn from the experiences of our advocacy services, helpline and online forums.

² Staff included service support managers, support workers, dementia advisers and home support workers.

Key findings

Issues faced by people with dementia and carers when managing money

People with dementia

- The symptoms of dementia significantly affect a person's ability to manage their finances. In our survey, 76% of people had experienced difficulties in managing their finances.
- People often find it difficult or feel uncomfortable talking about financial issues, especially in family settings.
- People said they sometimes felt pressurised when shopping in unfamiliar places because staff were unaware they had dementia.
- Highly technical personal banking security makes it difficult for people with dementia to manage their finances.

Carers

- More than a third (36%) of carers had experienced problems managing the money of the person they supported.
 - Many reported emotional and psychological barriers when taking control of someone's finances.
 - Having to suddenly take over as the primary person in charge of money in a relationship can be very difficult.
 - Lack of information about how to access support with managing money and accessing entitlements, and overall inadequate financial advice.
 - Many carers reported difficulties dealing with banks and other service providers when trying to take over someone's finances, leaving them feeling unsupported and confused.
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Perceptions and risks of financial abuse

- 15% of carers reported that the person they cared for had been subject to some kind of financial abuse.
- People with dementia and carers felt that a diagnosis of dementia could make people more vulnerable to financial abuse.
- Many people knew someone or had themselves experienced low-level financial abuse such as scams and cold calling. Some cited more serious abuse, such as cash being stolen from accounts or familial financial abuse.
- All groups thought that sometimes family and friends could financially abuse people with dementia. They felt this type of abuse was perhaps the most difficult to define and talk openly about.
- People living alone without any kind of support were felt to be the most at risk from exploitation because they are less likely to access services
- Nearly two-thirds (62%) of carers said the person they care for had been approached by unsolicited or unscrupulous cold callers or salespeople.

Identifying and detecting financial abuse

- Professionals felt that financial discussions were still taboo or difficult to talk about with families, however without asking them it was hard to approach the issue.
 - Professionals reported that they came across financial abuse quite often, and that it was probably under-reported due to the large amount that takes place within families and is not known about.
 - It is often difficult to prove when financial abuse has occurred, particularly when the person with dementia cannot provide sufficient detail about what has happened.
 - Professionals perceived bank procedures and rules as significant barriers towards safeguarding vulnerable adults from financial abuse.
 - Lack of data sharing capabilities and data protection procedures were commonly reported as barriers to safeguarding.
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Recommendations

- Recognise that people with dementia are at much higher risk of financial abuse.
 - Improve knowledge and awareness about financial management and planning among people with dementia, carers and professionals.
 - Improve awareness of effective prevention mechanisms to help stop people with dementia being repeatedly targeted by cold callers and scams.
 - Improve community support services for people with dementia to manage their money.
 - Strengthen the role of local trading standards departments to work closely with groups supporting people with dementia to protect people from financial abuse.
 - Ensure that banking systems are better equipped to support people with dementia and carers to manage money safely:
 - banks and building societies must become familiar with situations where customers may have dementia and provide relevant guidance to their staff
 - the powers of the Mental Capacity Act should be consistently applied across all banks and financial institutions
 - bank staff should be empowered to alert relevant authorities to suspected financial abuse.
 - Increase access to independent advocacy for people with dementia.
 - Bring together adult safeguarding and financial assessment teams within local authorities to work collaboratively on cases of suspected financial abuse involving a person with dementia.
 - Improve data sharing between agencies and local areas and ensure that multi-agency policies are consistently implemented to prevent and respond to financial abuse.
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