

Short changed: Protecting people with dementia from financial abuse



Document purpose

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.

Title	Short changed: Protecting people with dementia from financial abuse
Publication date	December 2011
Target audience	This report is intended for a range of audiences and is designed, ultimately, to help people with dementia and their carers to manage their money safely in order to prevent potential financial abuse. The recommendations aim to raise awareness among the public and those supporting and working with people with dementia about the issues relating to money management and financial abuse in the context of dementia.
Acknowledgements	Alzheimer's Society would like to thank the people with dementia and carers, Society staff and other professionals who took part in our focus groups and responded to our survey. All the information and evidence provided by them has made this report possible. Alzheimer's Society would also like to thank Professor Jill Manthorpe, Dr Kritika Samsi and Dr Joan Rapaport of the Social Care Workforce Research Unit at King's College London for sharing data from the Evidem Mental Capacity Act study, ¹ and for their assistance in compiling this report. The Society is also most grateful for the help and support of all those who have reviewed the report and provided feedback.
Author	Karishma Chandaria, Senior Policy Officer, Alzheimer's Society
Contact	Alzheimer's Society's Public Policy team can be contacted on 020 7423 3500 or at ppa@alzheimers.org.uk
Web	alzheimers.org.uk
Publisher	© Alzheimer's Society 2011. All rights reserved. No part of this work may be reproduced, downloaded, transmitted or stored in any medium without the written permission of the publisher, except for personal or educational use. Commercial use is prohibited. Supported by Nationwide. Alzheimer's Society maintains editorial independence over the content of this report.

¹ The Evidem Mental Capacity Act study is independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0606-1005). The views expressed in the publications from this study, some of which are reported in this report, are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. For more information see www.evidem.org.uk/projects/evidem-mca.htm

Contents

Foreword	iii
Executive summary	v
1 Introduction and background	11
1.1 Introduction	11
1.2 Background to dementia	11
1.2.1 What is dementia?	11
1.2.2 Key statistics	12
1.2.3 Carers of people with dementia	12
1.2.4 Dementia and mental capacity	13
1.3 Policy framework	14
2 Financial management, financial abuse and dementia	15
2.1 Financial management and dementia	15
2.2 Financial abuse and dementia	15
2.3 Prevalence of financial abuse	16
3 Experiences of money management and financial abuse in the context of dementia	18
3.1 Experiences of managing money among people with dementia	18
3.1.1 Maintaining the ability to manage money	18
3.1.2 Common problems that arise with managing money	20
3.1.3 Planning for the future	21
3.2 Carers' views on managing money	22
3.2.1 Difficulties with managing money	24
3.2.2 Problems with banks and services	25
3.2.3 Lack of understanding of substitute decision-making requirements	27
3.2.4 Concerns about paying long-term care costs	28
3.3 Perceptions of financial abuse: evidence from people with dementia	28
3.4 Perceptions of financial abuse: evidence from carers	30
3.5 Perceptions of financial abuse: evidence from professionals	32
3.6 Common types of financial abuse and abusers identified by carers and professionals	34
3.6.1 Abuse by family and friends	34
3.6.2 Threats to withdraw care and support	35
3.6.3 Crossing the line between caring and appropriation	36
3.6.4 Entitlements and paying for adequate care	36
3.6.5 Doorstep cold calling and miss-selling	37
3.6.6 Rogue traders	38
3.6.7 Nuisance telephone cold calling	39
3.6.8 Postal scams and competitions	39
3.6.9 Stranger abuse	40
3.6.10 Care workers and care homes	40
3.6.11 Personal budgets and direct payments	41

4 Identifying money management problems and financial abuse in people with dementia	42
4.1 Evidence from Alzheimer's Society staff supporting people with dementia	42
4.2 Evidence from adult safeguarding co-ordinators	45
4.3 Problems with the current system	45
4.3.1 Breaking down the taboo of discussing financial issues	46
4.3.2 Difficulty of proving abuse has occurred	46
4.3.3 Consistency of safeguarding policies and the prominence of financial abuse	47
4.3.4 Lack of data sharing among agencies	47
4.3.5 Responsibility for reporting	48
4.3.6 Problems with banking systems	48
4.3.7 Powers under the Mental Capacity Act	49
4.3.8 Department for Work and Pensions	50
4.3.9 Resource and time constraints	50
4.3.10 Data collection on cases of financial abuse	51
4.3.11 Staff training in financial abuse, dementia awareness and the Mental Capacity Act	51
5 Recommendations: how we can prevent financial abuse	52
6 References and further reading	59

List of tables

Table 1:	Key findings from survey of people with dementia	18
Table 2:	Key findings from survey of carers	22
Table 3:	Responses from people with dementia to three scenarios	29
Table 4:	Responses from carers to three scenarios	31
Table 5:	Frequency of money management issues reported by Alzheimer's Society staff working with people with dementia	42
Table 6:	Common signs of potential financial abuse reported by Alzheimer's Society staff	44

Foreword



Martin Lewis is an award-winning, campaigning TV and radio presenter, newspaper columnist and bestselling author.

Financial abuse seems a strange term, yet unfairly depriving someone of their assets garnered through hard work and effort over a life time can be just as destructive as the other forms of more commonly discussed abuse.

We live in a complex consumer society. I've spent my career focusing on how to help people save money and campaigning to stop them being ripped off. This is difficult enough for most people but navigating it when you have dementia is a darker challenge.

It leaves some feeling rage with infuriating obstacles that modern banking and technology put in their way. Some are overly trusting of salespeople's far-fetched yarns and worst of all others are led into the world beyond that of the criminal, scamster and rogue trader.

As this report shows, these issues are particularly pertinent for people with dementia. Shamefully it reveals these vulnerable people are being conned out of at least £100 million. In fact this figure is likely to be much higher as financial abuse often goes unreported. This is money that could be helping them live a good quality of life. It is money that could be used to pay for vital help with washing, dressing or eating and retaining their dignity.

The financial impact of caring for someone with dementia can be caustic too. Juggling the commitment to work, to care and to pay, what are likely to be increasing bills, is simply too much. While my usual call is that we need to be responsible consumers and borrowers, savvy and aware of what's going on to get the best deals, as a society we also need to help protect the most vulnerable.

The high levels of financial abuse and the difficulties experienced by people with dementia trying to manage their money have been left uncovered for too long. We need strong measures to prevent people falling victim to scams and ensure the companies and organisations they come in contact with help, rather than hinder.

I am therefore delighted to be able to support this report and look forward to seeing the changes it will inevitably help bring about.

Martin Lewis
Money Saving Expert

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.

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.

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.

1 Introduction and background

1.1 Introduction

There are 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 everyone deals with money is rapidly changing, with financial transactions becoming more personalised and differentiated – this may pose serious challenges to people with dementia, who require support to manage their money and stay safe from financial abuse. Most work on this issue so far has focused on older people generally, overlooking the particular circumstances of people with dementia. There is a need to gather new evidence in this area to support future policy practice and service development.

Alzheimer's Society has highlighted the particular vulnerability of people with dementia to abuse:

- Working with the Office of the Public Guardian (OPG) to inform people with dementia and carers about their rights under the Mental Capacity Act 2005 (in England and Wales). The Society helps to ensure that the OPG's policies and processes accommodate the needs of people with dementia.
- Contributing to the Law Commission's 2011 Review of social care law, the Society submitted evidence on ways to strengthen safeguarding legislation.
- In 2009, the Society submitted a comprehensive response to the inter-ministerial review of adult safeguarding, Safeguarding adults: a consultation on the review of the No secrets guidance (Department of Health, 2008).
- In 2009, Alzheimer's Society published Safeguarding people with dementia: Recognising adult abuse (Alzheimer's Society, 2009b). This booklet contains essential information on how to handle suspected abuse and where to access support or advice.

1.2 Background to dementia

1.2.1 What is dementia?

The term 'dementia' describes a set of symptoms that includes loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes. Dementia is progressive, which means people with dementia and their carers are coping with changing abilities over time. These include the person's capacity to make decisions about major life changes, as well as day-to-day decisions. Eventually they will need help with all their daily activities, from numerous agencies spanning health and social care.

1.2.2 Key statistics

- There are 750,000 people with dementia in the UK. This is forecast to increase to over 1 million by 2021 and 1,735,087 by 2051 (Alzheimer's Society, 2010). One in three people over 65 will die with a form of dementia (Brayne et al, 2006).
- Two-thirds of people with dementia live in the community. Some will be in the early stages of the condition, others will be in the later stages or at end of life (Alzheimer's Society, 2007).
- One-third of people with dementia live in care homes. Two-thirds of care home residents will have a form of dementia (Alzheimer's Society, 2007).
- At any one time, up to a quarter of hospital beds are occupied by people with dementia (Alzheimer's Society, 2009a).

Dementia currently costs the UK £20 billion each year. By 2018, that figure will have reached £27 billion (Alzheimer's Society, 2007). The total average annual cost of supporting a person with dementia, for the state, the person themselves, and their carer, is estimated as follows (Alzheimer's Society, 2007):

- people in the community with mild dementia: £16,689
- people in the community with moderate dementia: £25,877
- people in the community with severe dementia: £37,473
- people in care homes: £31,296.

The increasing numbers of people living with dementia, and the rising financial costs, have made dementia a major public policy priority. But so too has the growing recognition that the support for many people with dementia and carers is still not good enough.

1.2.3 Carers of people with dementia

There are an estimated 600,000 people in the UK acting as primary carers for people with dementia (Alzheimer's Society, 2007). As the person with dementia starts to require help with many aspects of daily life, carers can be placed under enormous strain. Unpaid carers provide much of the support that people with dementia receive. One study found that half of all people with dementia in the community received at least 35 hours of informal care per week (Schneider et al, 1999).

The costs of caring are significant. Many carers face financial hardship, having had to give up work and pay high care bills from limited income or savings. This is despite the fact that unpaid carers for people with dementia save the UK £6 billion a year (Alzheimer's Society 2007) – an average of around £10,000 a year for every carer (Alzheimer's Society, 2007). Supporting carers is therefore essential, particularly given current economic challenges. Without them, the cost of dementia to the state would be much higher. Providing effective support services for carers is fundamental to ensuring that money spent on dementia produces the best possible results.

1.2.4 Dementia and mental capacity

It is important to recognise that a diagnosis of dementia does not necessarily mean individuals can no longer make decisions for themselves. People with dementia lose this capacity over time, with variation between individuals. Furthermore, earlier diagnosis and new treatments are helping people to retain mental capacity for longer.

As in any other area, all practical steps must be taken to help an individual participate in financial decision-making. Even if the person with dementia can no longer make complex decisions, they may be able to make day-to-day decisions. Once the person begins to lose capacity to make decisions about financial matters, the carer or family should be fully involved in decisions about their welfare and treatment. The use of advocates may also be necessary. For those without carers, there are local and national systems that help people when they are no longer able to manage their money.

The Mental Capacity Act 2005 must underpin the decision-making and advanced planning process. The Act foremost assumes that all individuals have the capacity to make decisions for themselves unless otherwise determined. It provides a statutory framework to empower and protect people aged 16 and over who lack, or may lack, capacity. The Act was fully implemented in October 2007 and applies in England and Wales. It was amended in April 2009 to include the deprivation of liberty safeguards (DOLS). The act has three broad objectives:

- 1 To support people with impaired capacity so that they can make decisions for themselves.
- 2 Where they cannot take a particular decision for themselves, to provide them with a protective framework for decisions that are made about them.
- 3 To provide a framework for those who have to make and implement decisions in relation to people who do not have the capacity to make those decisions for themselves.

The act covers major decisions about someone's property and affairs, health care treatment (including consent to medical treatment), or where they live. It also covers everyday decisions about personal care. Safeguarding practitioners have reported overwhelming support of the Act, and feel that, alongside the frameworks for assessing capacity it also assists practitioners in assessing risk (Manthorpe et al, 2012a, in press). The act deals with two situations where a designated decision-maker can act on behalf of someone who lacks capacity:

- Lasting powers of attorney (LPAs) – The act allows a person to appoint an attorney to act on their behalf if they should lose capacity in the future. This is like the former enduring power of attorney (EPA), but the act also allows people to let an attorney make health and welfare decisions.
- Court appointed deputies – The act provides for a system of court appointed deputies to replace the former system of receivership in the Court of Protection. Deputies are able to take decisions on welfare, healthcare and financial matters as authorised by the court. They will only be appointed if the court cannot make a one-off decision to resolve the issues.

1.3 Policy framework

In 2000, the government published its multi-agency guidance No secrets (Department of Health, 2000), which made local authorities in England the lead agencies in protecting 'vulnerable adults' from abuse, mistreatment and neglect. The guidance notes that abuse takes several forms including: physical; sexual; psychological; financial or material; neglect and acts of omission; discriminatory; and institutional. No secrets was the catalyst at a local level for the development of policies and procedures for responding to the possible abuse of vulnerable adults. But the guidance lacked any statutory power to bring together all the relevant agencies, and no resources for this work were identified by central government.

One criticism of No secrets has been that it is too restrictive. It may be interpreted as not allowing for the identification and response to suspected cases of abuse where individuals are not receiving community services, or not enabling in depth investigations where abuse may be taking place in the person's home or family setting.

Reviewing the impact of No secrets in 2008, the Department of Health highlighted some key areas which are relevant to dealing with financial abuse of people with dementia, including:

- concerns about the ability of safeguarding staff in local authorities and partner agencies both to spot the signs of financial abuse, and to obtain information about transactions from banks to inform investigations
- a lack of knowledge in local authority safeguarding services and among safeguarding managers in partner agencies about how to approach and work with financial institutions
- a general lack of understanding about the powers and options available to address financial abuse
- a shortage of training in investigative skills
- older people's reluctance to pursue concerns if family members are the alleged perpetrators of abuse, for fear of losing contact with their family.

The review (Department of Health, 2008) called for greater focus in safeguarding policy on groups that were considered to be more at risk, such as older people. There were also calls from many quarters to introduce safeguarding legislation. In 2010, the government committed itself to updating the guidance in the light of the findings of the review. In early 2011, the Law Commission published its Review of adult social care law (Law Commission, 2011), setting out proposals relating to adult safeguarding that may form the basis of new legislative measures. In May 2011, the government announced it would strengthen safeguarding by making safeguarding adults boards statutory and introducing other safeguarding duties as part of a revised social care bill. Meanwhile there are many other ways in which financial abuse remains an area where more work should be done.

2 Financial management, financial abuse and dementia

2.1 Financial management and dementia

The fact that dementia is a progressive condition has particular implications when it comes to managing money. There is often a slow deterioration in the person's ability to carry out tasks such as paying bills, dealing with paperwork, or making decisions about property and investment. Part of the problem is that these tasks require memory, comprehension and the ability to assess risk (Tilse et al, 2009). The increasing prevalence of dementia means there will be more people needing support to manage their finances. People with dementia are likely to face the highest long-term care costs, so financial planning for the future is particularly important. Meanwhile, broader social and demographic changes are highlighting the importance of the issue of financial management for people with dementia:

- The way people manage their finances is changing rapidly. For example, online transactions, cash machines, telephone banking and declining use of cheques. This could make it more difficult for people with dementia to manage their own finances, and leave them more open to financial abuse.
- The number of people with dementia who have pensions, property and other resources may attract those keen to exploit them through fraud and theft. Meanwhile those who have few resources are less likely to plan for the future, and may struggle as their declining cognitive abilities make it harder to manage their money.
- Financial decision-making also presents wider concerns for people with dementia, including questions about inheritance, inter-generational relationships and debates about paying and charging for care.

2.2 Financial abuse and dementia

It is well recognised that people with dementia can be subject to abuse, in all care settings, by nurses, care workers and other professionals. They are also open to abuse by family members and people in their communities. Several factors can make someone with dementia more vulnerable to abuse:

- Having dementia can make someone an easy target: they may not have the capacity to understand what they are being asked or forced to do, and may not remember what has happened to them.
- Even when a person does disclose abuse they may not be believed. It might be assumed that the person is confused and cannot be a credible witness.
- Victims of abuse generally find it hard to talk about their experiences especially in cases where there may be levels of dependency for household tasks. This can be exacerbated for a person with dementia, who might already have difficulties communicating their experiences, wishes and feelings.

The abuse of people with dementia should be considered in the broader context of elder abuse. Action on Elder Abuse defines elder abuse as ‘a single or repeated act or lack of appropriate action, occurring within any relationship where there is an expectation of trust, that causes harm or distress to an older person.’³ There is low but growing awareness of what constitutes elder abuse, along with its prevalence, causes and prevention strategies. There is also concern that current evidence does not adequately reflect the ‘hidden’ nature of elder abuse (Boyd Associates for Age NI and Alzheimer’s Society, 2011).

Similarly, financial abuse suffers from poor general awareness compared with other, more obvious forms of abuse. No secrets defines financial abuse as that which:

‘Includes theft, fraud, exploitation, and pressure in connection with wills, property or inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits’ (Department of Health, 2000).

However, this definition was devised before the widespread use of the internet and changes in what is meant by an ‘expectation of trust’. Financial abuse is particularly hard to define, because the term can be applied to a huge range of acts, omissions and individuals.

An abuser can be a family member (close or distant), friend, neighbour, professional, or a stranger or gang member who has targeted an individual. Recent definitional debates highlight the importance of trust when talking about elder abuse, noting that ‘being attacked or robbed by a stranger or an acquaintance is assault or theft but not physical or financial abuse. However, harms inflicted by those who have a formal relationship of trust, or those who have otherwise assumed responsibilities and duties of care towards the victim, is both an assault or theft and physical or financial abuse’ (Dixon, 2010). It is important to emphasise that financial abuse is often tied up with other forms of abuse; Alzheimer’s Society believes the definition should be broadened to include, for example, rogue traders and internet fraud.

2.3 Prevalence of financial abuse

Evidence on the numbers of people with dementia who experience abuse cannot be reliably quoted. However, there is evidence that abuse of people with dementia is highly prevalent across informal and formal care settings. The Caring for Relatives with Dementia (CARD) study, using information self-reported by carers, indicates the prevalence of abusive behaviour by family carers towards people with dementia (Cooper et al, 2009). The study found that abusive behaviour is common, with a third reporting significant levels of abuse, and half some abusive behaviour. Verbal abuse was most frequently reported and physical abuse the least common. However, these figures are likely to be underestimates. The study relied on self-reporting, so some information may have been withheld. Furthermore, the study did not cover financial abuse. And more generally, it can be very difficult to identify abuse with confidence: what appear to be symptoms can actually be indicators of other conditions or situations.

³ For more information, see: http://www.elderabuse.org.uk/About%20Abuse/What_is_abuse%20define.htm

In 2004, Action on Elder Abuse reported that 20% of callers to its helpline had concerns about financial abuse, putting it second behind psychological abuse as the most commonly reported (Action on Elder Abuse, 2004). In 2007, a major study found that 0.66% of people over 65 in Britain who were living at home reported having been financially abused by a close friend, relative or care worker in the past year (O'Keefe et al, 2007). In 2006, a study explored the relationship between types of abuse and place of residence. It found that 7% of adult safeguarding referrals from residential homes concerned financial abuse. For referrals concerning people living in the community, the proportion was 25% (Cambridge et al, 2006). However, neither study specifically investigated the prevalence of financial abuse among people with dementia.

It is particularly difficult to estimate the overall prevalence of financial abuse among people with dementia, whether they live alone, with family, or in care homes. This is partly due to data collection challenges, but also to levels of under-reporting. Of the safeguarding alerts reported across Alzheimer's Society from April to September 2011, 20% had an element of financial abuse. The Society's advocacy service in Northern Ireland recently reported that, over its first two years, 34% of the abuse cases it has handled featured a financial element (Boyd Associates for Age NI and Alzheimer's Society, 2011).

3 Experiences of money management and financial abuse in the context of dementia

Managing money can create a number of challenges for people with dementia and carers. Being able to manage money requires the ability to mentally process complex concepts. These include: recognising money and its value; monitoring spending; deciding where to keep it; managing savings accounts; and using it for both pleasure and essential purposes. As dementia progresses, it can become increasingly difficult for someone to do these things. A person may need to rely on family, friends or carers for support; or they may develop new systems to remain independent. Each of these situations could put people at risk of financial abuse.

3.1 Experiences of managing money among people with dementia

3.1.1 Maintaining the ability to manage money

To understand how people with dementia manage their money, and what their experiences in this area were, we conducted two focus groups and surveyed people using our services.

Table 1: Key findings from survey of people with dementia

21%	managed their own money all the time
79%	either had a little help managing their money, or it was managed entirely on their behalf
75%	received help with shopping
70%	needed assistance with paying bills
65%	needed assistance dealing with the bank
76%	reported some kind of difficulty managing their money
77%	agreed it was important to make plans about how to manage their money in the future
72%	had a Lasting Power of Attorney in place
82%	had made a Will

Most people with dementia received some support to manage their money. Seventy-nine percent of people with dementia said either they had some support to manage their finances, or were not involved at all. Only 21% said they managed their money independently. When asked who helped them to manage their money, most people said their carer, who was most commonly a partner, spouse or family member. This pattern was reflected in the focus group discussions. All participants said discussions with partners, children and other family members were important when making financial decisions.

When asked about the common tasks associated with managing money with which they might need assistance, people with dementia strongly focused on daily household activities:

- doing the shopping: 75% needed some assistance
- dealing with the bank: 65% needed some assistance
- paying bills: 70% needed some assistance.

Other tasks that people reported needing help with included claiming benefits and paying for domiciliary care, gardeners and cleaners.

People with dementia managed their money in various ways and their approaches were shaped by living circumstances and relationships. Of those that retained some control of managing money, this tended to involve cash rather than other payment methods. Some reported changes in what they were able to do, with small rather than large routine tasks being possible. For example, being given a small amount of money each week by their carer to manage or spend at local shops was the way one person managed to keep their independence.

'My wife gives me money, she puts it in my wallet so I always have money on me.'

For those people who required more support, many used informal ways of managing money. These involved some risks, but could be seen as positive risk taking. Common examples included giving a PIN and bankcard to carers or relatives to draw out cash, or signing batches of cheques for small amounts that were then used by relatives to pay for services. Others had set up systems such as direct debits to pay bills, or had an online shopping facility set up by a family member. Many had more formal arrangements, with joint accounts with partners for managing household finances being very common, or giving lasting power of attorney to third party authorities on bank accounts.

3.1.2 Common problems that arise with managing money

We asked people with dementia whether they had difficulties managing their finances, and what tasks they were finding difficult. Of those surveyed, 76% experienced some difficulties in managing their money, with common problem areas including:

- shopping for things you need: 60%
- paying bills: 55%
- dealing with the bank: 76%
- making plans for the future: 40%.

In both the survey and focus groups, people with dementia described how their symptoms affected their ability to manage money. Being able to process information was viewed as central to handling money effectively; this can become increasingly difficult with dementia. The common problems people reported included difficulty with recognising letters and symbols, or confusing numbers and letters. This made several tasks more difficult. For example, filling in forms to pay bills, reading bills and bank statements, and monitoring spending. As these individuals reported, all of these tasks are essential for planning and keeping track of financial transactions, and where money is being spent:

'I have difficulty keeping a written record of money in and out, for example, each week or otherwise as needed.'

'Forms, letters, numbers and the alphabet have started to get muddled.'

'I find it difficult retaining verbal information. Therefore I need my wife to assist me with those matters. With single items or a short list I can shop independently, otherwise I need assistance.'

The daily physical handling of money was described by people with dementia as difficult. Counting out cash when purchasing goods and services was cited as a problem. One focus group participant said he had to give lots of change to shop assistants and rely on them to take the right amount. Other problems included handling coins; some people carried large notes instead, which could put them more at risk of theft or could simply get lost. Some reported that accessing money from different sources could be difficult. This stemmed from the tendency to forget the PIN and passwords needed for cash machines or banking transactions, or from being unable to sign cheques.

When shopping in unfamiliar areas or larger supermarkets, some people with dementia said they sometimes lacked confidence or felt pressurised. This was because they knew that staff were unlikely to be aware that they had dementia and therefore needed more time to count change or understand instructions. This is described by one focus group participant:

'You can't do that at a big supermarket so I just hand over a big note, when people are waiting behind you there is an added pressure.'

Some people clearly felt more comfortable buying smaller items and shopping in local shops where other people knew they had dementia and were able to help. One focus group participant explained that although his wife did almost everything, he was able to buy small items, like newspapers, but was not confident using cash. He felt more comfortable going to local shops where he had built relationships with shopkeepers.

There were some reports of difficulty using bank branches, and people said they needed more assistance and support when trying to access money. The support from bank staff was variable; people felt that staff might be made uncomfortable by their behaviour. There have been reports of people with dementia withdrawing large amounts of cash and having no recollection of where it had been spent, or being targeted at cash points by strangers. This story from a carer is one of several examples:

'I am worried about my sister. I think she has dementia. She forgets things easily and today she went to the bank to get money out. A person stopped her and said they would walk her home and then carried my sister's bag. When she got indoors, my sister found the money was missing but she cannot remember what the person looked like.'

The advent of chip and PIN and other electronic money management systems, and the decline of face-to-face banking, pose special problems for people with dementia. They may struggle to remember PINs, while their access to, and ability to use, email and online banking may be very limited. This increases the risk of financial exclusion and creates fresh potential for abuse to occur. However, these developments also potentially reduce risk by reducing the need to visit the bank or carry large amounts of cash. One focus group participant said:

'Technology is great but you don't know who you're dealing with. Another reason not to [do online shopping] is that you can't see what you're buying and if you see something new you might think I'll try something new this week.'

3.1.3 Planning for the future

In our survey, 77% of people with dementia said they felt it was important to make plans for how their money was to be managed in the future. Some added that this was necessary to prevent people taking advantage of them. One focus group participant commented:

'There must be someone that can handle these things in case you get ripped off.'

Of those surveyed, 72% had a lasting power of attorney in place, while 82% had made a Will. People in the focus groups acknowledged that openly discussing plans for the future might be tricky, especially for those who are not particularly close to their families or have few relatives.

This evidence suggests that people with dementia want to remain involved with managing their money wherever possible, even when their symptoms become more severe. It also demonstrates, however, that cognitive impairment can hugely affect someone's ability to look after their daily finances. Furthermore, major financial decisions can be particularly challenging because they can require memory, reasoning, comprehension, judgement and risk assessment. It is also clear that although people may find ways of managing some risks, these approaches can generate new risks.

3.2 Carers' views on managing money

It is clear from our research that most carers play a crucial role in helping people with dementia to manage their finances safely.

Table 2: Key findings from survey of carers

80%	helped the person they care for to manage their money
93%	have consent from the person who they are caring for to manage their money
73%	had spoken to the person who they care for about managing money in the future
62%	were supporting a person who had given a lasting power of attorney to someone
80%	helped the person they care for with shopping, paying bills and dealing with the bank
36%	reported difficulties in managing money for the person they care for
87%	stated that there needed to be better dementia awareness among staff working in banks and utility companies
76%	stated that bank staff needed better understanding of what an enduring or lasting power of attorney means and how it operates
83%	stated that there should be better support for carers who have authority to manage a person's finances on their behalf
63%	said they would like more information about managing money and financial matters for the person they care for

Carers are often the people who support those with dementia to deal with financial matters. In our survey, 76% of those providing support were a spouse, 12% were daughters and 7% were sons. Of the carers surveyed, 80% said they always helped the person to manage their money, while 88% did so to some extent with permission to do so from the person with dementia. The tasks they helped with included:

- doing the shopping: 86%
- paying bills: 83%
- collecting benefits: 52%
- dealing with the banks: 84%
- managing care costs (for example paying for care): 63%.

Other tasks identified by carers included general oversight of expenditure, and spending the money allocated to the person for welfare and care costs. Some carers had also found ways of trying to mitigate the risks of losing money. As one carer reported:

'Make sure they have cash (not too much). Take away from home any new cards that may not be being used or are not needed. Check bank statements and credit card statements and investments.'

However, there is not always proper recognition of these particular caring responsibilities by health, social care and commercial services, and local authorities. Nor is there always appropriate support.

Carers' feelings about taking on the role of managing money varied greatly. For some it came quite naturally, but many said the daily pressures of caring meant they didn't have adequate time to think about money. Some carers said it was not a role they felt equipped to take on, or in some cases, wanted to take on. Many raised the difficulty of trying to balance respect for someone's right to manage their money with the increased risks that dementia creates.

'Before he had dementia he managed our finances very well. So it has been an uphill struggle for me to take on this aspect of our lives. I think it would be useful if Alzheimer's Society could help with financial advice and management of finances.'

3.2.1 Difficulties with managing money

Carers encountered a range of difficulties in managing money. More than one-third (36%) reported experiencing problems in this respect. Many carers cited emotional and psychological barriers to taking control of another person's finances. These stemmed from wanting to maintain the person's independence and treat them as an individual, while also accepting that dementia has curtailed their ability to manage money. One carer outlined this dilemma:

'It is difficult to come to terms with the mindset of someone who has dementia and how their attitude to managing money can change. They can become very forgetful as well as overly trusting, which can lead to increased vulnerability to abuse.'

Taking over as the primary person dealing with finances in a relationship creates its own difficulties. Any role reversal can be very difficult, and having to manage money on top of caring can leave carers feeling particularly vulnerable and stressed. This was especially reported by female carers whose husbands had dementia. As one carer remarked:

'Dealing with my husband's investments and shares has brought problems as it was in his name only. As he dealt with all our finances before he became ill, it has taken a long time to get to grips with everything and is often very stressful at times, especially as some financial institutions have not been very helpful. There have been many obstacles put in our way and it has been very frustrating at times.'

Many carers stated that managing the money and assets of someone with dementia is a major yet seriously under-recognised responsibility. They often felt poorly prepared and supported. There was a feeling that the role needed greater recognition from professionals, particularly when assessing care and support needs. As one carer describes:

'Social services and other statutory bodies still think about caring in physical terms. Managing money, paying bills, arranging visits of plumbers, for example, and paying their bills all take up enormous amounts of time. The Department of Health definition of a carer is much wider but in practice social services think in narrower traditional terms.'

Nearly all carers in our research felt that there should be more information and support for people with dementia and carers regarding financial planning. It should be available at an early stage to help people decide the best approaches for their circumstances. Some carers called for specific financial support and advice when someone has dementia, and for people with dementia living alone. They felt this might be particularly helpful if provided by someone who understood the difficulties of their situation. Nearly two thirds (63%) of carers surveyed said they would like more information on managing money and financial matters for the person they care for.

There was agreement that information from local authorities (adult services) and the Department for Work and Pensions about entitlements and benefits is poor. People are often unaware how to access this information or that it is not available in one source. Some carers felt that social workers used to be more forthcoming with information about people's entitlements but that due to time and resource constraints they cannot always provide such support.

Several carers in the focus groups were concerned by the reduction and closure of local post offices. This was seen as a significant barrier in managing money safely: many people use their local post office to pay bills and access bank accounts. These concerns were particularly acute for those living in rural areas. One carer explained the impact of these developments:

'My problem is that I (an octogenarian) have to go to the bank (one mile away) each month and get one of the cashiers to make a transfer between her (my wife with dementia) accounts in order to have the necessary funds to pay for her care home fees.'

3.2.2 Problems with banks and services

Taking over someone's finances was consistently difficult for carers in our research. Nearly all carers reported having problems with banks and other services when trying to establish control over the person with dementia's money. This often left them feeling unsupported and confused, as this carer describes:

'Before the power of attorney was registered, utility companies and other organisations (where my husband was the first named or accounts were in his name) refused to deal with me and expected to ask him questions which he was not capable of understanding or responding to. When I asked the phone company how I could change the account to my name, as I paid the bills, I was told "only through bereavement". They eventually agreed that when the power of attorney was registered, I could send this in and they would change it. I know there is a need for safeguards, but it's all very frustrating.'

Many spoke of poor staff awareness about the power of attorney. This included not understanding the legal powers that those holding the power or deputyship can exercise over financial affairs, or the decisions they can make on someone's behalf. Carers reported various situations where banks had refused to acknowledge their legal status under a registered power of attorney:

'For several years I have been the attorney for my wife's enduring power of attorney. Even after this was registered with various banks, I continued to manage her accounts with no problems. When my wife's mental state deteriorated to such an extent that she no longer understood about money, my solicitor notified the Office of the Public Guardian and I notified the banks. This should have made no difference to my managing her accounts. However, about a month later, the bank, without warning, prevented me from accessing her accounts online. I am still, several months later, trying to get them to reverse this decision.'

'I did actually ring the Alzheimer's Society Helpline about a year ago regarding problems I was having with the bank. The bank would not accept the registered lasting power of attorney that my brother and I had obtained for my mum, who has Alzheimer's disease. They called it an unenforceable document, even though the Office of the Public Guardian had called it a perfectly legal document.'

Others who had held, or were holding, lasting power of attorney or deputyship for someone with dementia reported further access limitations. This anonymous source, quoted in *The Observer* (March 2010), typifies numerous reports of such frustrations:

'My 88-year-old mother's dementia deteriorated to the point where she could no longer manage her finances. My brothers and I hold lasting powers of attorney (LPA) and contacted X for a new cheque book and debit card so that I, as her main carer, could pay her bills. We took the documentation to a branch last June. Two months later, the branch contacted my mother but she could not help because of her dementia. Staff then phoned my brother, saying they had no record of my visit or contact details. I attended a second appointment and again X copied the documentation. Over the next few months, X sent me several letters about the account, but I still had no cheque book or card. In December, X wrote to my mother, saying it could not match her signature to the one on her records. This made her anxious and I made a formal complaint to X. In January, the bank wrote to her about my complaint, and the level of anxiety this caused made her ill. I complained again and for the third time was asked to send a copy of the LPA, a signature mandate, card application form and declaration of incapacity form. When the bank said the reason this had not been sorted out was because I needed to go to the branch to sign the terms and conditions for the debit card, I flipped. My mother has used this branch for 50 years and the manager has not even responded to my letter.'

A common complaint in this area was that bank staff appeared not to understand how a dementia diagnosis changes a person's circumstances and, over time, their mental capacity. Nor did staff seem to understand how this changed the way that someone needs to manage their money. It was felt that the systems and structures within individual banks were not flexible enough to accommodate these changes. As a result, people with dementia and/or their carers have to circumvent these systems to manage money, which puts both at increased risk. This carer summed up the frustrations:

'Staff from the bank always ring asking to speak to my husband, who I have explained is not well and has dementia. I have also mentioned that I had permission to speak to them on his behalf as I had a third party authority access on his account. They would not listen to me so had to get my husband to agree and pass through security before I could talk to them and answer the questions that they wanted. It is very stressful when you are trying your best to handle the situation and they make it so very hard.'

3.2.3 Lack of understanding of substitute decision-making requirements

The majority of the carers (76%) we surveyed had spoken to their relative about how they would manage their money in the future. However, many carers said having these conversations is difficult because they are so busy caring for the person with dementia. This carer spoke about the pressures involved:

'I've been in that situation myself, you are so stressed and pressurised and life is so complicated that you still say "yes" to things just for an easy life, don't you? I know I've done it and then you sort of think after, "have I been ripped off here?"'

Many carers felt speaking about advance planning while someone still has some capacity to make decisions was very important, because it can help avoid complicated and emotionally difficult conversations. They felt that future planning should be done with the person with dementia wherever possible. Carers also stressed that health and social care professionals needed much greater awareness of the necessity of future planning for people with dementia when talking to them about using services.

Some carers reported still being confused about the processes for managing money on another person's behalf. They said relevant information is hard to find, and awareness and information about legal safeguards still not widespread. Two carers offered their views:

'The main problem was really my own lack of awareness of the legal situation concerning the rights of both my wife and myself in all financial matters. I found dealing with the legal requirements of the Mental Capacity Act initially very demanding, and then expensive, which is not good when also having to cope with all the other stresses of coming to terms with such a life-changing event.'

'We need more public awareness of the problems that arise when we cannot manage our own affairs. This can happen in cases other than dementia. We should encourage people to make wills and take out powers of attorney. The cost of doing this should be less than it currently is.'

3.2.4 Concerns about paying long-term care costs

Residential care fees and how they would be managed caused anxiety for some carers. People with dementia face the highest care costs of any group and contribute the most towards them. There was anger at the way some local authorities conducted financial assessments and the lack of useful information for people funding their own care. Some carers had received calls from social services asking them when they were going to sell their relative's home to fund care costs. This picture of local authorities as being mainly interested in collecting money, accurate or otherwise, may influence how carers think about them as an information resource or a good source of impartial advice.

These findings show that the role carers play in helping people with dementia to manage their money is significant and complex. However, it often does not receive the recognition it deserves. Many carers feel unprepared and unsupported to take on such roles. The attitudes of banks and service providers are sometimes unhelpful, which exacerbates the stress and worry experienced by carers.

3.3 Perceptions of financial abuse: evidence from people with dementia

The reasons why people with dementia are often put into situations that carry more risk of financial abuse are complex. Indeed, we do not know much about protective factors. These risks may be heightened by a combination of problems relating to capacity, contextual factors, and caring or abusive relationships.

In terms of capacity, people with dementia may struggle to judge risk, making them less able to apply the precautionary measures that those without a cognitive impairment sometimes would. They might live in circumstances where there is a higher risk of abuse, for example, living alone without good social networks or support. They might be receiving services from several providers, relying on those who come into contact with them – professionals, family, friends and neighbours – to spot the signs of someone taking advantage of them. Despite the goodwill and generosity of those people, they may not always be able to identify the signs of financial abuse.

Any discussion of financial abuse requires a sense of what people with dementia perceive it to be. To put people at ease when talking about financial abuse, and to test awareness of what it might involve, we asked people with dementia to judge three fictional scenarios:

Table 3: Responses from people with dementia to three scenarios

Scenario 1

A person with dementia gives £20 to a friend to do their shopping. The friend keeps the change without asking the person if this is okay. Responses were:

- acceptable: 4.5 %
- sometimes acceptable: 4.5 %
- not acceptable: 90.9 %
- don't know: 0%.

Scenario 2

A family member takes £10 from the wallet of their relative who has dementia, without asking, to pay for some household items. Responses were:

- acceptable: 4.5%
- sometimes acceptable: 15.9%
- not acceptable: 77%
- don't know: 2.3 %.

Scenario 3

A family member has asked their relative who has dementia for their PIN and bankcard so they can pay for household items. Responses were:

- acceptable: 4.7%
- sometimes acceptable: 25.6%
- not acceptable: 65.1%
- don't know: 4.7%.

We also tested these scenarios in the focus groups. Some people considered these types of actions abusive, putting them on a par with theft. Others said the person involved and the nature of the relationship might blur normal boundaries. Some comments acknowledged that trust was central to such scenarios:

'If I didn't have my husband I would get myself into such a mess with money. I have to trust him that he will do the right thing.'

'It's theft if you don't ask or have not been given the money, it would be very foolish to give someone your PIN.'

'Not a very good friend if they do that. It's wrong; they should give the money back, it's theft. But it depends on the relationship. It's difficult. If it were your wife or husband there would be no issue. If it's a child some wouldn't mind but in my experience my son wouldn't do that. Money is serious; it is theft even if you're a friend.'

'That's wrong, they should ask, they need a telling off so they can learn that it's wrong. Children should grow up to learn what is right and wrong.'

Focus group participants raised concerns over the lack of support beyond family and friends. They expressed fears that people living alone could be exploited.

It is clear from these findings that people with dementia may be able to make judgements about situations that could be deemed financially abusive. For some, the nature of the relationship can blur the line between caring and abuse.

3.4 Perceptions of financial abuse: evidence from carers

We found that some carers were acutely aware of the risks of financial abuse to people with dementia. Around 15% reported that the person they care for had been financially abused. They cited a number of reasons why they felt that people with dementia were more at risk than others, including:

- the declining ability to process information, which results in forgetting PINs and passwords, and leaving bills unpaid
- the trusting nature of many people with dementia, which can leave them vulnerable and open to exploitation from strangers
- if someone lives alone, with little support from family or friends, their social isolation and loneliness may lead them to let anyone into their home
- people with dementia may lose the ability to judge the value of money – common scenarios include making large cash withdrawals, and/or keeping it in the house, which both carry risks
- if the person receives care from several different providers, this can increase the risk of abuse as it is not known who might have taken something
- limited mobility means the person with dementia may rely very much on family, friends or neighbours to go to the bank or post office with, or for, them.

Carers in the focus groups discussed the people they suspected were most likely to perpetrate financial abuse. The spectrum ranged from family members and care workers to rogue traders and cold callers. They noted how difficult it was to judge the line between money management and abuse, and that sometimes situations could escalate easily, for example, taking money intended for shopping which escalates into completely misusing money meant for household management. As one carer remarked:

'It's hard to draw the line due to practicalities. For example, when you buy food you often might keep the change. It's hard to constantly keep a paper trail. It's hard to draw the line and how would you police it anyway?'

This confusion over where to draw the line is reflected in the responses given by carers to three scenarios (the same scenarios that were presented to people with dementia in section 3.3) that may constitute financial abuse.

Table 4: Responses from carers to three scenarios

Scenario 1

A person with dementia gives £20 to a friend to do their shopping. The friend keeps the change without asking the person if this is okay. Responses were:

- **always acceptable:** 0%
- **sometimes acceptable:** 2.9%
- **not acceptable:** 97.1%
- **don't know:** 0%.

Scenario 2

A family member takes £10 from the wallet of their relative who has dementia, without asking, to pay for some household items. Responses were:

- **always acceptable:** 0%
- **sometimes acceptable:** 21%
- **not acceptable:** 79%
- **don't know:** 0%.

Scenario 3

A family member has asked their relative who has dementia for their PIN and bankcard so they can pay for household items. Responses were:

- **always acceptable:** 4%
- **sometimes acceptable:** 26%
- **not acceptable:** 68%
- **don't know:** 3%.

As with people with dementia, carers also acknowledged the role that trust played in the caring relationship and how this could make abuse more likely:

'It's just a case of dealing with the situation, but we have been married for 40 years so my wife trusts me to do everything for her. The money is a problem but I am on top of it and well organised. But if my wife didn't trust me I could quite easily clear her bank account out.'

It's clear from these findings that carers are acutely aware of how vulnerable the person with dementia is to financial abuse. They also clearly understand that relationships, caring responsibilities and living circumstances affect perceptions of what could be deemed financial abuse.

3.5 Perceptions of financial abuse: evidence from professionals

Various professionals are involved in protecting people with dementia from financial abuse, while empowering them to take positive risks and continue living their lives. The following risk factors for people with dementia were identified by a focus group held with health and social care professionals, interviews with 12 safeguarding co-ordinators working in local authorities and from the survey of Alzheimer's Society staff.

- There can be power relationships at work in care situations. People with dementia can be more vulnerable to abuse if they rely entirely on carers.
- Inability to process financial information, both cognitively and visually.
- Being socially isolated without a support network. Similarly not having access to services that could spot behaviour changes which may indicate financial abuse.
- A person's generosity, and their propensity to talk about their financial situation to strangers, may lead to them being taken advantage of.
- Poverty or a fear of it may predispose people to enter scam competitions and lotteries, and give money to people who promise to invest it on their behalf.
- People who lack company or social support may be targeted by befrienders offering to do odd jobs and over-charging them.
- Lack of mobility, for example, not being able to get to bank/post office, means people may rely on family, friends or neighbours who might abuse them.
- Forgetting passwords and PINs, disclosing them to family and carers, or writing them down so people can see them.
- Leaving money, bills and other financial information around the house.
- Making large cash withdrawals and keeping it on their person.

Some professionals acknowledged that the line between financial abuse and caring can become blurred. One spoke of the need to tread carefully:

'You need to be careful, as it's not always clear what is financial abuse. Using funds to enable visits to people with dementia or buying gifts on their behalf for grandchildren (as they did before) is not abuse in my opinion, but rather, a grey area that needs defining.'

People with dementia living alone were identified by nearly all groups in this research as perhaps the most at risk of financial abuse of any of the people who they worked with. Many people are living on their own with undiagnosed, or diagnosed, dementia. The number of people struggling to manage their money, and who might be at risk of financial abuse, could be far higher than society thinks. Socially isolated people are much less likely to see health and social care professionals, who are best able to notice signs of abuse. The case below shows how vulnerable someone living alone can be. While there was no indication of abuse, it illustrates the complexity of practise:

'A woman was taken into hospital after being hit by a car and then admitted to residential care. She had come to England as a young woman. She never married and her only sister died some years previously. Her family came over and offered to take on lasting power of attorney (LPA). The consultant felt she had capacity to make the LPA but the solicitor and others disagreed. The woman did not want the family to manage her affairs. She lacked understanding of what would happen if no-one was appointed and eventually it was decided that her nephew would apply for deputyship. The process was very long and complicated and there was no access to her finances while this was in progress. Her flat required complete clearing by environmental health at a cost of well over £1,000, but there were no funds to pay for this, or her care home fees, until the deputyship was granted some months later. The banks seemed unclear on what action to take and provided contradictory advice to the advocate.'

Several professionals and adult safeguarding co-ordinators reported coming across financial abuse quite often. Many suspected that a large number of cases go unreported, particularly because they often occur in family settings. One spoke about the relative frequency of financial abuse in their area:

'Financial abuse is the second biggest abuse that occurs in our area, it's the second biggest of our alerts. There are a substantial amount of people with memory impairment which leads people to believe that they can get away with it.'

It is impossible to estimate how many finance-related cases that are referred to adult safeguarding services in local authorities involve people with dementia. This is because referrals are not always recorded by the clinical or ‘user group’ categories (Manthorpe et al, 2011). Despite this, many felt that plenty of the referrals they received did involve someone with a memory problem or dementia. Other research identified two factors that health and social care professionals believed significantly influence the likelihood of abuse among older people: the older person’s mental capacity and the nature of the financial problem (Davies et al, 2011). If there are problems with the older person’s mental capacity then professionals seem to be more alert to the risks of financial abuse than if there are none.

3.6 Common types of financial abuse and abusers identified by carers and professionals

During our qualitative and quantitative research, several types of financial abuse were commonly reported as particularly affecting people with dementia. These are outlined below.

3.6.1 Abuse by family and friends

All groups thought that family and friends could sometimes financially abuse people with dementia. They felt this was perhaps the most difficult type to define or discuss openly, for a number of reasons. For example, the lines between care and abuse are often blurred, especially when complex relationships of power and dependency are involved or when a person with dementia may trust their family and not wish to speak out for fear of losing them. Studies of elder abuse have shown that over 70% of abusers are family members, with over half of acts committed by an adult son or daughter (O’Keefe et al, 2007). When abuse of a person with dementia is taking place within a family it can be harder to detect and stop.

In addition, many people feel very uncomfortable discussing behaviours that may involve one family member ‘taking advantage’ of another. They may deny that it is happening, or resist calling it abuse. An adult child may have always taken advantage of their parent, for example, by borrowing money without repaying it. It is difficult to know whether it becomes abuse once a parent has lost the capacity to consent to the situation. Understandably, a person with dementia may not wish to speak out for fear of losing their family. Nonetheless, despite these bonds Alzheimer’s Society advocacy services receive many referrals in this area involving family members suspected of being abusers, or situations where family conflict has led to financial abuse. We should not think that all cases go unreported and need to ensure that we are able to respond effectively.

Family conflict may result in financial abuse. In particular, situations where siblings or relatives accuse other family members of defrauding or misappropriating the money or property of the person with dementia can lead to complex abusive scenarios for professionals. The following example shows how complicated this can be:

'A woman was referred to the service by her daughter, who lived abroad. The daughter had concerns about how her sister had managed her mother's finances and suggested that her mother had been forced to change her Will under her sister's influence. The woman's condition was too advanced for her to verbally communicate her wishes in relation to her finances. The advocate remained involved with the family and provided guidance for them on how the safeguarding allegation process should be followed. The advocate also liaised with social services with regard to the safeguarding issues raised by the client's daughter.'

3.6.2 Threats to withdraw care and support

Some situations of financial abuse within the family may involve threats, for example: 'We will put you in a home/deny access to the grandchildren, if you don't give us money.' Professionals reported that in their experiences people with dementia are often very reliant on their families 'doing the right thing' for them. Often they do what their family wants for fear of upsetting them. One account illustrated the pressure that some people with dementia may face:

'A woman was resident in a care home but wished to move to another one. Her reasons were that the home she was in was too far out of town and she wished to be nearer to shops and the like. The daughter, who had enduring power of attorney (EPA), and son-in-law refused to support this. In fact, the son-in-law stated that he was in charge of the money and would do as he wanted, including refusing to pay any care fees if she moved. It also came to light that they had cashed in an ISA and given it to the woman's grandchildren. Although these issues were reported to the safeguarding team and Court of Protection, nothing could be done as the EPA was not registered, and the woman had some capacity and did not wish things to be pursued. With the support of the advocate she moved to her new home and was very happy. This would not have happened if she had not had support, as her family put a lot of pressure on her not to move.'

3.6.3 Crossing the line between caring and appropriation

Adult children with access to a parent's accounts may transfer money into their own accounts without permission, which potentially defrauds the person with dementia. This can be difficult to spot and may be done for good or innocent reasons. For example, the child might be shopping for their parent. However, knowing where to draw the line between managing money and appropriation was difficult for many carers in our research. Situations develop gradually and people may not have made legal arrangements. What starts as a carer doing the shopping may develop into them keeping the change and then further into general misappropriation. Some professionals thought that situations which start innocently could turn abusive as the person deteriorates and the balance of power changes. One recalled feeling powerless:

'And you think within families, you have to know what's normal in that family, without dementia or any other problems, before you can make any kind of judgement about whether there's abuse going on. I mean we have a man who took his sister's pension while she was unable to do so and gave her £20 a week for food for both of them and we were all absolutely appalled and got the social worker to look into it and so on. But it wasn't really very far removed from what normally went on in that family and sometimes it's none of our business I guess.'

3.6.4 Entitlements and paying for adequate care

Paying for adequate care can be difficult, particularly as costs spiral. Sometimes the family has no choice but to use capital or assets belonging to the person with dementia. In these situations, relatives or children may be unwilling to pay for care, as they want to preserve their inheritance, as indeed their family may have wanted. Denying quality care, or any care at all, could be seen as a form of abuse. In some cases, there appears to be a clear conflict of interest between the rights of the person with dementia to have their money and use it for their own benefit until they die, and the belief of family members that they are entitled to their inheritance. One advocate recalled a case which had given them cause for concern:

'A man was admitted to the rehab unit after a stay in hospital. Social services felt he needed to remain in care as care packages had failed on several occasions and his family, although appearing to be supportive, were actually unreliable. He told the advocate he did not want to go back home and gave valid reasons for this, such as loneliness, isolation and it not feeling like a home as his wife had passed away. The family disagreed and felt he should go home. After discussions with the daughter, and conversations witnessed between father and daughter by the advocate, it was clear that the motives were purely financial as he would be funding his own care and the family did not want the house sold to do this. His views and wishes were not taken into account by the daughter, who bluntly told him he could not afford to pay for care and he would be going home and that she would care for him.'

3.6.5 Doorstep cold calling and miss-selling

Nearly two-thirds (62%) of carers reported that the person they care for had been approached by unsolicited or unscrupulous cold callers, or doorstep salespeople. Usually the salesperson was trying to sell products and services to the person with dementia. Many carers thought that such people should have been aware that the person they were talking to was not able to consent to the terms involved with buying a product or service, or switching providers. Common examples included selling people goods they did not need, such as double-glazing, new windows, mobility aids, stair lifts and orthopedic beds as this case study demonstrates.

'An 80-year-old man with mixed Alzheimer's and vascular dementia lost over £1,000 after he was targeted by two companies who persuaded him to buy unnecessary new double-glazing. At the time he was living on his own. The first company sent a cold caller to his address and he paid him a £500 deposit for replacement windows. His son called the company to cancel the agreement that was accepted, but nearly a year later his dad still hadn't received the refund. He has sent them two recorded delivery letters, three or four emails and called many times to ask for the refund.'

The man's son ended up paying the second company £758 for them not to install the windows. Initially his father had given the company a deposit of around £50. The first his son knew about it was when he saw something on his dad's table. He called the company, explained his dad had Alzheimer's, and asked them if he could cancel the contract. The company told him that that wasn't possible and they were still coming to install the windows. They said the only other alternative was for him to cover the company's costs and the windows would not be installed. They had a list of questions they had asked his father to check he had capacity, but these were general, not dementia-specific.'

Utility companies or others on their behalf were regularly reported to be approaching people about switching their gas or electricity supplier. One son of a person with dementia recounts:

'Somebody knocked on the door and tried to persuade my mother to change electricity companies. He said it would take a couple of minutes and then he would leave. He was there for 25 minutes and he wouldn't leave. My wife was there on a visit when it happened. My parents don't remember much about it. I went to see them the day after and my mother said what had happened. I called the electricity company and said it wasn't fair. They said they would cancel it straightaway and would never call again.'

3.6.6 Rogue traders

About 15% of carers surveyed said the person they care for had either been approached by rogue traders trying to sell them needless items or building work, or had actually had unnecessary work done. This was described as a growing concern, particularly by professionals working with people with dementia who felt that organised criminals were becoming alert to the vulnerability of people with dementia. One carer's account shows how this can happen:

'A man called at my mother's home and said he would clean the driveway for £500. She went and withdrew the money from the bank saying he was a "lovely man" and "kind to her". He washed the driveway with her water. That took one hour and pocketed £500. No one could make her understand that he was a conman.'

Other examples included a person with dementia being persuaded that emergency work to their property is essential. For example, repairs to the roof, guttering, driveway or garden. Often the quoted price seemed reasonable and the person agreed. Sometimes the work was done, but to a poor standard. Sometimes it was not done at all. The trader may demand much more money than was verbally quoted. Victims can be intimidated into paying and may be physically taken to the bank or building society to get the money. Some professionals reported having seen people repeatedly victimised by a particular trader. They keep returning to a premises demanding more and more money. In many cases, the person with dementia will have no idea why they are paying, but are too frightened to tell anyone.

This example from an Alzheimer's Society support worker illustrates the risks, possibly of repeated abuse:

'I have had telephone calls to say that someone is coming round to pick up £450 cash from a client who had already been told to go to their bank and draw it out. The client said that he was coming round soon to pick the money up and she did not know what it was for. I arrived before the man came and answered the door. I told him in no uncertain terms that he was not getting the money and he could invoice us as the client had no cash or means to get any. I asked what it was for and he said it was for electrical work that he had carried out. I asked for his company's name and address and he also gave us his telephone number. I then rang the police to inform them what had happened. The daughter was alerted and she checked the address and telephone number, which were incorrect. The police rang me the next day for more information but nothing has ever transpired from the situation. This woman also lost £1,400 when a roofer came to her house and said that she needed work done, and he took her to the bank to withdraw the money for a job that he did not do.'

3.6.7 Nuisance telephone cold calling

The problems of people with dementia receiving unwelcome or nuisance telephone calls was very commonly reported by carers. More than two-thirds (70%) said that cold callers routinely targeted the person that they care for. Common hazards included inappropriate selling, such as an energy company repeatedly calling to ask the person to change supplier. There were instances of high-pressure tactics, where people were repeatedly sold things like memberships and subscriptions. There were also more complex ‘boiler room scams’. These involve someone ringing on several occasions pretending to be from a bank or other organisation. Having established a relationship with the person, they trick them into making investments or entering competitions. One carer describes the pressures on her husband:

‘My husband dealt in shares and was on the shares list available to others. He would regularly have calls from Switzerland and other places asking for his address so they could send him information about shares he could benefit from. He was once asked if he would be interested in gold or silver shares. As he couldn’t use the phone I dealt with all the calls. I noted down phone numbers and names and reported them to the Financial Services Authority to investigate. I haven’t had any calls now for about two months.’

3.6.8 Postal scams and competitions

People with dementia are often said to be chronic scam victims. Often the person will reply to one scam, then their details are added to lists shared with other companies using the same tactics. The Office for Fair Trading estimates that the average amount lost per person every year is £850 (Office for Fair Trading, 2006). Around 40% of carers reported that the person that they care for had been regularly targeted by scam mail. Some said their relatives had lost money by entering competitions. These may be set up as criminal enterprises. However, it can be hard to determine the exact cause unless there are large sums of money going missing or proof from different sources. From numerous people, we have heard that the person with dementia may perceive scam mail as an offer of friendship and contact, especially if they are lonely. It may even come from regulated sources. One carer said:

‘We regularly receive unrequested mail from companies we deal with, and from our banks, that is potentially open to misunderstanding from the person with dementia. When those companies and banks are contacted to stop them mailing they all say it will take 2–3 months to stop the mailing which is unacceptable in my view as a carer.’

This particular type of abuse was seen as a fairly new development by those taking part in our research. Because it is not generally perpetrated by those in positions of trust, its impact on a person’s health and well-being may be underestimated and overlooked by professionals.

3.6.9 Stranger abuse

Abuse by befrienders or groomers who target people with dementia in person, on the phone, or on email was seen as a growing problem by Alzheimer's Society staff and professionals. Typically in person they start by offering to help the person, often pretending to be care workers or professionals. They may build a relationship with someone with dementia who is lonely. Having gained their trust over time, they may be able to get the person to hand over financial information or money or valuables, or even to give them authority over their finances (power of attorney or appointeeship – the latter enabling them to collect their social security benefits or pensions). One example from a safeguarding co-ordinator illustrates the issue:

'We've done one [referral to the police concerning a person who had gained] power of attorney. He befriended a couple when they had capacity. The husband died and the wife gave him power of attorney. He moved into the property and moved her into a small room. The [person granted] power of attorney was not willing to spend money on her – for nightdresses and things when these were requested. We've gone to the court. The Office of the Public Guardian has asked for bank statements. We've moved the woman to a place of safety; he doesn't know where she is, while investigations are going on.'

Professionals and Alzheimer's Society staff also reported incidents where a stranger had targeted a person with dementia and asked them to make large cash withdrawals and hand it over, or transfer assets into their name. Many felt this type of abuse could be perpetrated by several different individuals, and was hard to pick up.

3.6.10 Care workers and care homes

The UK prevalence study that covered all forms of abuse found that 30% of financial abuse among older people living at home involved care workers (O'Keefe et al, 2007). Overall this is an area where we have very little research evidence. However, we know from anecdotal evidence that situations such as these can involve a mixture of the 'opportunistic' and the 'grooming' thief. For example, a care worker or home help may form a relationship with the older person and over time exploit that trust. This case study highlights this problem:

'A man caring for his wife with Alzheimer's employed a care worker when it came to the point where she could no longer dress herself and was becoming very frustrated. She had difficulty making cups of tea or a sandwich. At that time he employed a carer. The carer slowly but surely stole about £8,000 from two credit cards for which he had entrusted her with the PINs, and also stole his wife's jewellery.'

'His wife had a credit card on which she received her pension of about £600 a month. The carer was given this card to help buy clothes or pay for haircuts and so on for his wife. The carer bought herself things on this card, as well as regularly withdrawing £250 in cash from another bank account to which the husband had given her access for things like his wife's trip to the dentist.'

People who suffer financial abuse in care homes are likely to be in the later, more severe, stages of dementia. In this situation, people with dementia may be unable to make decisions in circumstances of risk, abuse or exploitation. They could be much less able to extract themselves from situations involving risk and abuse, or to remove abusive individuals from their lives.

Sometimes care home staff may be perpetrating the abuse. There have been several cases of staff misusing residents' bankcards and cheque books. Professionals also reported residents having problems accessing funds. For example, relatives did not provide the family member with their personal allowance, or were not paying the care home fees. Indeed, at times the two were related. Consequently the resident cannot afford to have their hair done or buy toiletries. An Alzheimer's Society staff member came across situation:

'We have recently been involved in a case where a member of staff in a care home advised carers when they visited that they could pay her to buy extra nice things for their relative – carers handed over the money over a period of time but none of this money ever was spent on the person with dementia.'

Elsewhere, a carer reflected on the risks that can occur in care homes:

'Both my parents have vascular dementia; my father was in a residential home for four months prior to my mother's diagnosis; she visited him daily. She had a phone call from the bank when someone had written a cheque for £2,000 and tried to cash it. She had no idea the cheque book was missing. This monthly bill was for the amount to the residential home. I can only assume that this was a person from the home and am grateful to the bank for being so quick to realise that this was unusual.'

3.6.11 Personal budgets and direct payments

Professionals were particularly concerned that personal budgets⁴ and direct payments⁵ might result in abuse of people with dementia, particularly those with impaired or declining capacity to make fine judgements (Manthorpe et al, 2012b, in press). In particular, they feared that people with dementia may not understand the possible risks of employing unregulated people (working casually or self-employed) to provide care and that they may be exploited or neglected.

'The risks are all there and how will they be managed? It seems to me it's been rushed in without a lot of thought. The government didn't wait for the pilots to complete their work. There seems to be a view that safeguarding is the antithesis to personalisation instead of part of it. It's a one size fits all.'

⁴ Personal budgets are an allocation of funding given to people eligible for publicly funded social care, following an assessment and agreed support plan. People can take a personal budget as a direct payment, or their relative may be deemed suitable to take on this responsibility.

⁵ Direct payments are cash payments given to service users or others. They take the place of social care services which the person has been assessed as needing, and are intended to give users greater choice in their care. They are the form in which the use of personal budgets is being encouraged.

4 Identifying money management problems and financial abuse in people with dementia

To reduce money management problems and financial abuse among people with dementia, those who are supporting them must understand the risk factors that make such abuse more likely, and be able to spot the signs that it may be happening. They must also be familiar with the policies and procedures available for making referrals and the type of information that might be needed in an investigation. The sections below set out the signs that various professionals working with people with dementia felt could indicate that someone is at risk of financial abuse.

4.1 Evidence from Alzheimer's Society staff supporting people with dementia

We surveyed Alzheimer's Society staff involved in supporting people with dementia including managers, support workers, dementia advisers and home support workers about how often money management issues came up in their daily work. The graph below shows that 48% had frequently encountered problems involving money management.

Table 5: Frequency of money management issues reported by Alzheimer's Society staff working with people with dementia

4.8%	Never
18.1%	Rarely (less than three cases a year)
28.9%	Occasionally (three to six cases a year)
48.2%	Frequently (more than six cases a year)

We used a set of possible scenarios developed by researchers at King's College London from multi-agency safeguarding policy and procedure documents and from recent suggestions about money management which highlight legal and moral 'grey areas'. It referenced a range of situations where a person might be vulnerable to financial abuse and asked staff if they thought a person with dementia was being abused in these circumstances. Some scenarios focused on the individual, others related to their environment and social situation.

Staff identified several warning signs that indicate the person with dementia may be experiencing money problems or is vulnerable to abuse. Among the first signs are confusion when handling money, no recognition of the various values of money, difficulty in understanding the bill payment process, forgetting that bills have already been paid, or leaving large amounts of money lying around the house.

Another very common sign was significantly negative changes in living situation, or poor living circumstances. This could be caused by lacking the money required to buy food and clothing. Sudden changes in a person's behaviour were also seen as relevant. One staff member described some of the changes they have seen in people who are being financially abused or experiencing money problems:

'The person becomes withdrawn, more confused, stops attending social clubs, their standard of personal care deteriorates, they seem paranoid and frightened of anyone official becoming involved.'

New interest or involvement from a third party in the person's finances was given as another indicator of risk. In this case, common examples included someone befriending the person with dementia, gaining their trust and offering to do odd jobs for them, which the person then feels they should pay for, despite not being sure of the value of money.

The behaviour of the person's family was another possible indicator. Examples here included family members moving into the person's home and taking complete control of their finances; families refusing to pay for care services; or relatives pressuring the person to change their financial matters.

Table 6: Common signs of potential financial abuse reported by Alzheimer's Society staff

49.4%	Appearing withdrawn
78.8%	Big differences between finances and living conditions
85.9%	Evidence of stealing from home or person
83.5%	Being approached by unknown befrienders
90.6%	Financial irregularity in accounts or bills
81.2%	Being approached by rogue traders
88.2%	Someone with dementia paying someone to do their shopping
85.9%	Withdrawal of unusually large amounts of money from a person with dementia's bank account
84.7%	Well recognised scams (eg winning a pretend lottery abroad)
70.6%	Being asked to pay a workman/care worker in cash to avoid VAT or National Insurance
84.7%	Abuse of Lasting Power of Attorney (financial provisions)
84.7%	Reports of pressure to change wills or receive gifts

4.2 Evidence from adult safeguarding co-ordinators

Twelve adult safeguarding co-ordinators (ACS) based in local authority adult services departments were presented with the same 12 situations as Alzheimer's Society staff.

This group's views were largely in accord with the views and experiences of Alzheimer's Society staff reported above. They too agreed that a person's general appearance or behaviour could strongly indicate things were not well. Sudden changes in circumstances were also said to be potentially indicative. External warning signs included the state of the home, having little food in the house, bills remaining unpaid and neglected building work. Any of these might indicate that the person was struggling to manage their finances and could be at greater risk. The behaviour of those around the person was also cited as a possible risk indicator. For example, a third party suddenly taking a great interest in the person with dementia and offering to organise their finances could be indicative of things going wrong.

The group stressed that the signs were not definitive; many older people with dementia would rightly insist that they were managing. However, collectively their experience had led them to see unpaid bills as important, lack of money as worth exploring, and social isolation as something that can increase vulnerability. They were also watchful for coercion from people close to the person.

Another area highlighted as a potential risk of abuse was powers of attorney. This group was concerned that the person with a lasting power of attorney (LPA), the family, or another person, might not be acting in the best interests of the person with dementia. Some reported that people fail to register the LPA but portrayed themselves as acting like they had done this. Others noted that people holding the LPA sometimes act as though the money was their own instead of in the best interests of the person with dementia.

There was a consensus among Alzheimer's Society staff and safeguarding co-ordinators that having dementia often automatically puts someone at risk of money management problems and sometimes also financial abuse. This is supported by recent research into cues that alert professionals to the risk of abuse and the need for support. Studies have found that where an older person is identified as lacking capacity to make financial decisions, suspicion was immediately raised among professionals about the potential for abuse (Davies et al, 2011). Our discussions with carers also pointed out these risks.

4.3 Problems with the current system

Detecting financial management problems and financial abuse in people with dementia is a very complex area. It needs to be slightly set apart from broader debates about elder abuse or vulnerable people generally. This is due to several reasons. Dementia gradually robs people of their ability to communicate, especially verbally, making it impossible for some people to say what is happening to them. Where family is involved, people with dementia may avoid speaking out against relatives for fear of losing their support network. The person with dementia may also have low expectations for themselves, and feel too grateful for services to question potentially abusive situations.

In this section the specific roles of partner agencies that are involved in supporting people with dementia and carers are discussed. The current barriers to dealing with and minimising the risk of financial abuse are assessed, alongside the enabling factors which have proven helpful in this respect.

4.3.1 Breaking down the taboo of discussing financial issues

The difficulty of discussing financial issues was one of the most common problems raised by professionals undertaking safeguarding work with people with dementia. Finances are often seen as a personal or private matter for most of people, and many are reluctant to admit they are having difficulties, or have been scammed or similar. Without these discussions, however, practitioners found it hard to talk with families. Being able to ask relatives the right questions can help to detect signs that someone is at risk.

Others felt it was difficult to distinguish the line between caring, resource sharing and abuse. For example, relatives could be using the personal budget of a person with dementia to fund a holiday. Intergenerational issues, such as deciding who property belongs to, can also make it difficult to safeguard the person with dementia.

4.3.2 Difficulty of proving abuse has occurred

Many professionals highlighted the difficulties of proving that someone with dementia has been financially abused. For example, they felt that in cases where only the person with dementia has seen the abuse (for example, when a care worker steals their money), 'the authorities' will not accept the person as a reliable witness. This was said to be a barrier to making a complaint. They also highlighted the complex nature of gathering evidence when a person with dementia was involved; for instance, it might require seeking corroboration from several professionals, or covert action, such as video recording. They noted that in cases where relatives are the alleged abuser(s), the person with dementia may not want to testify for fear of losing family support. This view was held by one member of Alzheimer's Society staff:

'The police very rarely prosecute where family members have been involved in financial abuse, even though there has been strong evidence to support the allegation.'

Some Alzheimer's Society staff raised the issue of the person with dementia not being able to give evidence in court, which they felt may make authorities reluctant to pursue a case. The quote below illustrates this frustration and suggests that local safeguarding services have a role in debating such cases on a multi-agency basis:

'I came across financial abuse first-hand in my position six months before a man became my client. He was being taken by someone known to the police to the cash machine and they were taking money off him regularly. The local police force, although they knew who was committing the crime, decided that there was no point in taking it to court as the person with dementia could not testify.'

On top of this problem of access to justice, the person's symptoms may mean that they think they are being stolen from when they are not. Indeed, they may be forgetting that they have spent the money themselves.

4.3.3 Consistency of safeguarding policies and the prominence of financial abuse

A recent analysis of safeguarding documents (Stanley et al, 2011) showed that financial abuse is sometimes seen as secondary to other forms of abuse. From this perspective, it is often revealed through 'primary' abuse, such as physical abuse. This implies that financial abuse is somehow less serious than other forms of maltreatment. Another definitional problem stems from the use of the term 'vulnerable adult' in many of the documents based on the statutory guidance of No secrets (Department of Health, 2000). This covers a wide range of individuals, and lacks any specific focus on older people and people who lack capacity, although this situation has been changed by the Mental Capacity Act 2005.

4.3.4 Lack of data sharing among agencies

Most Alzheimer's Society staff and professionals in our focus groups and interviews agreed that, more than ever, professionals needed to work together to protect people with dementia from financial abuse. Inadequate or patchy inter-sector working makes it harder to robustly protect people's rights. No secrets emphasised the need for professionals to work together, with social services as the lead agency. Now all local authorities have multi-agency policies and procedures for addressing abuse of vulnerable adults. But despite this, safeguarding is still being undermined by poor data sharing capabilities.

Several professionals highlighted that because different agencies that come into contact with a person with dementia have strict policies on disclosing information, they are not able to easily share it. This makes it difficult to build a picture of where and how problems are occurring. The delays this reportedly creates in dealing with problems could put someone at greater risk of abuse, or get them into further financial difficulties, damaging their welfare.

This case study from Alzheimer's Society's advocacy services highlights the problem:

'A woman who had long advocacy involvement was admitted to care with full healthcare funding. She had no relatives to manage her finances. The authority took on appointeeship. But no one was looking at deputyship until the advocate pointed out that she has property and savings, and also many outstanding bills, as she had not been able to manage her finances for some time. The local authority finance department said they could not apply unless requested by the social worker, who had failed to do so even though it had been discussed with the advocate several times. The advocate ensured that the referral was made, but the process is a long one. Meanwhile, bills remain outstanding and the house stands empty.'

The stringent customer data protection policies operated by banks were identified as another major barrier by safeguarding co-ordinators and Alzheimer's Society staff. In their current form, these policies often make it very difficult to investigate suspected abuse. Where suspicious or fraudulent activity had been detected, said some, this information was rarely passed to local police. Furthermore, banks rarely reacted to requests made to them as a result of a recommendation from an adult safeguarding case conference or strategy meeting. This quote articulates the frustration that professionals feel:

'We suspected someone was being frogmarched down to the cash point, virtually every day, to get money for alcohol for the rest of the family, but there was reluctance from the bank to engage. Banks don't see it upon themselves to investigate if they have someone who is possibly being defrauded of their money. I think there's more they could do.'

4.3.5 Responsibility for reporting

The cultural barriers within professional groups and organisations were said to inhibit the reporting of abuse. Many felt that these barriers need to be broken down, but that this could only be done if agencies communicated better at a local level. Those working in safeguarding services also highlighted the apparent reluctance among some health professionals, who felt it was not part of their remit. As noted above, those working in safeguarding also reported that banks sometimes refused to act when there were good grounds for suspecting a person with dementia was struggling to manage their money or being abused.

4.3.6 Problems with banking systems

Carers and professionals consistently highlighted the variable service that people with dementia and carers receive from banks to help them manage their money safely. The following themes were identified that were said to serve people with dementia poorly.

Many carers reported that banks do not properly understand how the different symptoms of dementia can affect an individual's ability to manage their finances. Nearly 90% wanted better dementia awareness among bank staff. Common problems included great variation in the speed with which banks acted to prevent a person with dementia becoming at risk from financial abuse. This example from a member of Alzheimer's Society staff illustrates the point:

'A social worker asked me about a client she is concerned about. He has dementia and a power of attorney is registered with his daughter. However, this is quite recent and he keeps going to his local bank to try and withdraw money. The bank, on a number of occasions, have asked him to leave and have phoned his daughter saying he has been disruptive and irate when they won't issue him money. It has escalated to a point where they have called the police. His social worker reports that he is not disruptive or aggressive by nature, but he is obviously becoming more and more frustrated at the bank. I know this is more of a general dementia awareness problem on the bank's part.'

There was felt to be generally poor awareness of the Mental Capacity Act 2005 and similar legal frameworks among staff. Three-quarters (76%) of carers we surveyed said that banking staff needed greater understanding of what enduring or lasting power of attorney (LPA) means, and how it operates. At branch level, staff understanding of how provisions such as LPAs and deputyship orders work, and when they should be used, was felt by many carers to be sparse. Carers also highlighted poor staff understanding of the access that attorneys and deputies have to a person's finances, and when they can make decisions on that person's behalf. In several reported cases, banks placed restrictions on the attorney's access, as this example illustrates:

'I have recently registered the enduring power of attorney (EPA), which my mother set up in 1998 for me for when the time came. She is now 88 and has dementia and has reached the point where she needs help with her finances and banking, but still lives at home. I am her only child and I live in the north of England, whereas she lives in the south. When registering the EPA, I was advised by my lawyer that my mum would still be able to use her cash card and sign cheques. She needs this for her independent living. She uses cash to pay for food, her gardener and the like. When I took the document to the bank I was again advised that my mum would be able to continue to access her account in this way. However, once the documentation had got to the bank's head office, I received a letter informing me that her card had been cancelled. Then after various discussions and differing advice from the bank, I was informed that she now was not able to operate her account or sign cheques and that the account was now in my name and she has no access to any money. I am not allowed to have a debit card on this account. This is absolutely devastating.'

4.3.7 Powers under the Mental Capacity Act

Professionals and Alzheimer's Society staff cited the service provided by the Office of the Public Guardian (OPG) as providing crucial protection from financial abuse for people with dementia. The service helps them to plan how their money will be managed, and organise deputy systems. The majority felt that LPAs and deputyship orders, when properly operated, effectively protect people from abuse. However, they highlighted several areas where things could be improved.

While the majority of people with dementia that we surveyed (77%) said it was important to make plans for their finances, only a minority seemed aware of how to go about this. The majority of people will only use the OPG service out of necessity, namely, 'when something goes wrong'. For example, when they cannot access or manage their accounts. Many carers we spoke to felt that current guidance on LPAs was lengthy, complicated and written 'by professionals for professionals'. They called for short and simple leaflets that explain the benefits of LPAs and how they work.

The process for LPA and Court of Protection applications was seen as being too slow. Many carers and relatives approach the OPG when their relatives are losing, or have lost, capacity. This can be an extremely stressful period which presents many unfamiliar demands. Sorting out their relative's financial affairs can be another large burden, with some having to pay bills themselves until the LPA or deputyship is confirmed.

Another concern was the issue of unregistered LPAs and EPAs. The OPG has reported receiving safeguarding alerts about unregistered EPAs, but it has no jurisdiction to investigate pre-registration transactions. This remains the case even when there is evidence of direct impact on the donor's financial situation. It is easy, therefore, for a potential attorney to play the system by financially abusing the donor prior to registering the EPA.

4.3.8 Department for Work and Pensions

A person with dementia may eventually become unable to manage their income from benefits. Someone else may then need to administer this income in the person's best interests, to ensure that all benefits are claimed and essentials paid for. This can be arranged through an 'appointeeship'. An appointee can deal with benefits claims and payments, and by doing so avoid the need to assign a 'receiver'. The Department for Work and Pensions (DWP) must satisfy itself that the person needing the help of an appointee is unable to manage their own affairs, for example by visiting and if necessary getting medical evidence.

Some professionals expressed concerns about the way that appointeeship works for people who lack capacity. These included the inadequate support offered to appointees regarding spending the person's benefits in their best interests. This could lead to inappropriate management of the person's funds, or even deliberate misappropriation. There were calls for greater clarity about appointees' responsibilities, and also for better monitoring.

Professionals also highlighted the time it takes to create an appointee. Some lamented the absence of a fast-track system to help people when all the necessary information is in place. Others voiced concerns about the limited monitoring process for appointees, and the lack of checks in the system. Further concerns included difficulties sharing information, and the variable responses to problems from the DWP, local police and banks.

4.3.9 Resource and time constraints

Adult safeguarding services play an essential role in receiving referrals about financial management problems and financial abuse. They ensure a balance between protecting people with dementia and allowing them to make their own decisions. From our interviews with safeguarding co-ordinators, and recent research by Davies et al (2011), it is clear that professionals face barriers when investigating cases of abuse. These include inadequate staffing and resources, and inconsistent policies and procedures for dealing with financial abuse cases where the person may lack capacity. Such constraints clearly affect how well allegations and suspicions can be investigated. Cuts to local authority budgets could make things tougher still. Other concerns included the time it takes for criminal court investigations to be concluded and the potentially negative impact of this on the alleged victim and their family could deter them from reporting abuse.

4.3.10 Data collection on cases of financial abuse

One of the key problems in identifying the extent of financial abuse cases involving a person with dementia or cognitive impairment is that current data collection systems within local authorities are not set up to collect information by user group (Manthorpe et al, 2011). In addition, it is difficult to determine how great the risk of abuse is from unregistered EPAs, because there are no data on them as they are not registered until the moment of need. However, more data will come from LPAs as the system matures and the use of EPAs declines.

4.3.11 Staff training in financial abuse, dementia awareness and the Mental Capacity Act

There was concern that key groups are not receiving adequate training on financial abuse and money management. This could be a barrier to detecting and responding to potential problems. The groups highlighted were health professionals, care workers, banking staff, and those working in services used by people with dementia. Some professionals also commented that safeguarding procedures seem to have a very limited focus on financial abuse, despite prevalence rates probably being much higher than estimated. This comment from an Alzheimer's Society staff member articulates some of these concerns:

'I think it is imperative that anyone working with a person with dementia should know the possible signs and symptoms of abuse. Everyone needs a basic awareness about what constitutes abuse and how to recognise it. I would imagine there are many smaller care organisations that do not carry out the necessary training and therefore have unsupervised staff that would not recognise the signs of financial abuse.'

Several people suggested that some health and social care professionals needed greater knowledge of the Mental Capacity Act, specifically how to establish the mental capacity of a person with dementia. While awareness among social care staff tends to be strong, there remain areas of practice where staff may not feel confident using the provisions of the act as the King's College London EviDEM study has shown. This makes staff less able to help a person with dementia make decisions that might empower and protect them from financial abuse.

5 Recommendations: how we can prevent financial abuse

We must find practical ways to empower people with dementia to be involved in financial decision-making, and these must be based on their preferences. We need to support carers to be confident in adopting the role of managing finances. We must also ensure that professionals working with people with dementia are able to spot the signs of financial abuse and feel confident to take action. Systems and processes for managing personal finances must better meet the needs of people with dementia and carers. With these elements in place, we would be in a stronger position to prevent financial abuse and protect people with dementia.

Based on our research, the following recommendations are made to address these needs.

1 Recognise that people with dementia are at much higher risk than others of financial abuse

Professionals who provide support for people with dementia, including safeguarding and financial assessment, must better understand that these individuals are more at risk than others of money management problems, and potentially more vulnerable to financial abuse. Furthermore, the definition of financial abuse needs to be much clearer, and have a higher profile within safeguarding policies, procedures and training across local authorities, health and social care. This would help professionals to spot the signs earlier.

To clarify the true prevalence of financial abuse among people with dementia, data coding and collection mechanisms must be enhanced. The goal should be to introduce a system where suspected cases of financial abuse can be recorded by user group across all settings.

2 Improve knowledge and awareness about financial management and planning among people with dementia, carers and professionals

If people with dementia are going to be helped better to manage their money, and protect themselves from abuse, they must be empowered to talk about finances openly. This applies to conversations with each other, their families, and health and social care professionals, both before and after diagnosis. It is therefore crucial that people with dementia are equipped with financial management skills. They also need accessible information about financial planning and their options over planning for the future. The important topics range from day-to-day money management, like banking and drawing benefits, to legal frameworks such as lasting powers of attorney, to planning for long-term care costs.

Professionals who support people with dementia require more training on money management, and improved knowledge of the Mental Capacity Act. This will help them ask the right questions about a person's wishes and ensure that appropriate measures are in place to meet them.

3 Improve awareness of prevention mechanisms to help stop people with dementia being repeatedly targeted by cold callers and scams

Several systems are available to help people with dementia and carers reduce telephone cold calling and scam mail. However, awareness for them is low. Information about these options should be made available more widely through channels such as GP surgeries, memory clinics and local dementia services. They include the mail and telephone preference systems, local safer neighbourhood schemes and safe trader schemes.

Case study

Preventing nuisance calls

Currently, there are several systems for preventing cold calling and nuisance calls available. Some are simple like the telephone preference system, which can block some nuisance calls. Others are more sophisticated, including devices that plug into your landline and intercept nuisance and telemarketing calls. The device remembers two lists of numbers: one for approved callers, such as friends and family, and one for unwanted callers, which can be added as calls are received. If the device doesn't recognise the number, it will ask the caller to give their name before letting the homeowner know that there is an incoming call. The device will then tell the homeowner the caller's name, and the homeowner can decide whether to take the call, have the caller leave a full message, or have the device notify the caller that the homeowner does not wish to speak with them.

Case study

Tackling rogue traders⁶

The Help Direct Safe Trader Scheme is funded by Lancashire County Council and managed by Lancashire Trading Standards Service. The scheme aims to help people in Lancashire find reliable traders, which in turn supports local businesses. Participating firms agree to a code of practice which demonstrates their commitment to treating customers honestly and fairly. The available services range from aerial and roofing services to plumbing, building and electrical.

⁶ For more information visit: www.lancashire.gov.uk

4 Improve community support services for people with dementia to manage their money

This research shows that, where possible, people with dementia would like to stay involved with managing their money, even when they are substantially affected by their symptoms, but that cognitive impairment can hugely affect someone's ability to do so on a day-to-day basis. Alzheimer's Society would like to see more widespread support for people with dementia who want to retain control over their finances and remain involved in decision-making wherever possible.

One way of achieving this would be to look into developing money management services to help people living alone or with minimum support. Run by local authorities, voluntary organisations or independent third parties, such services would support the person in daily tasks such as shopping, paying the bills and going to the bank. This would be monitored to ensure the person has adequate funds to meet their needs, and managed safely to protect the person from abuse. An existing example of this is the Money Carer Foundation.

Case study

The Money Carer Foundation:

Daily money management services and deputyship⁷

Managing the daily money management needs of vulnerable people can be an expensive, time-consuming process for care providers, local authorities, family members and support teams. Providing an effective service, which may also involve acting as the appointee, can often be difficult for organisations that do not have the right technology or expertise.

This daily money management and deputyship service provides a comprehensive, innovative and caring approach to this important and often complicated area.

Liaising with the Department for Work and Pensions benefits department and other organisations, an experienced team provides clients with enhanced money management support which is independent and free from conflict of interest.

⁷ www.moneycarer.org.uk

5 Strengthen the role of local trading standards departments to work closely with all groups supporting people with dementia to protect people from financial abuse

Alzheimer's Society would like to see local trading standards departments better supported in working with local partners to prevent financial abuse of people with dementia. These departments can play a crucial role in preventing abuses like doorstep crime and miss-selling. They can warn, for example, about the dangers of agreeing on the doorstep to work offered by rogue traders. They should work with community-based organisations to raise public awareness by distributing booklets and door-stickers. There are several examples where trading standards have worked well with local partners, including the 'no cold calling zones' that have been established in some areas.

Case study

Local 'no cold calling zones', Hampshire County Council

No cold calling zones (NCCZ) are an initiative to combat the problem of doorstep crime. Supported by Hampshire County Council, Hampshire Constabulary and partners, NCCZ try to make residents feel safer in their own homes.⁸ NCCZ do not ban cold callers or create exclusion zones. However, they can effectively deter unscrupulous cold callers from approaching people living in the zone and give residents the confidence to say 'no'.

NCCZ can be set up from local intelligence or on request, however, both require a consultation process. Door stickers and signage are then provided which demarcate the zone and empower the residents. Evidence shows it is effective. NCCZ have been successful across the county.

6 Ensure that banking systems are better equipped to support people with dementia and carers to manage their money safely

Banks have an important role to play in preventing financial abuse of people with a cognitive impairment or dementia. However, the banking system is not currently supporting people with dementia and carers to manage their finances safely. There are several key areas where we would like to see banks take action:

Banks and building societies must become familiar with situations where customers may have dementia and provide relevant guidance to their staff

It is vital that frontline staff become familiar with signs and symptoms of dementia, so they can spot customers who may need extra support. This applies both to branch and telephone banking. In branches, staff may get to know a person with dementia well over time; they might therefore notice unusual behaviour. For instance, a customer might become forgetful, perhaps visiting the bank repeatedly to make the same withdrawals. In telephone banking, staff may notice the person continually forgetting a security password or other memorable information, or being unable to answer questions about their account. They may be told by a carer that the account holder is not able to come to the phone, or cannot answer the questions being asked. In such cases, this information should be flagged so that extra support can be given if appropriate, provided that someone trained in capacity issues is available.

⁸ www.hants.gov.uk/tradingstandards/tradingstandards-nocoldcalling.htm

The powers of the Mental Capacity Act should be consistently applied across all banks and financial institutions

It is imperative that the powers of the Mental Capacity Act are applied consistently across banks and financial institutions. Many carers report that they receive inconsistent information about how they can exercise a power of attorney, or other powers under the Mental Capacity Act, when trying to manage the finances of a person with dementia. This can cause considerable frustration and stress. There is also confusion and inconsistency regarding how banks should comply with the act's key regulations. When dealing with representatives of the person with dementia who are managing their finances, banking staff need greater understanding of the access that attorneys and deputies have to someone's financial affairs, and the powers they have to make decisions.

Bank staff should be empowered to alert relevant authorities to suspected financial abuse

The Mental Capacity Act is clear that one must assume an individual has mental capacity unless it can be demonstrated otherwise. However, if staff suspect someone is being financially abused, they should be confident and proactive in sharing their concerns with their manager. This is the best way to ensure that appropriate action is taken to safeguard the customer's interests. We would therefore like to see bank branches have a nominated safeguarding officer who can take responsibility for customers about whom there are concerns. Following this, there are several steps that staff can take. These may include seeking advice from the local Alzheimer's Society branch or adult services department, particularly if there are concerns about the risk of financial abuse. They could also contact the Office of the Public Guardian for guidance. If staff have suspicions that someone is being financially abused, they should also inform the police.

Case study

Local bank

A local high-street bank in Bournemouth worked with a specialist multi-disciplinary team and a member of Alzheimer's Society seconded to them to train bank staff to spot the early signs of dementia among their customers. When they had concerns, they alerted local health staff working in a specialist multi-disciplinary team.

7 Increase access to independent advocacy for people with dementia

Accessing justice and independent support is a major issue for people with dementia who have been subject to financial abuse. When a person with cognitive impairment or dementia has been financially abused, particularly by family members, it is vital that they are supported to communicate their experience and seek redress.

When important financial decisions are being taken on behalf of a person with dementia, who it has been decided is unable to make informed judgements, the person should have an advocate acting in their best interests. Alzheimer's Society would like to see more support for advocacy services to support people with dementia who are at risk or have been financially abused.

Case study

Age NI/Alzheimer's Society Advocacy Service

In October 2009, Comic Relief provided continuation funding for Age NI and Alzheimer's Society to deliver the Uniting Against Elder Abuse (UAEA) project. The project aims to provide independent advocacy for frail older people and those with dementia. It also raises awareness of elder abuse. Independent advocacy helps vulnerable adults to make their voices heard and ensures that older people have someone on their side who is entirely independent from the other people in their lives.

8 Bring together adult safeguarding and financial assessment teams with local authorities to work collaboratively on cases of suspected financial abuse involving a person with dementia

Staff working in financial assessment visiting teams, or those processing charges for social care services, in addition to those responsible for collecting social care income, all have a responsibility to flag concerns that a vulnerable adult is being financially abused. Visiting officers from financial assessment teams are often the first local authority staff to scrutinise a service user's financial documents and they may be able to identify large or regular cash withdrawals or unexplained payments. Local authorities need robust communication systems so that the staff are clear about safeguarding procedures and how to alert other professionals to the possibility of abuse taking place.

Social workers must recognise that an alert from someone working in the corporate debtors team should not be ignored or lack priority simply because of the belief that authorities want social workers to become debt collectors. Where staff involved in adult social care finance functions have strong links with the authority's safeguarding teams, the identification of financial abuse often occurs much earlier. This means that action can be initiated in a more timely manner, possibly preventing further abuse and safeguarding the vulnerable adult. The following case study shows how this can work in practice.

Case study

Safeguarding and financial teams working together

A woman approaches the local authority to request assistance with funding for her aunt's care in a residential home. She had previously made arrangements for her aunt to go into the home on a self-funding basis. The financial assessments visiting officer collected details of the aunt's financial situation from her niece. Meanwhile, colleagues in the processing team scrutinised the information to confirm that the case met eligibility criteria for funding. This process identified £150,000 of expenditure that was unaccounted for. During a joint visit from a member of the financial assessments team and a social worker, the aunt revealed that she did not know that her niece had sold her home and spent the proceeds. The aunt was happy to proceed with a police investigation, and, although her capacity fluctuated, she was adamant she had not given her niece 'carte blanche' to spend her money. The crown prosecution service agreed to prosecute and the niece (and her husband) both received custodial sentences.

9 Improve data sharing between agencies, and consistently implement multi-agency policies to prevent and prove financial abuse

Since the No secrets guidance (Department of Health, 2000) was published, there has been good progress on developing multi-agency responses to protecting vulnerable adults from abuse. However, this is not consistent across the country, especially with regard to data sharing, which has pockets of good and not so good practice. Regions must develop area-specific processes underpinned by agreements to share data. This will enable authorities to highlight people with dementia who are either at risk of abuse, or have been abused, so that swift action can be taken. A good example of this starting is the pan-London adult safeguarding procedures (Social Care Institute for Excellence, 2011).

Case study

Pan-London safeguarding process⁹

An example of the main statutory agencies – local councils, the police and NHS organisations working together to both promote safer communities that prevent harm and abuse, and also to deal effectively with suspected or actual cases can be seen in the Pan-London process document, Protecting adults at risk: London multi-agency policy and procedures.

⁹ Full report available at www.scie.org.uk/publications/reports/report39.pdf

6 References and further reading

Action on Elder Abuse (2004). Hidden voices: Older people's experiences of abuse – an analysis of calls to the Action on Elder Abuse helpline. Action on Elder Abuse, London.

Alzheimer's Society (2007). Dementia UK: a report to the Alzheimer's Society by King's College London and the London School of Economics. Alzheimer's Society, London.

Alzheimer's Society (2009a). Counting the cost: caring for people with dementia on hospital wards. Alzheimer's Society, London.

Alzheimer's Society (2009b). Safeguarding people with dementia: Recognising adult abuse. Alzheimer's Society, London.

Alzheimer's Society (2010). Update to figures from Alzheimer's Society (2007) Dementia UK: A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK produced by Kings College London and the London School of Economics. Alzheimer's Society, London. [online] Available at: alzheimers.org.uk/dementiaUK [Accessed 28 October 2011].

Boyd Associates for Age NI and Alzheimer's Society (2011). Evaluation of the uniting against elder abuse project. Boyd Associates for Age NI and Alzheimer's Society: Belfast.

Brayne, C, Gao, L, Dewey, M and Matthews, FE (2006). Dementia before death in ageing societies: The promise of prevention and the reality. PLoS Med 3 (10): e397.

Brown, H (2003). What is financial abuse? Journal of Adult Protection, 5 (2): 3–10.

Brown, H, Burns, S and Wilson, B, (2003). Suspected financial abuse among cases administered by the PGO, Journal of Adult Protection, 5 (2): 26–37.

Brown, H (2011). Abuse in care homes for older people: the case for safeguards, in Denning, T and Milne, A, Mental Health and Care Homes. Oxford University Press, Oxford.

Cambridge, P, Beadle-Brown, J, Milne, A, Mansell, J and Whelton, R (2006). Exploring the incidence, risk factors, nature and monitoring of adult protection alerts. Tizard Centre, University of Kent, Canterbury.

Cooper, C et al (2009). Abuse of people with dementia by family carers: Representative cross sectional survey, BMJ, 338: b155.

Crosby, G, et al (2008). The financial abuse of older people: A review from the literature. Help the Aged, London.

Davies, M (2011). Detecting and preventing financial abuse of older adults: An examination of decision-making by managers and professionals [online] Available at: <http://bura.brunel.ac.uk/handle/2438/5831> [Accessed 30 October 2011].

Davies, M, et al (2011). Factors used in the detection of elder financial abuse: A judgement and decision-making study of social workers and their managers, International Social Work, 54: 404–420.

Department of Health (2000). No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse. Department of Health, London.

- Department of Health (2008). Safeguarding adults: A consultation on the review of the No secrets guidance. Department of Health, London.
- Dixon, J (2010). Defining elder mistreatment: Reflections on the United Kingdom study of abuse and neglect of older people. *Ageing and Society*, 30: 403–420.
- Law Commission (2011). The Law Commission review: Adult social care. The Stationery Office, London.
- Langan, J and Means, R (1996). Financial management and elderly people with dementia in the UK: As much a question of confusion as abuse? *Ageing and Society*, 16: 287–314.
- Mandelstam, M (2009). Safeguarding vulnerable adults and the law. Jessica Kingsley, London.
- Manthorpe, J, Stevens, M, Hussein, S, Heath, H, and Lievesley, N (2011). The abuse, neglect and mistreatment of older people in care homes and hospitals in England: Observations on the potential for secondary data analysis [online] Available at: www.kcl.ac.uk/sspp/kpi/scwru/pubs/2011/manthorpeetal2011abuse.pdf [Accessed on 27 October 2011].
- Manthorpe, J, Samsi, K and Rapaport, J (2012a, in press). Capacity is the key: Investigating new legal provisions in England and Wales for adult safeguarding, *Journal of Elder Abuse and Neglect*
- Manthorpe, J, Samsi, K and Rapaport, J (2012b, in press). Personal budgets for people with dementia and risks of financial abuse: Findings from an interview based study with adult safeguarding coordinators, *British Journal of Social Work*.
- McCawley et al, (2006). Access to assets: Older people with impaired capacity and financial abuse, *Journal of Adult Protection*, 8 (1): 20–32.
- Office for Fair Trading (2006). Research on the impact of scams: A summary of research into the impact of scams on UK consumers. Office for Fair Trading, London.
- O'Keefe et al (2007). UK study of abuse and neglect of older people prevalence survey report. National Centre for Social Care Research, London
- Schneider, J, Murray, J, Banerjee, S, Mann, A (1999). Eurocare: A cross-national study of co-resident spouse carers for people with Alzheimer's disease: factors associated with carer burden, *International Journal of Geriatric Psychiatry*, 14: 651–661.
- Social Care Institute for Excellence (2011). Protecting adults at risk: London multi-agency policy and procedures. [online] Available at: www.scie.org.uk/publications/reports/report39.pdf [Accessed 28 October 2011].
- Stanley, D, Gilbert, A and Penhale, B (2011) Phase III: Financial abuse of older adults in England: A policy analysis perspective. Working Paper 8, NDA project: Detecting and preventing financial abuse of older adults. (Series Editor: M Gilhooly), Brunel Institute for Ageing Studies: Brunel University.
- The Observer (2010). Barclays wouldn't give us power of attorney over our confused mother's finances. [online] Available at: www.guardian.co.uk/money/2010/mar/21/barclays-power-of-attorney [Accessed 28 October 2011].
- Tilse, C, Wilson, J and Setterland, D (2009). Personhood, financial-decision making and dementia, in O'Conner, D and Purvis, B (Eds) *Decision-making, personhood and dementia: Exploring the interface*. Jessica Kingsley, London.

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

Alzheimer's Society
Devon House
58 St Katharine's Way
London E1W 1LB

T **020 7423 3500**
F **020 7423 3501**
E info@alzheimers.org.uk
alzheimers.org.uk

