

Experiences of Unpaid Carers for someone with Dementia

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EXECUTIVE SUMMARY

Carers Trust Wales wanted to understand experiences faced by unpaid carers for people with dementia. An exploratory piece of work, the findings contribute evidence to better equip the charity to campaign nationally for appropriate, targeted support for carers. The findings will also contribute to developing resources to raise awareness amongst policy and decision makers regarding unmet need. Rather than understanding macro-level, wider patterns of behaviour, the ambition of this project was to have a richer, contextual understanding of experiences. Therefore, to collect evidence, in-depth semi-structured interviews were carried out with eight carers. The following themes emerged:

1. The carer role is not something that is well recognised but also not clearly defined

Carers reported that it took time for them to self-identify as carers. Many considered the caring activities they undertook as expected because of the relationship they had with the person they cared for e.g. their partner, child/parent or grandchild/grandparent. Care work would fluctuate over time in terms of intensity and specific duties, adding to the lack of a clear definition. Overall though, it would be a trajectory where care activity increased. **The lack of recognition, as well as the lack of a regular formal review of needs, potentially leads to missing out on appropriate support until crisis point is reached.**

2. The identity of the individual can be intertwined with caring

Caring can come to define the unpaid carer. Many carers felt that the demands of the role meant that caring was who they were. There was little or no time to pursue personal interests. Some recognised this and actively sought other activities e.g. through work or exercise. However, even in these instances, carers recognised that they were always 'on call' in terms of their care work and anything they did was significantly influenced or had to fit in with their care role. When their care role was over, some reported that it took time and was difficult to get used to their changed situation. Support was still required long after they had finished being a carer. **Care work should be recognised as a highly significant part of a person's life and sufficient support should be given for as long as needed both for the duration they are caring but also afterwards, as they adjust to a new way of living themselves.**

3. Care work often negatively impacts on carer wellbeing

Carers often found their experience was lonely, stressful and depressing. The psychological strain was significant to many, and this was exacerbated by the COVID-19 pandemic which put the cared for person at high risk and put restrictions both on support services available as well as opportunities for any form of respite (formal and informal). **Self-care is vital and a concerted effort should be made to provide opportunities for carers to be able to have the space and resources to achieve this.**

4. The changed relationship between the carer and cared for can be particularly emotive

Due to the nature of the relationship between the carer and cared for, it can be particularly emotive. This is sometimes due to the tasks involved in providing care or the resulting symptoms, such as personality changes or forgetting the carers name. This adds additional strain to what can already be a highly stressful situation. **When supporting the carer, it should be recognised that progressive illnesses such as dementia may provoke particularly sensitive issues that require additional assistance.**

5. Carers want a different relationship with Social Services

Many reported feelings of being ignored and excluded by Social Services, both in the provision of any support for themselves as well as being involved in future planning for the person they care for. They felt that, had they a different relationship, this would have a better long-term outcome for everyone. **When developing a sustainable plan of care for the cared for individual, it is essential that unpaid carers are included, playing an active and meaningful role. This will encourage the suitability and sustainability of plans as well as a better quality of life for all parties.**

INTRODUCTION

Dementia is not a single disease but an umbrella term to describe many progressive symptoms that affect the brain. According to Dementia UK there are over 200 different subtypes of dementia[1] though some are considerably more prevalent than others. The most common forms include Alzheimer's disease, vascular and frontotemporal dementia. It is possible for a person to have more than one form of dementia and whilst many symptoms may be synonymous with certain forms of dementia, the extent and impact of a dementia diagnosis differs between different people.

Symptoms are varied and extensive including behavioural changes and memory loss. It can also affect judgement and the ability to recognise everyday objects or even loved ones.[2] Symptoms can also be unpredictable and, though a progressive illness, the speed of change can also be variable.

Primarily regarded an age-related disease, 1 in 6 people over 80 will have some form of dementia. [3] There are currently almost 885,000 people living with dementia in the UK with approximately 42,000 of these living in Wales. However, it is not exclusively associated with age and those under 65 can be diagnosed with what is known as Young Onset Dementia.[4] There are currently approximately 40,000 people living in the UK with this condition.[5]

Caring for someone with dementia can be rewarding but many find it a challenging experience. Associated tasks can include assisting with washing, cooking, dressing, managing medication and providing emotional support. Unpaid care is often undertaken by a family member, friend or neighbour. It can be very consuming both in terms of time but also the emotional burden it carries. A study by Carers Trust Wales found 68% of older carers stated caring has had a negative impact on their mental health.[6] Carers can often feel stressed, frustrated and overwhelmed with little time for themselves.[7]

[1] <https://www.dementiauk.org/about-dementia/dementia-information/what-is-dementia/> [accessed 10.03.22]

[2] <https://www.ageuk.org.uk/information-advice/health-wellbeing/conditions-illnesses/dementia/understanding-dementia/> [accessed 10.03.22]

[3] <https://www.nhs.uk/conditions/dementia/about/> [accessed 10.03.22]

[4] Wittenberg et al. (2019) Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040. The London School of Economics and Political Science

[5] <https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-uk-report> [accessed 09.03.22]

[6] <https://carers.org/news-and-media/news/post/79-carers-trust-wales-launch-new-guide-to-support-carers-looking-after-people-with-dementia-> [accessed 03.09.21]

[7] Bashir, F. et al. (2020) Caring for someone with dementia. Carers Trust Wales.

CONTEXT

Against this backdrop, Carers Trust Wales, funded by the Shaw Foundation and the Waterloo Foundation, wanted to understand the experiences and needs of unpaid carers for people with dementia.

The purpose is to use the findings to provide recommendations to policy and decision makers and to add to the body of evidence to be best equipped to campaign nationally for better support for carers, raising awareness of unmet needs.

Whilst the initial objective was to understand carer experiences, data collection took place at the height of the COVID-19 pandemic. It has already been well articulated that the pressures associated with the events of 2020/21 have exacerbated issues for many carers^[1] but due to the seismic impact it has had, it was inescapable that many of the experiences discussed by carers were heightened due to the restrictions and associated concerns.

METHODS

Eight in-depth interviews were undertaken with carers of someone with dementia. Unfortunately, due to technical issues, data is only available for seven though information from the additional interview did inform understanding of data from the others. All interviews were undertaken remotely either online through video call or by telephone. The length of interviews varied between 42 and 73 minutes (mean length 63 minutes).

Three male carers and four female carers were interviewed. All interviewees cared for a family member with two carers looking after at least one grandparent, four caring for a parent and one caring for a spouse.

Interviews were semi-structured to provide a guide but to allow for detailed, richer responses. This ensured the priorities of the carer took precedent whilst specific areas of focus could be explored further. It was never the purpose of this study to capture generalisable, summative data.

The topic guide established to provide a broad framework included the following:

- What everyday life is like for the carer and the person they care for.
- Experiences with health care and social care.
- Where, if anywhere, support is accessed.
- Challenges faced such as to the carers' well-being, accessing short breaks or concerns about finances.
- Anything else they wished to share about their caring role.

Recruitment took place by advertising via social media and through Carers Trust network partner organisations.

Participants were given an information sheet and consent form. Interviews were recorded, transcribed, and thematically analysed by two researchers separately with findings then compared.[9]

FINDINGS

The following are the key themes to emerge:

1. The Carer role is not something that is well recognised but also not clearly defined
2. The identity of the individual can be intertwined with caring
3. Care work often negatively impacts on carer wellbeing
4. The changed relationship between the carer and cared for can be particularly emotive
5. Carers want a different relationship with Social Services

The Carer role is not something that is well recognised but also not clearly defined

The purpose of this study was to understand the experiences and challenges of unpaid carers for people with dementia. By the very nature of recruitment methods, it was dependent on two assumptions: there was a medical diagnosis of dementia and the role of 'carer' had been recognised and defined, at the very least by the carer themselves. Even so, during interviews, many carers reported how it took time before they recognised themselves or felt recognised by others as a carer. Before this, they would have identified themselves more as 'family member', 'spouse' or 'friend', undertaking these activities as part of this relationship to the cared for person. Identification is something of an existential premise and for many carers it is simply not something they have stopped to consider:

"When you are a carer, priority is all about things like the next prescription etc. You don't stop to think 'you are a carer'."

The tasks and 'doing' of care work are what takes priority and what these can be bound up to signify and represent are not always felt relevant for many carers.

To complicate the notion of 'carer' further, it was highlighted during interviews that 'care' is not static. This reflects the way in which symptoms and associated needs of the person with dementia are not static. It is not a simple dichotomy where a person is a carer or is not. One carer reported that he initially agreed to take on tasks for his grandparents as he had time available and over the years, the extent of his caring responsibilities increased as required, often without him being conscious to this:

"...I was caring a long time before feeling recognised as an 'official carer'."

This is a common theme and can lead to complications as it is not recognised by either the carer or other friends and family that the associated pressure that comes with the role may have increased until crisis point is reached.

Another carer noted that he had undertaken multiple caring roles throughout his life and could therefore recognise marked differences in the levels of responsibility as well as time pressures that came with each:

“My father passed away when he was a young man, my sister had a congenital heart defect and my brother had learning difficulties, so I was pretty much always helping them with different help and support and that was from a very young age really. And then my mother had mixed dementia for 10 years and then I started to care for her. That’s a different type of care in many ways. I had to pick my game up a lot more.”

As a progressive disease, carers of people with dementia are particularly likely to see their responsibility levels increase over time. This highlights the importance of both having a carer assessment in the first instance but also reviewing these regularly as responsibilities and associated impact changes.

When carers have been caring for a significant proportion of their life, it is not necessarily something that they recognise as being separate or ‘changed’ from any other way of life:

“I was caring for members of my family, and I thought then as a child and teenager well that’s what you do, it’s your family. Which is not wrong, it’s quite right but as the years go on you become a hidden carer. You have to register to access services you are entitled to.”

Lack of self-identification as a carer prevents access to vital support and certain entitlements. It is worth remembering here that this became evident during interviews with carers who had already identified themselves as carers, hence volunteering to participate. There are many carers who would find the label problematic and struggle to recognise distinctions between care work and the work expected of a family member or friend. This restricts access to advice and support.

In addition to both the lack of awareness of a carer definition and the fluidity within the role, one young adult carer reported moving in and out of the role altogether. She described sharing responsibilities with her sister which meant that she was a full-time carer for a set period and then attended full-time study. Though an uncommon arrangement, the move in and out of a care role could potentially be problematic to access support which many describe as slow moving and inflexible.

Others describe how the caring role fluctuates, varying in levels of intensity and responsibilities changing as circumstances do but, nevertheless, always present. The needs of the cared for person changes and therefore so does the tasks of the carer. For example as one carer explains:

“Even when he was in a care home, I had to do things. I managed errands.”

It would be easy to assume that admission of the cared for person into a care home would absolve the carer of further responsibility or at least reduce the pressure. In fact, as noted above, this is not necessarily the case; the role and duties evolve instead, potentially blurring the lines and making it difficult in terms of determining where responsibilities lie. Again, this fluid nature of caring adds to the complication of identification and recognition both by the carer and statutory services which offer support.

The identity of the individual can be intertwined with caring

Many carers described their caring role as a 24/7 arrangement. The nature of dementia means that symptoms vary but the cared for person may require attention or assistance at all hours. Even if the role of the carer is less time consuming than this, the relationship between carer and cared for and the care work itself may come to embody the 'personhood' of the carer. During interviews, when discussing interests outside of the caring role, most interviewees stated that they found this very difficult or would describe any hobbies in the past tense:

"What I have done is put my life on hold. You can't just sit at home and wait for the phone call, which is what I was doing. There is no alternative though. I love my mother."

Another carer reported:

"Juggling things was really hard. I was busy from 8am to 2am.... It stopped me going out....my life finished...I had to make sure I was on the end of a phone for them."

Some interviewees were particularly aware of the potential for the carer role to define them and consciously resisted in allowing themselves to be solely understood by this role. A carer for her mother was very keen to continue her work as a Teaching Assistant. She recognised its importance to her holistically:

"Sometimes I am exhausted mentally but I love my job. It's quite a competitive job, and I've done all these qualifications now and I think 'ooh, I don't want to give it up or cut my hours'. It's my release, I enjoy the job I do, it's my identity."

Care duties are significant, but this carer also reflected that it was important to her to have other things in her life. By describing work as her 'release' it meant that by identifying with other work, she is better equipped to also undertake care work.

The young adult carer who split her carer role with her sister took this even further and felt she had to make up for the young adult experiences that she lost during time spent undertaking her carer role. When with her grandmother she reflected that:

"It can be really interesting if you, like, take yourself down to that kind of slow pace a little bit. But you do need the balance because otherwise, if you're too slow, I'll just go mad. Like if I don't have a few days to go travel, run around, or do something, that's not good."

This carer felt that when she was not caring, she made the most of the lack of responsibility and was particularly care-free, making up for 'lost time'.

The difficulty for the carer to have their own interests and lives is apparent and highlights the need to support carers as individuals in their own right. Support should not just be for the purposes of assisting to continue in their caring role but recognise that, often due to the role, many carers are not able to access other aspects of living. They should be afforded the support to do this as an end in itself.

Carers described that the responsibility whilst caring can have long lasting effects, even after their care role has come to an end. This can also have significant ramifications for identity, personhood and sense of purpose. As one carer stated:

"After he went to the care home I was lost. When you're used to doing things 24/7, you're lost then. It takes time to settle. It took me a year to get over things."

If the carer has spent a significant amount of time putting their all into being a carer, it is perhaps unsurprising that when this role changes, reduces or stops altogether, it can be difficult for them to find ways to fill this void. Another carer explained that the additional blow of bereavement, the reason he ceased being a carer, had a significant additional impact:

"My brother died suddenly in the night....and then my mother who was carrying dementia passed three months later then about two years later my sister passed.... I try to talk about it but bear in mind when it happened, 2017, I hardly said two words to anyone for over 12 months really. When I was caring it can be isolating and stressful.... With the grief that came on top of it all its fair to say I had a bit of a 'melt down'."

This carer received support and counselling both during and after his care role had finished. He highlighted the importance of continuing to receive support after the caring role which was much appreciated as he recognised it is not something offered universally.

Carers also noted the value and importance of using their experiences to benefit others whilst it simultaneously helping them to find purpose, to fill the gap left by their care role finishing. One carer reported taking up multiple volunteer roles to support carers:

"Going through that now has given me a purpose, to get some focus back into my life."

Supporting opportunities such as providing ex-carers with the training, resources and time to share their experiences with others provides invaluable support to existing carers whilst simultaneously adding to the skills, confidence, purpose and sense of worth for those ex-carers providing the support.

As before, support for the carer should not simply be to allow them to undertake their caring role but to provide support for them in its own right. Therefore, if the impact of caring means the individual continues to require assistance, even after the caring role changes or stops, this should be available and offered whenever possible.

Care work negatively impacts on carer wellbeing

So far, considerations have focussed on caring for someone with dementia at a holistic level in terms of carer self-recognition and identity. What is equally, if not more important to understand is the day-to-day, lived experience of the carer.

Many carers often reported feeling isolated, lonely, anxious and depressed. As discussed, the interviews took place during the COVID-19 pandemic. Whilst the impact of the pandemic was not an area of specific focus here, it is inescapable that it had a fundamental impact which often seemed to exacerbate existing issues further. As a carer for her mother states:

"It's because I was locked in, I was locked in with my mother and psychologically it wasn't my choice and...I was put in there and sometimes when you don't choose it there is a little bit of resentment. I was angry and resentful against the disease, and I bruised my hand as I lashed out at the wall out of anger."

This carer moved in with her mother at the start of the covid-19 lockdown to provide support. Whilst initially assuming she would cope well, the sudden increase in intensity with little sign of respite led to her eventually reaching crisis point. This came as a shock to her, and the unforeseen stress knocked her confidence. This additional pressure was felt throughout most of the interviews.

For many it was the strain of the work coupled with its repetitive nature and lack of respite which carers found particularly challenging. However, others described that being physically separated from the person they care for also adds to the pressure. One carer described how, when away from her mother, she would feel anxious and guilty, often unsure if she was doing the right thing:

"I have to go to work to pay my bills. My mother doesn't want help at home and insists she is fine but then phones me up shouting 'where are you? you're meant to be with me, you're my carer'. It is difficult to hear."

Many carers reported finding no time for themselves or for their own wellbeing. Even if they wanted to, this was simply not an option given the level of responsibility that comes with looking after someone with dementia. Some carers recognised the impact caring had on them, but for others this only became apparent during a period of reflection. As one carer states:

"At the time it was like, okay, do what you've got to do to get through the day kind of thing. And you don't have time to think, again, think about it, I definitely feel like the effect came later on".

A young carer suggested that the lack of boundaries or structure when it comes to caring plays a role here:

"it's difficult because when you go to a job, you put a certain amount of effort in and then you can stop. But when it's someone you care about, and you love, and it's at home, it's very difficult to put a stop button on how much effort you do."

Another stated:

"Caring can be isolating and stressful but, for a loved one, I would do it all again."

The lack of boundaries (both time and space) and, often, the sense of duty means that the carer has no parameters to separate themselves from the role. They often put the cared for person ahead of themselves and this then becomes second nature.

This lack of self-care could be a significant contributing factor to carers reaching crisis point before seeking or agreeing to support. It would be hugely beneficial to support carers to recognise that self-care is vital, having a positive impact both on themselves and the person they care for as well as ensuring they have the right support and infrastructure to take any opportunities available.

The changed relationship between the carer and cared for can be particularly emotive

Care work, particularly care work for someone with an age-related disease such as dementia, can challenge traditional role expectations and assumptions within a relationship that many find very difficult to reconcile, especially when confronted with it for the first time. Whilst a carer will often be responsible for a family member, with dementia, it is particularly likely to be a partner or parent, who the carer had a different relationship with prior to diagnosis. In many instances, such as the child now caring for the parent, activities are inverted from what has gone before. Interviewees discussed their lack of preparation for how difficult they found this dynamic to be. A carer looking after his mother explains:

“Sometimes I had to step in in terms of personal hygiene and, of course she’s my mother, I am going to find things like that difficult, but you get into a situation where you’ve got no choice and you have to step in.”

In addition to the emotional aspect of performing personal tasks, knowing the person, the relationship as it was and seeing it change was also reported as something which many carers found particularly difficult. The same carer goes on to say:

“She (mother) would go into conversations that didn’t make any sense.... when that first happened, I would say that’s wrong. You just wanted it to be ok because it’s painful watching a loved one like that. It was really painful.”

“She went through a short period of time where she didn’t know who I was. That’s incredibly painful.”

Care work can already be exhausting and overwhelming, but this additional emotional strain can be very difficult. Emotional support and advice, such as the Dementia Guide produced by Carers Trust Wales[10], can be vital in helping to prepare and support here.

Carers want a different relationship with Social Services

Throughout this paper, the importance of receiving adequate support for the carer has been highlighted. However, it was widely reported by carers during interviews that working with Social Services can be challenging. Whilst it must be recognised that interviewees were self-selecting, and therefore it is plausible that some came forward with a specific grievance to communicate, nearly all interviewees had frustrations, to varying extents, working with statutory services.

Levels of frustration can be broadly categorised in two. The first is a frustration of a perceived lack of support to the carer specifically whilst the other is a lack of carer involvement in the decision making for the cared for person.

In terms of support for the carer, it was felt that the lack of reliability and flexibility are difficult. One interviewee described his experience:

"It's like hitting your head against a brick wall. The social worker never rings back."

It feels like a fight to receive any support. Others did recognise that support was available but felt it was inconsistent:

"Where you live depends on what sort of diagnosis you get, what information you get, what support you get and how helpful it is or not".

This can add to the sense of confusion and demotivation amongst carers. A young adult carer felt that any support offered was inappropriate for her needs:

"I need to be with people my age and pursue my career interests."

Rather than support that provides escape or respite, this carer felt support that provided opportunities to continue with other aspects of her life, such as training or career preparation, was more important. This resonates with a report from Public Health Wales highlighting that participation in tertiary education was 10% lower for young adult carers than the general population.[11]

Whilst there were frustrations at the lack of available, appropriate support, it was also felt by some carers that there was a lack of empathy towards carers as well. There was a sense that the social worker felt their professional responsibility began and ended with the cared for person so the carer and their needs were ignored:

"The social workers should care for the carers. Show them some sympathy now and again. Have some empathy...I would love it if a social worker said to me just once 'I know what you're going through' because they've had practical experience, but they haven't so they don't.... Healthcare staff are a lot better. The district nurses are always really sympathetic and if social workers had even a dab of empathy, then that would be great. If there was more sympathy from the social workers, then a lot of the grumbles I have wouldn't exist. The social worker should care for the carers."

[11] <https://phw.nhs.wales/news/closing-educational-engagement-gap-for-young-carers-is-key-to-improving-health-and-wellbeing-of-future-generations/> [accessed 03.09.21]

This sense of being excluded extended beyond support for the carer directly. It was felt that all aspects of caring and being unpaid carers were regarded by social services as less important, lacking credibility and professionalism on the one hand whilst being taken for granted on the other. Carers would express frustration about being excluded from the conversation when it came to the person they cared for. It was felt that it would be far more advantageous if they were given an equal footing to other care providers and stakeholders in the decision making. Their intimate knowledge of the person being cared for, the sensing of subtle changes that may be important, are absent from the conversation yet are felt to be vital to ensure the cared for individual receives optimum care. As one carer put it:

"I've lived with them all my life; I know what is normal and what is not normal."

The perceived reductionist process of matching care needs upset carers who felt their loved one was being dealt with as a number rather than an individual, with decisions already determined with little regard for the individual preferences of the person with dementia or their carers as to what might be the best course of action. As described by another carer:

"I used to get upset by social workers. They are there to do a job, they are professionals, but I found they wouldn't work alongside me. I'm a carer and her son and they should work alongside me. I had to work alongside them as well. We had to meet halfway, and it didn't happen. I went to meetings where I felt decisions had been made beforehand."

This carer recognised that social workers had a difficult job to do and conceded that he needed to give ground as well. It was felt by many interviewees that if they were partners in the process, the arrangements were far more likely to be successful, thus leading to a more successful outcome all round with far fewer situations reaching crisis point. It was seen as a missed opportunity as unpaid carers input could provide better, more sustainable solutions to the care needs required.

RECOMMENDATIONS

During interviews, carers were asked what single message they wanted to convey to decision makers. In addition to this question, other themes emerged, and the combination of these approaches leads to the following suggested recommendations:

1. Concerted and sustained efforts should be made to recognise 'hidden carers', carers who do not recognise themselves as such. Health and Social Care professionals should be encouraged to recognise and identify unpaid carers so that they can access any necessary support, advice and entitlements accordingly.

2. Caring is a fluid process. People can move in and out of care and the care they give can range in terms of intensity during this process. Support offered needs to mirror this. It needs to be responsive, flexible and agile enough to reflect the ever-changing nature of care provided. No two situations are the same and support offered must be able to recognise this in its approach.

3. Support offered to carers needs to be both during their care role but also after they stop providing care for as long as required. This includes offering emotional support as well as more practical opportunities for carers to be able to feel a sense of purpose that may have been lost when the care role finished.

4. There are differences between someone who cares for a person who has always needed support and caring for someone who has started requiring care, particularly if the relationship between carer and cared for is significantly different to what has gone before. This needs to be recognised and reflected in the support given the unpaid carer.

5. Listen to carers and work in partnership with them. There has been legislation passed in Wales and the publication of several guidance and policy documents such as 'A Healthier Wales: our Plan for Health and Social Care'[12] and Social Services and Well-being (Wales) Act 2014[13]. These reports have stated the essential role unpaid carers have as well as the necessity for all parties to work closely together for the good of the cared for person. However, this is something not being felt by carers. It is essential that the carer is felt supported as well as being intrinsically involved in the decision making for the person they care for when it is right and appropriate to do so. This will help to reduce the likelihood of the caring situation at home reaching crisis point which, in the long-term, benefits everyone.

[12] <https://gov.wales/healthier-wales-long-term-plan-health-and-social-care> [accessed 03.09.21]

[13] <https://www.legislation.gov.uk/anaw/2014/4/contents> [accessed 03.09.21]