




# Understanding the financial impact of a diagnosis of young onset dementia on individuals and families in the United Kingdom: Results of an online survey

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## Abstract

Although literature on postdiagnostic support for people affected by young onset dementia acknowledges financial concerns, this topic has remained underresearched. The aim of this study was to explore the financial impact of a diagnosis of young onset dementia on individuals and families. An online survey, comprising binary yes/no, multiple-response and open-ended questions, was codesigned with people living with young onset dementia. The survey was promoted via networks and online platforms. Data were collected from August to October 2019. Survey respondents across the United Kingdom ( $n = 55$ ) who had received a diagnosis of young onset dementia were aged between 45 and 64, were at different stages of dementia and had been diagnosed with thirteen different types of dementia. Of the 55 respondents, 71% ( $n = 39$ ) had received assistance from family members when completing the survey. The main financial impact of a diagnosis of young onset dementia resulted from premature loss of income and reduced and often deferred pension entitlements. In some cases, care-costs became unaffordable. Lack of clarity of processes and procedures around needs assessments, carers' assessments and financial assessments by different organisations resulted in some families having to ask for legal advice and, in some cases, involved lengthy appeal processes. Future research needs to involve Adult Social Care and Third Sector organisations to help codesign and test financial management interventions to support people affected by this progressive health condition.

## KEYWORDS

assessment, care costs, financial advice, financial impact, personal independence payment (PIP), social care, young onset dementia

## What is known about this topic?

- Support needs of people with young onset dementia are different to those of people with later onset
- Literature notes financial concerns, but this topic has remained underresearched.

**What this paper adds:**

- The combination of living with a progressive illness and requiring care that falls outside the remit of the NHS is adding avoidable pressures and anxieties to families.
- Assessment processes are perceived to be complex and confusing and require expert assistance to navigate.
- The triple effect of income losses, depleted savings and unexpected care costs creates a ripple effect and anxieties around how to afford life now and how to pay for care in the future.

**1 | INTRODUCTION AND BACKGROUND**

In the United Kingdom, an estimated 42,500 people have been diagnosed with young onset dementia (age at diagnosis < 65; Prince et al., 2014), predicted to rise to 50,400 by 2025 (Carter et al., 2018). The differences in support needs of people with young onset compared to those who are diagnosed post retirement are well documented (Appelhof et al., 2019; Carter et al., 2018; Greenwood & Smith, 2016; Mayrhofer, Mathie, et al., 2020; Mayrhofer, Shora, et al., 2020; Sakata & Okumura, 2017; Sansoni et al., 2014; Tan et al., 2019). Contributing factors include a greater likelihood of rare dementias (Harding et al., 2018), which cause a range of different symptoms and consequently unpredictable illness progression in younger onset (Kilarski et al., 2015). An unexpected diagnosis received 'out of time' (Greenwood & Smith, 2016) and premature loss of employment and income present a significant challenge to many because of age (Cations et al., 2017; Gibson et al., 2014; Stamou et al., 2020). Literature acknowledges financial impact (Galvin et al., 2017; Johannessen & Möller, 2013; Kochovska et al., 2018; Roach & Drummond, 2014), but research on this topic is lacking (Wheeler et al., 2015).

People diagnosed with other progressive neurodegenerative conditions such as Parkinson's or Huntington's disease also lose income when no longer able to work. However, unlike those living with young onset dementia, the postdiagnostic health care and support needs arising from these conditions are largely met by specialist services through professionals such as Parkinson's nurses, for example. Parkinson's nurses work in the community and in hospitals and are employed by the NHS and in coordinated multidisciplinary support (Parkinson's UK, 2020; The Huntington's Disease Association, 2020; Huntington's Disease Association UK, 2020). Equivalent systems of support, working across health and social care that are available to people living with Parkinson's Disease and Huntington's Disease, are not available to people living with young onset dementia, although the condition is as irreversible and progressive as Parkinson's or Huntington's (Draper et al., 2016). People diagnosed with young onset dementia do however remain under the care of a general practitioner or consultant to monitor medication.

**1.1 | Assessment options, processes and procedures**

Assessment options for support and related application processes are sometimes poorly understood by those enquiring about

postdiagnostic support. There is little awareness that support for families affected by young onset dementia is assessed separately from the needs of the person diagnosed with the condition. Assessment options include (a) personal independence payment (PIP), (b) needs assessment for the person requiring care, (c) carer's assessment and (d) financial assessment to assess the contributions the individual would be required to pay in return for the social care provided under the funding criteria for England and Wales (assessments may vary in Scotland and Northern Ireland). In some cases, NHS Continuing Health Care is available.

Assessments are set out below:

- PIP*: This benefit can be claimed from the Department for Work and Pensions and is designed to support people who incur extra costs through long-term health conditions (UK Government, 2020). Claims are assessed in relation to daily living, for example, the ability to prepare or eat food, personal care, managing medication, financial decision making and mobility.
- Needs assessments*: Needs assessments are also referred to as care needs assessments and/or social care assessments. Needs assessments are for adults (18 years of age and above) who may require help (Carers UK, 2020). These assessments are carried out by social care professionals in relation to criteria of daily living.
- Carer's assessment*: Carers' assessments can be undertaken independently from needs assessments. A person in need of care may refuse to have a needs assessment carried out. The carer, however, may still need support and is entitled to it from their local authority under the Care Act 2014 but may not qualify if they are in receipt of another benefit. Both the needs and carer's assessment aim to establish the type of help required and to design what is referred to as a care package to support independent living. These assessments precede Social Care Financial Assessments.
- Social care financial assessment*: Once a care package has been proposed, households will be assessed and means tested to establish the financial contribution a family will need to make to receive such care.
- NHS continuing health care*: 'Some people with long-term complex health needs qualify for free social care arranged and funded solely by the NHS. This is known as NHS continuing health care' (NHS England Continuing Healthcare, 2020). Eligibility for NHS continuing health care is determined via assessment by a team of health care professionals.

A person newly diagnosed with young onset dementia is, in most cases, not aware of any of these options (Jones et al., 2018). To understand the implications of reduced household income, and what it means not being able to navigate financial support whilst coping with a terminal condition, we undertook a survey that explored the financial impact of a diagnosis of young onset dementia on individuals and their families.

## 2 | METHODS

There is no national dataset for people living with young onset dementia that can be used as a sampling frame. To include as many people as possible and to achieve broad representation from across the United Kingdom, we designed an online survey to capture topic relevant information and respondents' basic demographic details. The survey questionnaire was developed in discussion with eight experts by experience who are members of an Alzheimer's support group for younger people with dementia and their caregivers/carers. The information sheet, which formed part of the questionnaire, stated the title of the study and explained its aims. Consent to participate in the study was implied by respondents' participation. The survey consisted of a total of 26 questions which were a mix of binary yes/no, multiple response and open-ended questions. Questions covered demographic information and asked respondents to indicate whether they completed the questionnaire on their own and, if not, who had assisted them. Multiple choice questions, for example, 'how did the financial impact arise', asked respondents to tick as many options as applied and were followed by 'if other, please explain'. Open-ended questions asked about the financial impact of younger onset dementia on individuals and their families, and about support seeking, for example. No exclusion criteria were set, except that participants had to have been diagnosed below the age of 65, which is a nationally accepted threshold. The survey was hosted on Online Surveys™ (OnlineSurveys, 2019) and took approximately 30 to 40 min to complete. The weblink to access the survey was promoted on online platforms such as the national YoungDementia UK Network and NHS Foundation Trusts, distributed by members of the British Psychological Society who facilitate young onset dementia support groups, sent to charities that support younger people with dementia and to carers groups and network, and promoted via social media. The survey remained active for three months from August to October 2019. We posted a reminder on Twitter, encouraged 'Followers' to take part in the study and asked them to forward the URL to the survey to their networks. The information sheet invited potential participants to contact us should they prefer paper copies. In the absence of a sampling frame, we did not have an expected/estimated response rate. Ethics approval for this study was granted by the University's Research Ethics Committee (Reference HSK/SF/UH/03799).

### 2.1 | Data analysis quantitative

Completed surveys were downloaded from Online Surveys™. Quantitative analyses reflected the questions asked and were

performed using descriptive statistics. As all data were categorical, associations between potential explanatory factors and types of financial impact were investigated using the chi-squared test and Fisher's exact test; analyses were performed using SPSS v26 (IBM-Corp, 2019).

### 2.2 | Data analysis qualitative

Although the survey provided 1,000 characters for answers per open-ended question, respondents provided only brief statements, if any at all. There were no data to be transcribed. The statements provided were grouped and coded manually per research question, for example, how the financial impact arose and what the consequences of this were for participants and/or their families. Representative quotes are reported verbatim per emerging theme, for example, the financial impact of care costs, the complexity of assessment processes and consequences for families and intergenerational households.

### 2.3 | Public involvement in the study

We attempted to obtain feedback (Mathie et al., 2018) on the findings from the Alzheimer's support group who helped develop the survey questionnaire. Due to Covid restrictions, the group no longer met. We contacted the Alzheimer's Society dementia support worker, who had worked with the group over a number of years, and had facilitated the development of the survey questionnaire, to provide feedback on our findings, based on her knowledge of the group and our previous discussions during questionnaire development. This feedback helped to set out and clarify the different types of assessments (discussed in the previous section) that respondents did not differentiate between when reporting on the types of support sought.

## 3 | FINDINGS

The survey yielded a total of 61 responses. Fifty-eight questionnaires were completed online, three on paper. Several returns were not usable due to lacking age-related information ( $n = 1$ ), a diagnosis having been made aged  $> 65$  years ( $n = 1$ ) and blank returns ( $n = 4$ ). This resulted in 55 valid responses.

### 3.1 | Sample characteristics

Survey responses were received from England ( $n = 47$ ), Northern Ireland ( $n = 1$ ), North Wales ( $n = 1$ ) and Scotland ( $n = 6$ ). Of the 55 respondents, 35 were male and 20 were female. All but one respondent spoke English as their first language. Age at diagnosis ranged from 45 to 64 years (Table 1).

Table 2 reflects the respondents' self-reported stage of dementia. They were asked to choose one of four options (early, middle stage, more advanced and don't know). Findings suggest that participants were approximately equally spread across the different stages.

Of the 55 respondents, 71% ( $n = 39$ ) received assistance when completing the survey. Respondents who completed the survey on their own ( $n = 16$ ) reported being in the early stages ( $n = 11$ ) or middle stages ( $n = 5$ ) of dementia. Four respondents in total were unsure which stage they were at. The main types of dementia respondents had been diagnosed with were Alzheimer's disease ( $n = 16$ ), posterior cortical atrophy ( $n = 15$ ) and fronto temporal dementia ( $n = 9$ ). Lewy body dementia, vascular dementia and mixed types of dementia were less frequent. Genetic and rare dementias included familial Alzheimer's disease ( $n = 1$ ), Fahr's disease ( $n = 1$ ) and logopenic aphasia ( $n = 1$ ).

### 3.2 | Care costs

Care costs were more often identified by those who had required assistance in completing the questionnaire, older participants at diagnosis and current age and those reporting an advanced stage of dementia. Statistically significant associations between care costs and participants' demographic characteristics are shown in Table 3.

Findings presented in Table 3 are based on the question: 'How did the financial impact arise?' The options were (a) loss of income, (b) care costs, (c) increased transport costs, (d) other (please describe). Please tick as many options as apply. This question did not ask participants to specify care costs by type. However, although respondents in the early stages of dementia had enquired primarily about support for costs such as respite care, day care and carer support, cost items in the more advanced stages of dementia included a night-sitter (ID 27), admiral nursing (ID16), incontinence care (ID53), nursing home care (ID5; ID10) and costs for specific support such as a wheelchair (ID11).

The following section reports respondents' statements made in reply to specific questions on the financial consequences of a diagnosis of young onset dementia, the variety of support needs, support seeking and help to cover care costs. Emerging themes were the impact across three generations and emotional impact and distress. Anonymous respondent quotes are included with ID numbers.

**TABLE 1** Age at diagnosis by gender

	Gender (%)		Total (%)
	Male	Female	
Age at diagnosis (years)			
45–49	1 (3)	0 (0)	1 (2)
50–54	7 (20)	11 (55)	18 (33)
55–59	14 (40)	2 (10)	16 (29)
60–64	13 (37)	7 (35)	20 (36)
Total	35 (100)	20 (100)	55 (100)

### 3.3 | Financial consequences of a diagnosis of young onset dementia

In most cases, loss of income was a direct consequence of a diagnosis of young onset dementia as people retire usually prematurely. However, respondents lost not only their incomes but also the ability to make further contributions to pension funds. A male participant explained: '... I had to retire on medical grounds, lost a good wage and the ability to continue paying into a pension' (ID60). One respondent, diagnosed at the age of 53, stated that he had to give up work but still had a mortgage to pay. He too lost the ability to contribute to his private pension (ID42). In some cases, people experienced a loss of two incomes (and associated pensions) when a spouse gave up their paid job to care. On average it takes about 4.5 years from early symptoms to receiving a

**TABLE 2** Self-perceived stage of dementia by current age

	Current age					Total
	50–54	55–59	60–64	65–69	70–74	
Early stages of dementia	3	6	9	0	0	18
Middle stages of dementia	0	7	6	4	0	17
Advanced stages of dementia	0	3	8	3	2	16
Don't know	0	2	2	0	0	4
Total	3	18	25	7	2	55

**TABLE 3** Financial impact due to care costs by key explanatory variables

	Number (%)	<i>p</i> value <sup>a</sup>
Assistance received in completing questionnaire		0.005 <sup>a</sup>
Yes	18/39 (46)	
No	1/16 (6)	
Age group at diagnosis (years)		0.027 <sup>a</sup>
45–54	6/19 (32)	
55–59	2/16 (13)	
60–64	11/20 (55)	
Current age group (years)		0.001 <sup>a</sup>
50–59	5/21 (24)	
60–64	6/25 (24)	
65–74	8/9 (89)	
Perceived stage of dementia		<0.001 <sup>b</sup>
Early	0/18 (0)	
Moderate	7/17 (41)	
Advanced	12/16 (75)	
Don't know	0/4 (0)	

<sup>a</sup>Chi-squared test.

<sup>b</sup>Fisher's exact test.

formal diagnosis (Draper et al., 2016; van Vliet et al., 2013). One person reported: '... I had to stop work 12 months before receiving a formal diagnosis, because I could not cope. I lost my income as a result and had no entitlement to a pension or other benefits' (ID26). A female participant who was diagnosed at the age of 54 stated: '... I am single and have no income, so I am having to live off my savings and that was for my retirement and my future' (ID29). Clearly there are not only current financial consequences but also longer-term implications, leading to anxieties about how to manage both present and future needs.

### 3.4 | The variety of support needs

The variety of support needs as determined by illness progression is reflected by the enquiries made. Of the 55 respondents, 51 (93%) described their support seeking activities. Of these, 42 (82%) identified the need for assistance to cover medical costs, transport costs and other family expenses. Examples included personal care such as '... someone to help my wife to shower and dress me' (ID10) as this demands much physical strength, and help with taking medication (ID18).

Other respondents described the unpredictability of whether they would be assessed as eligible for financial support to live independently. They described situations where services failed to understand how living with young onset affected their activities of daily living. One participant who applied for PIP and carers allowance explained '... initially I was refused PIP, but we reapplied a year later and attended assessment with an Admiral nurse who was able to confirm what we were saying, and PIP is now issued' (ID20). Another respondent received disability living allowance (DLA) and employment and support allowance (ESA) on appeal (ID43). Both types of support can be claimed via the Department for Work and Pensions.

One female respondent, diagnosed with posterior cortical atrophy (PCA) in 2013 at the age of 51, explained that when the condition progressed: '... we applied for a specialist wheelchair to cope with my complex postural needs. The NHS wheelchair service refused unless my husband could guarantee that I would be taken out in it at least three times a week' (ID11). The family had to purchase the wheelchair privately because this could not be guaranteed. In contrast, one respondent received a grant for house-adaptations and was able to '... install tracking hoists and a wet-room. Equipment is on long-term loan' (ID13). These examples highlight variation in assessing eligibility for support.

### 3.5 | Assessment options and processes: Complexity and confusion and the voluntary sector

Respondents described how they had been unsure of whom to contact, and their lack of experience in distinguishing between the benefit system (PIP), needs assessments, carers assessments, and social care financial assessments for means testing. Of the 55 respondents, 23 had what they referred to as a 'financial review', but it was not clear who had carried this review. Five respondents were supported by a charity to complete application forms, 17 had a social care

assessment. Only one respondent reported having had an assessment via the Department for Work and Pensions. However, when asked about the type of support received, 12 participants indicated receiving PIP which is claimed from the Department for Work and Pensions. This is indicative of the lack of clarity around different types of assessments and loosely used terminology such as 'financial review' or 'financial assessments', when participants referred to both social care assessments and assessment for PIPs. The remark: '... the system is too complicated to understand' (ID61) was typical of respondents' perceptions. They characterised the experience of applying for support as stressful, a struggle (ID6), presenting too many hurdles (ID54), taking a long time (ID13) and often requiring repeated assessments (ID3; ID59; ID43). One person applying for financial support toward care costs stated: '... it took a year to secure an accurate assessment as my local authority insisted that my pension fund should be treated as available capital. It took a financial advisor, the stress of appealing decisions and 12 months of difficult phone calls to sort this out. We now have the principles established that should allow me to access support if I need to move into residential care' (ID43). Some respondents were assisted by a charity to fill out forms and were going to receive support from the charity in case the claim was refused (ID17). Charities were described as '... very helpful, in fact they explained every detail to us and also gave us written evidence, actually filling forms in with us explaining the questions as they went through the forms' (ID44). As expressed by one respondent: '... my husband and I worked all of our lives and do not know our way around the benefits system, which is difficult to negotiate; I could not do it alone' (ID26).

Overall, learning about support options, applying for financial support and getting accurate assessments were perceived as very challenging. The Alzheimer's Society dementia support worker pointed out that making a claim for PIP is often perceived as a complicated process. Claimants feel that forms with tick-boxes do not convey their situation fully or adequately. In contrast, face-to-face and/or telephone assessments ask very specific questions, which claimants are not always prepared for. Other problems associated with assessments include failures to obtain relevant information from other key agencies involved with an individual's situation, and/or information about an assessor's recommendations for a care package being rejected by a social care panel.

### 3.6 | Financial impact of care costs

The threat of losing their home due to having to pay for care costs was a constant worry for some. As one respondent reported: '... the house had to be sold to pay for care as all savings have been depleted' (ID5). A person diagnosed at the age of 50 stated: '... we are selling our house and downsizing to pay off loans that have accumulated' (ID25). One person who had to move to a care home said: '... apart from PIP I get no support and my savings are quickly depleting. We let the family home to pay towards the fees, but even the rental income from a four-bedroom house only covers about a quarter of the monthly fees' (ID24).

One person in the advanced stages of dementia remarked: '... having been awarded Continuing Health Care alleviated the stress' (ID27).

### 3.7 | Consequences for entire families and inter-generational households

Twenty-five of the 55 respondents (45%) indicated that the financial impact of young onset dementia affected not only those living in the same household but also adult children and relatives. One respondent stated: '... my husband and I both worked full time for a total of 85 years. We are spending our savings on care, there will be nothing left to pass on to our children' (ID15). Another respondent reported: '... we had our son and grandson living with us who had to move out straight away as housing benefit meant they became the sole person responsible for all the bills like full rent/council tax, and our claim was unable to proceed if they remained living with us ... they could not afford all those bills in our house so they had to find somewhere else to live' (ID22). Along similar lines, a further respondent commented: '... my daughter who lives with me now has to pick up the cost of heating and council tax' (ID9). The financial impact of young onset dementia affected not only adult children but also parents. As one respondent reported: '... parents from both side of the family travel 150 miles and 80 miles respectively on alternate weeks to provide 2–3 days additional support' (ID 11). In addition to financial and generational impact respondents also described emotional consequences.

### 3.8 | Emotional consequences of financial impact

Respondents indicated that the main reasons for anxiety, worry and depression related to finances, highlighting that they: '... struggle to make ends meet' (ID13), and worry about funding care (ID24), future finances (ID 32; ID26) and: '... spiralling costs as my illness progresses' (ID11). Respondents referred to: '... no longer being able to provide for my family' (ID31), 'worrying about losing our home' (ID60) and about 'whether finances are enough for daily living' (ID61). Seventy-three percent of respondents reported anxiety and depression.

The combination of living with a terminal and progressive illness, requiring care that is not provided by the NHS, and having to deal with various organisations to enquire about and hopefully obtain financial support added enormous pressures and anxieties to families affected by dementia. It was striking how few of the responses identified effective ways to access support and reconcile their radically changed financial situation.

## 4 | DISCUSSION

Findings highlighted aspects of the financial consequences of a diagnosis of young onset dementia for individuals and families.

Premature retirement resulted in an immediate loss of income, in reduced pension entitlements and ongoing financial insecurity. This applied to both the person with dementia and their family carer if they gave up their paid job. The triple effect of income losses, depleted savings and unexpected care costs created a ripple effect and anxieties around how to afford life now, and how to pay for care in the future. How can the future be managed when savings are depleted, reduced pensions may not be worth much and homes may need to be sold? This caused much anxiety, a sense of disempowerment, lack of control, and fear.

These issues were exacerbated by a reported lack of information on various assessments options and on expert advice to secure financial support (Jones et al., 2018). Various support mechanisms are available, but the dominant message was one of confusion as to which benefit or support for care can be applied for, which authority, department, agency or charity to approach and which processes to follow. This lack of information and knowledge was compounded by assessors who did not understand respondents' situation and applied benefit rules that reduced rather than optimised available family support.

At the time when needs and carers assessments are carried out families are usually unaware of the contributions which they will need to make toward their care package if it is approved. If, following the social care financial assessment, this amount turns out to be too high, individuals and families may have to decline the support that is being offered. Research on social care funding (Bottery, 2019; Jarrett, 2019) and an investigation into means-testing in adult social care (Mayhew, 2017) has begun to address some underlying issues at the systems level.

As the Alzheimer's Society dementia support worker explained, many people with younger onset dementia are under the care of their GP unless there are specific health issues that require otherwise. Nonurgent referrals for social care assessments by GPs can take a long time. It is up to the individual with a diagnosis of dementia to find their way around the various agencies which may be a struggle for those who are not computer literate or do not have a computer. This may be one of the reasons why social care assessments may not take place and/or benefits are not claimed. As reported, for one family, having been awarded NHS Continuing Care made all the difference. Similar findings were reported by Stamou et al. (2020).

The difficulties of navigating the benefit system are well documented (Woolham et al., 2017). However, for those living with a terminal condition, having to negotiate such complexities is an enormous burden. Findings hint that some of the experiences described are not inevitable. Some respondents were supported with the different assessment processes and achieved successful application outcomes.

Defining dementia as a social care issue had a major impact on eligibility. Financial loss was characterised by ongoing uncertainty, and the undocumented financial costs on the wider family were significant. There was evidence that this can be avoided, but at the moment who does and does not get help seems arbitrary.

## 4.1 | Strengths and limitations of the study

This study was limited by its small sample size. People diagnosed with young onset dementia are a geographically scattered population and most studies rely on small groups who are already meeting. Data on educational background, marital status or ethnicity could have been collected, but during questionnaire development the priority was to keep the survey manageable. Seventy-one percent of respondents received assistance when completing the survey, which could be seen as a limitation. Although findings are not generalisable, respondents' statements add depth to our understanding of the financial and emotional impact a diagnosis of young onset dementia can have across three generations.

## 4.2 | Conclusion and recommendations

To our knowledge, this is the first study that has focused on the financial impact a diagnosis of young onset dementia can have on individuals and families. The combination of living with a progressive and terminal illness and requiring care that falls outside the remit of the NHS adds avoidable pressures and anxieties to families. Future studies need to test different interventions that are likely to improve the awareness of, and access to, financial information and support over time.

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### AUTHOR CONTRIBUTIONS

All authors made substantial contributions to this paper. Conception and design (AM, NG, NS); Public involvement: facilitation and input (AM, KA, LB); Design of online survey (AM, NG, NS); Data analysis (AM, NG, NS); Interpretation of data (AM, NS, LB); Involved in drafting the manuscript and revising (AM, NG, NS, KA, LB, SS, CG); Gave final approval of version to be published: all authors.

### DATA AVAILABILITY STATEMENT

Research data are not shared via any publicly available repositories.

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