**The legalities of managing finances and paying for future care in dementia: A UK-based qualitative study**

**Clarissa Giebel1,2,\*, Kath Halpin2, Lena O’Connell1,2, Joan Carton2**

1 Department of Primary Care and Mental Health, University of Liverpool, Liverpool, UK

2 NIHR ARC NWC, Liverpool, UK

*\*Correspondence should be addressed to:* Clarissa Giebel, University of Liverpool, Email: Clarissa.giebel@liverpool.ac.uk

**Abstract**

**Background:** Managing finances in dementia and on someone else’s behalf can be difficult, especially with navigating the legalities surrounding this activity. With a lack of previous evidence, the aim of this qualitative study was to explore how people living with dementia and unpaid carers are planning the financing of dementia care and deal with legal issues surrounding finances.

**Methods:** We recruited people living with dementia and unpaid carers from across the UK between February and May 2022. The topic guide was developed with two unpaid carers as advisers, and both contributed to the analysis and interpretation of findings, as well as dissemination. Participants were interviewed remotely, and transcripts analysed using inductive thematic analysis.

**Results:** Thirty unpaid carers and people with dementia participated. We generated three themes: Changes to family dynamics; Barriers to implementing legal arrangements in practice; Planning to pay for future care. Arranging financial management involved difficult family dynamics for some, including strained relationships between the carer and person cared for, and among carers. There was little to no guidance on how finances should be handled, causing difficulties in the implementation even when legal agreements were in place. The lack of guidance was equally experienced for information about how to pay for care and plan for paying for future care.

**Conclusions:** Post-diagnostic support needs to include legal and financial advice, with clearer guidance on how to access financial support to pay for care. Future quantitative research should explore the link between economic background and access to financial support.

**Introduction**

With over 900,000 people living with dementia in the UK, numbers are expected to reach 1 million by 2024 (Wittenberg et al., 2019). Dementia is a global public health concern, which not only affects the person living with the condition, but also their family members and friends, and thus their unpaid carers. With advancing symptomatology, people living with dementia are increasingly reliant on unpaid carers to support them with activities of daily living, including more complex instrumental ones such as preparing a hot meal, medication or finance management, and more basic activities of daily living, including bathing, feeding, and using the toilet (Giebel et al., 2017).

The ability to manage finances, from making bank transactions to using a cash machine and paying in shops or virtually online, is one of the first complex instrumental activities of daily living to deteriorate in dementia, often up to 10 years pre-dementia diagnosis (Peres et al., 2008). With a shift towards online banking and virtual money, there are new potential barriers for people living with dementia which have not received much attention in the literature to date. Whilst a growing body of research is looking at the potential benefits of Assistive technology for people with dementia (i.e. Brims & Oliver, 2019), there has been no focus on the digitalisation of finance management skills. Using the tab function with one’s debit card (contactless payment) and having to remember the pin to pay over a certain threshold can all be additional difficulties, or benefits (tab function), to managing finances these days, and research needs to explore how the shift to virtual finances is affected.

In order to support someone living with dementia with their finance management, putting legal measures and agreements into place as early as possible is important. Whilst people living with dementia ought to be encouraged and supported to maintain their own financial independence for as long as possible, similar to all other instrumental and basic activities of daily living (Metzelthin et al., 2017), at some point someone may have to make decisions in the person’s best interest on their behalf. Therefore, putting a Power of Attorney in place when the person living with dementia is still fully able to make their own decisions is important.

Another important legal matter to consider is to complete an Advanced Care Plan (ACP). Whilst research into ACP is a growing field (i.e. Davies et al., 2021, Sussman et al., 2021), research into the financial aspects of care planning and the roles and experiences of people living with dementia and their carers appears to be limited to non-existent to date. In England, ACP guidance is provided by the National Institute for Health and Care Excellence (NICE) (2019). NICE guidance provides an overview for registered managers of care homes and home care services when and how to best conduct an ACP with service users and residents. Considering the deteriorating cognitive functioning of people living with dementia, and thus changes in mental capacity, conducting an ACP as early as possible is strongly recommended, although the guidance also reiterates how some people may not wish to go through an ACP (NICE, 2019).

The advantages of ACP are reported numerously. Advanced Care Planning has been linked to reduced hospitalisation in people living with dementia, as reported in a recent systematic review (Wendrich-van Dael et al., 2020). However, the process of ACP was not always straightforward and fraught with difficulties for many. Synthesising evidence from 19 reviews and 11 primary studies, Wendrich-van Dael et al. (2020) showed how many people living with dementia had a need for resources when trying to plan their ACP and experienced different levels of willingness to plan in advance. The lack of willingness was also reported in a subsequent study in Canada, which evidenced how many people living with dementia only focus on their current situation and fail to consider conversations about their future wishes of care with their family to be important (Sussman et al., 2021). This in turn can lead to concerns for families and thus unpaid carers, who would prefer clear guidance on their relative’s wishes. Findings based on ACP may be related to how people living with dementia, and unpaid carers, deal with planning for Power of Attorney and how financial matters are dealt with. Considering the limited financial support for social care and support from the Government in England, people above a current threshold of savings of £23,250 have to fully fund their care needs themselves depending on an additional needs assessment. The means test takes account of the person’s savings and income, and, if the person enters residential care, the value of their home is treated as part of their savings from 12 weeks after admission unless their spouse or other qualifying relative continues to live in it. This makes advanced financial decisions surrounding care crucial. The Government planned to increase the limit to £100,000 and to introduce a lifetime cap of £86,000 on the amount people would be required to contribute to the costs of their care. While the Government had planned to introduce this reform in October 2023, they have announced a two-year postponement of implementation. However, decisions for funding care services for dementia remain important to consider as early as possible, and research is required to investigate this.

The aim of this qualitative study was to explore how people living with dementia and unpaid carers are planning the financing of dementia care and deal with related legal issues. Initial analysis of the data focused on the advanced digitalisation of finance management skills in dementia (Giebel et al., 2023). However, to date, there is no evidence on this topic despite its relevance to the everyday management, and planning for, dementia care, and its severe legal implications if not dealt with correctly. Findings from this study are hoped to provide a first understanding of how people with dementia and carers deal with financial matters surrounding care, especially in the light of the current cost of living crisis.

**Methods**

**Participants and recruitment**

Ethical approval was obtained from the University of Liverpool [Ref: 10612] prior to study begin. People with dementia living in the community and unpaid carers, living in the UK, aged 18+, were eligible to participate. People with dementia had to have capacity to consent. Mental capacity was assessed by a research team member (LOC) with experience in conducting research and working with people with dementia and assessing capacity, using the Mental Capacity Act (2005). For this purpose, people with dementia had had the opportunity to read the study information sheet and express an interest in taking part. Their understanding of the study, what it entailed, their ability to withdraw at any time point and thus their voluntary participation was assessed by the researcher at the beginning of the interview prior to the informed consent process. This entailed the researcher asking the person with dementia to describe the study and what is involved in their own words, the fact that the study is voluntary and that they are free to withdraw at any point.

Participants were recruited via Charity organisations such as Together in Dementia Everyday, the Liverpool Dementia and Ageing Research Forum, NIHR Join Dementia Research, as well as social media, by sharing a study flyer and participant information sheet. Interested participants contacted the research team.

**Data collection**

Semi-structured topic guides were developed jointly with the two public advisers and carers (KH, JC), building on their own experiences of caring for someone with dementia and how the questions should be phrased for fellow carers. The topic guide is included in Appendix I, and includes questions about generic difficulties in managing everyday activities, focusing specifically on finance management, how the pandemic has affected spending habits, and how care is paid for.

Semi-structured interviews were conducted remotely via Zoom or telephone, and audio-recorded. Prior to the interview, informed auditory consent was obtained and recorded. Interviews lasted between 20 and 60 minutes, and on average 30 minutes. Audio files were transcribed anonymously by a professional transcriber from the University of Liverpool.

In addition, participants were asked about basic demographic characteristics (age, gender, ethnic background, living situation (alone/with someone)). All carers were asked about their relationship with the person with dementia they were caring for.

**Data analysis**

Anonymised transcripts were coded by one researcher each, shared among all research team members (CG, KH, JC, LOC), using inductive thematic analysis using the 6-step approach by Braun and Clarke (2012). Each researcher familiarised themselves with the data and generated initial codes by coding transcripts manually. In team discussions, we jointly searched for themes by presenting the codes to one another, reviewed them by going back to the transcripts and finally defining the themes. In the final step, we wrote up the themes with sub-themes. The two public advisers (KH, JC) were provided training and support to analyse two transcripts each.

**Public involvement**

Two unpaid dementia carers (JC, KH) have been involved in this study, from developing study materials including information sheets and topic guides, to analysing some of the qualitative transcripts with training provided from academic research team members, to interpreting the findings jointly and dissemination. Public advisers were involved in all team discussions as equal team members, including in the generation of themes and subthemes from the data. Public advisers were reimbursed according to NIHR INVOLVE guidance (2005), and were recruited via the Liverpool Dementia & Ageing Research Forum.

**Results**

**Participant demographics**

Thirty participants – 23 unpaid carers and seven people living with dementia – took part in the study. The majority of carers was female (n=17; 74%), with people living with dementia being approximately similarly gender distributed (nfemale= 3; nmale = 4). Carers were on average 64 years old (+/-8 years Standard Deviation) [Age range: 48-81], and people with dementia were on average 70 years old (+/- 12 years Standard Deviation) [Age range: 52-88]. Four people with dementia lived alone. One interview was conducted with a husband and wife who were former carers for the husband’s mother. Twelve carers were spousal carers, nine were adult child carers, one carer looked after her sister. All participants were from a White British ethnic background.

**Qualitative findings**

Using inductive thematic analysis, we developed three overarching themes with different subthemes: Changes to family dynamics; Barriers to implementing legal arrangements in practice; Planning to pay for future care.

**Theme 1: Changes to family dynamics**

**Relationships between carers and person living with dementia**

Putting legal measures in place to allow the unpaid carer to make informed decisions about their relative with dementia’s care and well-being sometimes resulted in strained relationships. Often, the carer saw the importance and necessity of having the Power of Attorney, whilst the person living with dementia felt they did not need it. At times, this resulted in frustration for the carer and led to arguments with the person living with dementia:

*“I was shouting, ‘You've got dementia, for God's sake!’ I mean, I just thought, stop blaming me. And we need to, you know, get a power of attorney. He said ‘I don't want it though.’ You see, and I'm saying, ‘Well, either way, in three years’ time, you need to make these [care planning] decisions.’ So I don't say I did it the best way but I couldn't just get through to him that you have to make decisions when you are well. I can't be making decisions from him where he's going to be buried or what’s going to happen, and we need to have these conversations”*

(ID27, Carer, Female, 71)

Not restricted to Power of Attorney alone, some carers reported on how they were initially concerned about how their relative with dementia would consider their spending on the relative’s behalf. One adult daughter was particularly concerned and worried at first that her mother would consider her patronising, when all she did was manage her mother’s finances on her behalf diligently ensuring her mother’s wishes were taken care of. When discussing this with her mother with dementia, she was assured that there was no problem and her mother felt well taken care of.

 *“And I said, are you okay with me talking about me and you and your finance? And she said, Oh, yes, that's fine. And I said, Have you found it in any way difficult me stepping into managing your finances. And I suppose in my head, I was expecting her to say not in so many words, but that it was somehow kind of infantilizing, because my mom is very much still there. She's still my mom. And what I anticipated her feeling was that it was somehow distressing to go out, or to or to not be the person that was in charge of the money to not be the person that was carrying the handbag. And all she said to me was I trust you with my money.”* (ID06, Carer, Female, 49)

**Relationships among carers**

Relationships between family members caring for the person living with dementia were often put under strain when families attempted to put in place the Power of Attorney for making decisions about the person’s health and wellbeing as well as finances finances:

*“And I said to my sister, we need to register the power of attorney. And what my sister did was she went ahead and she registered enduring Power of Attorney just in her name... She did it… She hadn't discussed it with me and I wouldn't have agreed to that. And she didn't refer to the enduring power of attorney that we had already in place to us. She ignored that. So I told her, she couldn't do all that. But it was already done and she wasn't going to change it”*

(ID30, Carer, Female, 63)

Some people living with dementia felt the need to ‘protect’ their family members from tensions that may arise from discussions about who should have the Power of Attorney. In some cases, people living with dementia went into elaborate arrangements, splitting the Power of Attorney between their legal representatives, family members and friends in order to prevent the deterioration in relationships between close family members:

*“I have sorted out my Power of Attorney.., my solicitor is my Power of Attorney over my money when the time comes and I can no longer look after my money on my own… I’ve got a friend who has got the Power of Attorney over my health as well as my dad. So half my family and half my friend, the power of attorney is split over my health.”*

(ID02, Person with dementia, Female, 52)

Other participants living with dementia felt that they would cause tensions among their family members if they decided to put the Power of Attorney in place. This precluded them from initiating the necessary steps, and left them with no protective arrangements in place for the instances when health, wellbeing or finance-related decisions may need to be made on their behalf.

*“I have four children. And I couldn't if I asked one to do that [have the Power of Attorney]. There would be, they'd all be very argumentative about it. I mean, if I asked my eldest daughter to do it, my other children will be very angry because they will say ‘No, I want to!’ So what would I do about that?”* (ID26, Person with dementia, Female, 62)

**Theme 2: Barriers to implementing legal arrangements in practice**

**Trying to manage banking without support**

While most participants reported that registering the Power of Attorney was relatively easy, many described facing challenges when implementing legal arrangements in practice. For example, some experienced difficulties when trying to manage online banking on behalf of the person living with dementia because the Power of Attorney offers limited options for managing finances remotely:

*“There's only so much you can do with a Power of Attorney. I couldn't set up new direct debits on his [husband’s] account, for example, without going into the bank. I couldn't do it with the online banking, there are certain things that you can't do.”* (ID17, Carer, Female, 65)

However, the same participant generally also experienced positive support at the beginning of the dementia diagnosis from the bank, with their existing financial outgoings in place being supported by the bank:

*“I’d say the bank was hugely supportive, the bank manager herself got involved to persuade [husband] not to have online banking so that he wouldn't make more purchases that he didn't intend to make, was the way she, she phrased it. And we were able, with her support, to put the controls on the on the debit card. So the amount he can lose is, is limited now. And when there is an issue, when one of these authorised push payments goes through, or he forgets the pin number on his debit card, the bank is able to sort that out very, very quickly.”*

(ID17, Carer, Female, 65)

Generally though, carers received limited to no support in managing their relative’s finances or next steps to put in place after the dementia diagnosis. For some carers, this was distressing and frustrating, given the importance of being able to manage someone’s finances. Carers felt left and alone without the necessary support from vital system infrastructures, including banks and the memory services/NHS more broadly.

*“No, I don't think I had any support from them. We just got on with it, to be quite honest. So even if there was support available, wasn't aware of it, as well as we didn't have any, any support at all from any of them.”* (ID01, Carer, Female, 56)

Carers reported that many banks and utility companies did not treat their legal documents with appropriate care and attention, and did not understand or value the importance of the Power of Attorney document to the carer and the person living with dementia. This often resulted in certified copies being lost by companies and banks, with carers having to pay more money to the issuers of the documents to rectify this. Thus, carers had to navigate the financial system themselves without any guidance, often despite Power of Attorney in place:

*“Most of them [banks and utility companies] demand to see the Power of Attorney [document]… You have to present these things physically, or send them off to be scanned. And if you've ever seen a Power of Attorney, it’s copious numbers of pages. And these people don't ever seem to understand the fact that it's a precious document to you and you need it back. And then they've lost it. And then they find they scanned it onto their system and lost the original. And then you have to have a scanned copy back. And that's not a certified copy. They [companies] can be very laissez faire with things that you consider really precious to you. Because without [husband’s] power of attorney, I cannot function for his financial world.”*

(ID14, Carer, Female, 64)

*“Managing investments for him, so I wanted to set up savings account that paid more than his own bank. But that's very difficult because not many allow you to do that with a Lasting Power of Attorney. If you've got a savings account in place, you can sort of put a say, a Lasting Power of Attorney on it. But it's quite difficult to open new things with a Lasting Power of Attorney, and they want paper copies, they don't tend to post them back.”*

(ID17, Carer, Female, 65)

**Fewer worries with early banking arrangements**

Some carers had already started being part of their relative’s (parents’ or spouses’ finances) prior to the dementia, so were less affected by the dementia diagnosis and sudden need to manage more activities of daily living. In some cases, carers immediately arranged the banking after the diagnosis, to ensure the person with dementia had capacity to agree to the changes and ensure greater safety and reassurance for both

*“When she was diagnosed quite early on, my parents took a lead themselves in sorting out lasting power of attorney… And the financial side of things [was] all ticked off. So that was all done. And actually, it wasn't a sort of gradual transition, as it perhaps has been for other people… It [ability to manage finances] just literally stopped. COVID happened and I stepped in.”* (ID06, Carer, Female, 49)

**Theme 3: Planning to pay for future care**

***Anxiety about high care costs***

Both people living with dementia and unpaid carers expressed concerns about paying for future care. The costs of care were high for many, with little or insufficient financial support from the local council to pay for care now and in the long-term (specifically institutional long-term care). As a result, some family carers, particularly adult child carers, gave up working as paying for their relative’s care via paid carers was not feasible.

*“And I just didn't feel comfortable that mummy's money was being, you know, going down so rapidly. I was quite concerned. So we felt that when mummy has a lot less capacity, we may need more finances to help support her living comfortably. So I decided to take the impact of giving up work so that mummy's finances could be kept secure.”*

(ID01, Carer, Female, 56)

Some PLWD reported spending their savings to pay for care while living independently. This may leave them with little resources to cover the future costs of increased needs for paid home care or residential care. Specifically, many were anxious about covering the high costs that institutional long-term care facilities charge:

*“I live on my own with dementia, I self-care, I have to do my own cooking, my own meal prep and everything else. So I don't know what will come when I get to the point where I do need to get assistance to come in. I know it's a bit of a postcode lottery where you get and what you get. Sometimes you only get assistance or help for maybe one or two hours a week. And eventually, you can find that it eats into any savings that you've got. Or at some point I'm likely to have to go into a care home… But when you consider the amount of costs that these people are charging, it's phenomenal!”* (ID03, Person with dementia, Male, 78)

Many carers also reported feeling anxious when considering how to cover future care costs of their relatives living with dementia. Often, they felt the only option available to them was to sell the property of their relative, with some carers not interested in the money they would receive for the house given care caps and having to pass on the money made from the sale to the local authority.

*“This [paying for care] is always in the back of our mind about dad going into care, we're absolutely past ourselves about the cost of the care! I know some people use the parents’ house. So okay, but my mum still lives in it, you know, if anything happened to dad, my mum still lives in the house. So how would we pay for that? If there's a house to sell, god no, you just don't know… But that is, we're always worried about that. Because dad, we know, is going to need an EMI setting [Institutional long-term care] and nursing care. And that's not the cheapest of care. So we have got that always at the back of our mind.”* (ID12, Carer, Female, 58)

***Inequalities in paying for care and receiving support***

Overall, inequalities emerged not only between people with dementia and carers who had the necessary financial means to pay for care, but also in how some were accessing support for this. People with dementia and carers who did not have available resources to cover care home fees for example had to sell assets urgently to pay for care, which led to people feeling under a lot of pressure. This resulted in some carers and people living with dementia becoming vulnerable to being financially exploited and having to accept a lower price:

*“I mean, trying to sell my mum's house, we ended up selling it at the end, because I was so stressed, I was almost ready to sell the house to pay for the care home fees. And we… basically got ripped off by the agent, the housing agent that took over, and the people who did the house clearance.”* (ID04, carer, female, 64)

People living with dementia who had a stable income, such as a private pension and other sources of income, reported that they were able to pay a legal representative for advice and facilitation of the Power of Attorney process. On the other hand, this left those people living with dementia without sufficient funds with difficulties in navigating the legal process. Being able to afford legal processes and planning for care in advance can provide people with dementia with the confidence of feeling safe and looked after, even when living alone without a carer, something which may be lacking for people from poorer socio-economic backgrounds.

*“to protect me, especially the financial side of it. And what I want for when the time comes, if I end up in institutional care, or pass away. Obviously, I created a will it same time, so I'm covered by the will, the lasting power of attorney for both health and financial aspects of life. I went to see a solicitor, and he advised it and so on. […] they were a necessary evil, put it that way, because I like to be in control. But there might come a time where I can't. So that will protect me financially and medically. I set that up about, probably about six years ago, something like that.”* (ID10, Person with dementia, male, 72)

People living with dementia, as well as carers, who had additional income sources also reported feeling content with their current and future care arrangements, having put in place long-term care plans, including selecting a care home and paying for their funeral in advance.

*“So I had some money, because when I first got my house, I took out a critical illness policy you get with a mortgage, and then when I got diagnosed that came to power and paid for my mortgage for me. So my house is my own now. So I had some money, and had some money come through as well from somewhere else and I paid for my funeral. So my funerals are paid for, my family don't have to worry about that… I’ve also done a living will as well, so that I will stay in my house for as long as possible, and then you have to go into a home if need be not to be reliant on my family. So it’s just things like that, that I wanted to do right now so that I don’t have to worry about sorting it when my memory finally decides to fail.”*

(ID02, Person with dementia, Female, 52)

On the other hand, those people living with dementia who had no assets, savings or sources of income other than their pension (considering all people with dementia were retired), reported having little knowledge about future care options available to them, not having the Power of Attorney in place and not knowing where to get advice.

*“I’ve no money. No money, no house. I've been divorced. I've been married three times so divorce lawyers got all I had, got the house… I've lost everything… And I ended up in the council [flat], no money. So I've nothing. All I have is, I have all my books, so I have nothing, really… And I'm not sure how that system [social care system] works… I don't have experience of any of it. And I would like to know, because it would be really nice for me to find out... And there may be a point where I might need somebody to come and…to provide some support that they [family] can't, basically.”*

(ID26, Person with dementia, Female, 62)

***Need to be proactive***

The worry and concerns about how to pay for care was amplified by the lack of suitable information about finance management and care systems in general once a diagnosis was made. Based on participant experiences, there was little or no information available to carers and people living with dementia about what care options may be available or suitable to them throughout the dementia trajectory. As a result, finding avenues of financial support in order to access the care they need was obstructed, likely resulting in higher unmet needs.

*“Well, that's [paying for care in future] always a concern. And, you know, I'm unsure on what the current situation is. My reading of the situation is that we live in a very nice house, which will probably have to be sold to pay for care, if that's the case. But it’s the last thing, you know, I want to consider because, you know, as long as I'm able, my wife will stay at home.”*

(ID23, Carer, Male 78)

*“But I don't know how the care system would work for me, how much I would have to pay and what how it would? I don't know. I have no idea. There is no one there, doesn't seem to be anybody who would be willing to tell me.”* (ID26, Person with dementia, female, 62)

Carers and people living with dementia described that they had to find the information about benefits they are entitled to or to learn about financial support by doing their own research and being proactive. They called for independent advice on planning and paying for care, accessing benefits and making financial decisions to support their future needs and care choices:

*“But I do think that there ought to be something there, just to help you navigate the benefit system. Because for us, certainly, we've worked all of our lives, so going into a benefit system was very new for us. And then you get confronted with a 40-page form to fill in, you don't know what you're entitled to. So you're on Google left, right and centre. And I do think there should be more support and just somebody to let you know what might or might not be available to you rather than you having to navigate that yourself.”* (ID21, Carer, Female, 62)

*“Well, I would like somebody who was, I can't think what the word is, but not somebody from a care home. Somebody who is, what is the word where they're not involved? Independent? An independent advisor, yeah, yeah, yeah. Somebody may be from a council, or who was not tied to a company who could provide me with some independent, informed information.”*

(ID26, Person with dementia, Female 62)

**Discussion**

This appears to be the first study to have explored how people living with dementia and unpaid carers are facing financial legal issues surrounding the dementia diagnosis, and how these impact on their ability to plan for future care costs. Many participants reported severe difficulties in accessing help, support, and information about legal matters surrounding finances. Even with Power of Attorney or joint bank accounts in place, carers still reported difficulties in implementing certain financial decisions on behalf of their relative, without much or any support provided by banks or other support institutions. This was despite the Care Act (2014) stating that every individual needs to receive independent advice on financial matters regarding care and support.

Participants with greater financial security appeared to experience fewer or no issues, whereas those who needed support to finance care services often lacked the information to know where to seek support in the first place. These enabled inequitable access to a key aspect of living independently. Socio-economic deprivation has repeatedly been linked to poorer health outcomes (Fone et al., 2014; Head et al., 2021), with this study adding additional insights into how poorer economic background appears to be linked to less knowledge about support systems relating to financial issues in dementia. Future research needs to complement these exploratory qualitative findings by conducting a national survey on access to finance management support systems and associated legalities, whilst also collecting data on income and deprivation levels, to establish whether the here indicated link is replicated in quantitative data as well.

Enabling better support systems and early access to information is particularly important considering the potential damage to a person’s livelihood that reduced financial capacity and management skills can have. Research indicates that people with Alzheimer’s Disease pathology for example are already at increased risk of financial exploitation prior to a dementia diagnosis (Fenton et al., 2022), with the vulnerability increasing with advanced cognitive, and mental capacity, deteriorations. To ensure that people with dementia are better supported and the possibility for financial exploitation is reduced, earlier information and education needs to be provided to the person and their family. In addition, there also needs to be greater awareness among the general public/families to spot the early signs of dementia via increased risk of financial exploitation and early reductions in the general ability to manage finances (Peres et al., 2007).

Without adequate support systems, navigating the legalities and financial organisations to support their relative with finances and paying for care can be stressful for many carers. Carers are often already burdened with increased caring duties and the emotional aspect of supporting their relative with dementia (van den Kieboom et al., 2020). In addition, managing finances for a relative with dementia was found to impact on some carers’ family relationships, such as among siblings. This complements and adds to existing, limited, evidence on the impact of general unpaid dementia care on family relationships and dynamics. Smith and colleagues (2022) evidenced frequent communication breakdowns among family carers within the same family, and different levels of contributions to the unpaid care, with family members with fewer caring duties often unable to comprehend the full impact of caring on the primary carer. To alleviate some of the stresses experienced with trying to navigate an unknown system of finance legalities, and to avoid potentially strained family dynamics of differing opinions on how the person with dementia’s money should be spend, discussions on how to support someone’s finances and budget for future care costs should be part of everyone’s ACP. Considering the advantages of ACP (Wendrich-van Dael et al., 2020), enabling these discussions as early as possible is important.

Based on the findings, we provide the following two key recommendations for improved dealings with financial matters in dementia care – both to support the person with dementia and their unpaid carer (if available):

1. People with dementia, and their carers, should receive information about legal and financial matters in one package at the time of diagnosis, to provide increased access to information on how to manage finances and how to access additional support. This should include information on how to pay for care services and budget for care, and should be offered by the memory clinic or other healthcare professionals providing the diagnosis. This can be linked to ACP.
2. Banks need to provide greater support for unpaid carers to manage their relative’s finances and to navigate the set up of joint bank accounts after a diagnosis.

Whilst this study benefitted from having interviewed a relatively large number of participants until data saturation was reached, and having employed well integrated public involvement, there are some limitations to consider. Fewer people living with dementia than unpaid carers participated, minimising the representative voice of those living with dementia, and there was no ethnic diversity in the participant group, again minimising different cultural impacts of finance manage. Whilst we did not collect data on income and wealth as background information, previous research has received limited information from people with dementia and carers about this as people tend to be reluctant to disclose (Giebel et al., 2021). Future research could collect postcode data to generate an Index of Multiple Deprivation (IMD) to inform about participant’s neighbourhood deprivation levels as an indicator for socio-economic background. As part of this, participants could be clustered by more and less disadvantaged background.

**Conclusions**

People with dementia and their carers need to be provided with a package of information and support about managing financial matters and associated legalities at the point of diagnosis. This can be linked to ACP, which anyone with dementia should be completing to discuss their care preferences. By facilitating early discussions and support systems, clear preferences can be drawn up for the carer on how the person with dementia’s money should be spent, which may also avoid or reduce potential strains on family dynamics where different family carers have different opinions on budgeting and care financing. Future research should conduct large-scale quantitative assessments of financial management and planning skills and stages in dementia, and investigate any relationships with socio-economic background, including deprivation. In summary, this study shows that in addition to being supported to meet their day-to-day and mental health needs, people with dementia and their carers require assistance to address the legal and financial challenges that arise from having dementia.

**Acknowledgements**

We wish to thank all participants who have offered their time to take part in this study and shared their experiences. We also wish to thank Together in Dementia Everyday (TIDE) and the NIHR Join Dementia Research Network for supporting recruitment. Special thanks to Maxine Martin and Lynne McClymont for transcribing the audio files.

**Conflicts of Interest**

None

**Funding**

This study was funded by the Standard Life Foundation. This is also independent research funded by the National Institute for Health Research Applied Research Collaboration North West Coast (ARC NWC). The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care.

**References**

Brims L, Oliver K. Effectiveness of assistive technology in improving the safety of people with dementia: a systematic review and meta-analysis. Aging & Mental Health 2019;23(8):942-951.

Davies N, de Souza T, Rait G, Meehan J, Sampson EL. Developing an applied model for making decisions towards the end of life about care for someone with dementia. PLOS ONE 2021;16(5):e0252464.

Fenton L, Weissberger GH, Boyle PA, et al. Cognitive and neuroimaging correlates of financial exploitation vulnerability in older adults without dementia: Implications for early detection of Alzheimer’s disease. Neuroscience & Biobehavioral Reviews 2022;140:104773.

Giebel CM, Sutcliffe C, Challis D. Hierarchical decline of the initiative and performance of complex activities of daily living in dementia. Journal of Geriatric Psychiatry and Neurology 2017;30(2):96-103.

Giebel C, Flanagan E, Sutcliffe C. Predictors of finance management in dementia: managing bill and taxes matters. International Psychogeriatrics 2019;31(2):277-286.

Giebel C, Robertson S, Beaulen A, Zwakhalen S, Allen D, Verbeek H. “Nobody seems to know where to even turn to”: Barriers in accessing and utilising dementia care services in England and the Netherlands. IJERPH 2021;18(22):12233.

Giebel C, Halpin K, Tottie J, O’Connell L, Carton J. The digitalisation of finance management skills in dementia since the COVID-19 pandemic: A qualitative study. Dementia 2023;doi: 10.1177/14713012231159156

Fone D, White J, Farewell D, et al. Effect of neighbourhood deprivation and social cohesion on mental health inequality: a multilevel population-based longitudinal study. Psychological Medicine 2014;44(11):2449-2460.

Head A, Fleming K, Kypridemos C, et al. Inequalities in incident and prevalent multimorbidity in England, 2004-19: a population-based, descriptive study. The Lancet healthy Longevity 2021;2(8):489-497.

Metzelthin SF, Zijlstra GAR, van Rossum E, et al. ‘Doing with…’ rather than ‘doing for…’ older adults: rationale and content of the ‘Stay Active at Home’ programme. Clinical Rehabilitation 2017;31(11):1419-1430.

National Institute for Health and Care Excellence (NICE). *Advance Care Planning.* London, England (2019): NICE. Last accessed 08/03/2023: https://www.nice.org.uk/Media/Default/About/NICE-Communities/Social-care/quick-guides/advance-care-planning-quick-guide.pdf

Peres K, Helmer C, Amieva H, et al. Natural history of decline in instrumental activities of daily living performance over the 10 years preceding the clinical diagnosis of dementia: a prospective population-based study. Journal of the American Geriatrics Society 2007;56(1):37-44.

Shepherd V, Griffith R, Hood K, Sheehan M, Wood F. ‘There’s more to life than money and health’: Family caregivers’ views on the role of Power of Attorney in proxy decisions about research participation for people living with dementia. Dementia 2021;20(1):308-325.

Smith L, Morton D, van Rooyen D. Family dynamics in dementia care: A phenomenological exploration of the experiences of family caregivers of relatives with dementia. Journal of Psychiatric and Mental Health Nursing 2022; doi: 10.1111/jpm.12822

Sussman T, Pimienta R, Hayward A. Engaging persins with dementia in advance care planning: Challenges and opportunities. Dementia 2021;20(6):1859-1874.

Van den Kieboom R, Snaphaan L, Mark R, Bongers I. The trajectory of caregiver burden and risk factors in dementia progression: a systematic review. Journal of Alzheimer’s Disease 2020;77(3):1107-1115.

Wendrich-van Dael A, Bunn F, Lynch J, Pivodic L, van den Block L, Goodman C. Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences. International Journal of Nursing Studies 2020;107:103576.

Wittenberg R, Hu B, Barraza-Araiza L, Rehill A. *Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019-2040.* Care Policy and Evaluation Centre LSE 2019: London, England.