

Carers of People Living with Young Onset Dementia

Survey Findings



Background

There are about 850,000 [1] carers of people living with dementia in the UK. They do a fantastic job, saving the state £13.9 billion a year, but many say that they do not have the services and support they need. Caring for someone with dementia can, at times, be challenging, isolating and exhausting but it can also be very rewarding.

Together in Dementia Everyday (tide) is a UK-wide charity that focuses on encouraging carers and former carers of people living with dementia to recognise their own value and use their lived experience to influence positive change in policy, research and practice tide is determined to change the way carers are recognised, valued and treated. tide believes that services and support for carers of people with dementia are a fundamental and necessary human right. It is our mission to ensure that the needs of these carers are recognised and valued by absolutely everyone in the UK; from decision-makers to the general public.

Dementia is often regarded as a disease of the elderly, however although certainly more prevalent in the older population, current figures suggest there are over 44,000 [2] people living with Young Onset Dementia (YOD) in the UK. YOD is also known as early onset or 'working age' dementia and is defined as dementia diagnosed before the age of 65/ In those diagnosed with dementia over the age of 65, the majority will be diagnosed with Alzheimer's disease, vascular dementia or mixed dementia. People diagnosed with YOD however have a much broader range of diagnoses, including Alzheimer's disease and Vascular dementia but also much rarer forms such as Frontotemporal Dementia, Dementia with Lewy bodies and Korsakoff's syndrome. According to recent information from Young Dementia UK, people with YOD are also more likely to have a genetically inherited form of dementia.

These rarer forms of dementia are much more difficult to diagnose and the actual figures of those living with YOD may therefore be higher than the estimated 44,000. The associated difficulties in making a diagnosis therefore often lead to a delay in receiving a diagnosis. It can take twice as long for a person with YOD to receive a diagnosis when compared to someone with later onset dementia. Also as symptoms can be wrongly attributed to other medical conditions, a misdiagnosis is more common in younger people. Memory problems may not always be the main symptom and often people with YOD have a higher likelihood of behavioural problems so that misdiagnosis of a psychiatric condition, such as depression is often common.

A diagnosis of dementia at any age can be devastating, both for the person diagnosed but also their family members, however the impact of a diagnosis of YOD can be extremely hard to come to terms with. When Younger people receive this diagnosis, they may be still working, have a mortgage and other debts to pay, be caring for a young family and/or caring for aging parents themselves.

Some tide carers have shared their experiences and thoughts and feelings about caring for a loved one with YOD. Natasha Hamilton (tide carer from East Kilbride) has written a blog called '[The identity that I didn't ask for](#)' about her thoughts on caring for her mum who was diagnosed aged 56 with YOD.

One tide carer quoted Jonathan Safran Foer:

"Sometimes I can hear my bones straining under the weight of all the lives I'm not living".

Jackie Powell (tide carer from Leeds) has spoken about what a devastating impact Covid 19 had on her ability to continue caring at home for her husband, Keith (who was diagnosed aged 53). This is captured on the tide website in a [blog article](#) she wrote.

Linda Barnes (tide carer from Leeds) writes a daily blog about what life is like , caring for her husband with YOD in her blog: [Dementia Diaries](#), and has shared her thoughts on how and why she began to blog on the tide website.

[1]<https://www.nhs.uk/conditions/dementia/about/#:~:text=Research%20shows%20there%20are%20more,because%20people%20are%20living%20longer>. [Accessed: 27.11.20]

[2] <https://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia#:~:text=Over%2042%2C000%20people%20in%20the,the%20early%20stages%20of%20dementia>. [Accessed:27.11.20]



Rationale for survey

As a result of tide carers sharing their stories of caring for a loved one with YOD, and of hearing their concerns about services or a lack of them and of all the difficulties encountered as a carer of someone with Young Onset Dementia a survey was developed. The survey specifically targeted carers of people with YOD and was circulated through the network of tide carers and also on social media.

The purpose of the survey was to see what the main specific issues were for those carers, what they had found to be the hardest part about caring for someone with YOD and what they felt would have helped them at point of diagnosis and during their time as a carer. Some of the questions were closed, whilst others invited comment. Many respondents wrote detailed responses, highlighting many issues and areas of concern about their life as a carer of someone with Young Onset Dementia.

In total, 91 people responded to the survey and 80% of them were current carers.

A common theme of carers and former carers on the tide network is lack of recognition by others of their carer status and sometimes uncertainty by the carers themselves.

"My husband is in a care home, society no longer recognises me as a carer but I believe that I am still a carer for as long as he lives".

"I only became aware that I was a carer when I went to the GP for my annual flu jab. There was a lady there from Carers Trust who informed me that I was a carer. No one had pointed that out to be before. If I had known it would have opened a door for me for benefits which I had no idea about. Also there would have been a reduction in my Council Tax if I had known about this earlier. There is not a lot of joined up thinking between all the different organisations which could signpost people to get help"



Discussing the diagnosis

The average age of diagnosis was 55, although many respondents stated their loved one received a diagnosis in their late 40's. As previously mentioned, there was a problem with length of time it took to achieve a correct diagnosis and issues of misdiagnosis, which added to the stress and anxiety to the carers as well as the person with YOD.

Respondents also stated that symptoms had been there much longer in hindsight but because there was not always a memory issue present, dementia was not necessarily something that was considered to be the cause, either by the person or their family or indeed even healthcare providers. Some of the comments from the respondents talked about a lengthy wait for a diagnosis; one person stating it took nearly 18 months, another person: 2 years and the longest waiting time given was "several years":

"Young onset Dementia symptoms are sometimes dismissed as "stress" . This delayed diagnosis for several years and we could have been helped earlier in the disease and had better quality of life".

"My husband demonstrated symptoms of short term memory loss, and loss of concentration etc. for approximately five to six years prior to diagnosis. Very difficult to receive a definitive diagnosis".

"GP's need to have better awareness of dementia, the different types and that it can affect any age. Husband was misdiagnosed as having depression and anxiety".



Impact of Diagnosis

82% of carers said there was not information available to them at the time of diagnosis.

From a carer's perspective, the diagnosis of YOD for their loved one often impacted all areas of the respondent's lives, from their relationships, not just with the person who has received the diagnosis but also the entire family unit. There is a huge psychological impact as a result, as well as more practical considerations such as what effect it will have on work for both the person with dementia and the one caring for them as well as for the finances, household responsibilities and driving



Lack of available information

82% of respondents to the survey felt that the information made available to them at the point of diagnosis was insufficient.

Carers were also asked what they would have liked more information on at the point of diagnosis. The answers varied but the common themes were - more detailed information on the disease itself and its progression. Comments included information about prognosis, disease progression and what they could do to access help.

"The condition itself. We would have liked to have a family room and nurse to explain the progression (same as you get if diagnosed with cancer). We would have liked the information we were eventually given to be a) provided sooner and b) provided in a more useful way; it was actually all thrown at us at once"

"How better to deal with symptoms, from those who had good knowledge of FTD (Frontotemporal Dementia). I've had to find them myself "

Others commented that they felt abandoned after their loved one had received the diagnosis. They did not know who to turn to for help or advice and they felt there was no follow up available or care plan going forward.

"To be informed about organisations which we would turn to for help and information. The consultants didn't offer any help. In fact I had to ask for the diagnosis "

At what was an extremely traumatic time, both for the person receiving the diagnosis and for their family members, it was even more devastating for families to feel like there was nothing more being offered to them at the time of diagnosis.

For some respondents, the diagnosis had taken long enough to achieve, so to have finally been given that news but then with no idea of 'what happens next ' felt like another blow at a time when they were already struggling to take the information in. Comments included:

"We were given the diagnosis, told someone would be in touch in 12 months time and then sent home".

"Our experience was not too pleasant as we were given a large bundle of Pamphlets and forms and shown the door".

"We were basically told what it was and left to it, 6 month hospital appointment there after "



Post Diagnostic Support

The lack of post diagnostic support that was offered was a huge issue for many who responded to the survey. Some carers commented about feeling a need for counselling to be offered to the entire family to help them all come to terms with the enormity of the diagnosis.

A common theme that emerged was that respondents stated that a dedicated support worker or key worker would have made a tremendous difference. To have someone specific that they could contact for advice and ongoing support was regarded as vital by many people.

Many respondents commented on the loneliness that they felt after their loved one's diagnosis and how they struggled to access suitable support. Some felt that they were handed leaflets giving them information but that what they desperately needed was one to one support of someone who would stay on the journey with them. There was also a common theme around a need for counselling services and something more tangible than leaflets or a key worker who was there for their whole journey who was a regular point of contact that they could get in touch with. Other comments were:

"Need more joined up care after diagnosis. Specialist passes you back to the doctors who don't tell you how to get help, just monitor the medication".

"To have had some support, it was the most isolating experience of our/my life".

"Having a one stop place where you go and then someone there could direct you to help and support specific to the particular situation. I'm 45 and my husband is 61 and I still haven't connected with anyone my age who is going through this and it is hard.

"Admiral Nurses are needed all over the country "

Other respondents talked about the need for support systems and to talk to others who had been through similar experiences:

"A support system that understand from the carer perspective and also not having to fight so much red tape".

"Someone to talk to, who knows what it's like".

A lack of suitable services was also raised in response to this question and a need for flexibility:

"I could have done with someone being my Support Worker helping me through the mine field of finding out what if any help was out there for us. When you receive this type of news I was grief stricken, couldn't think straight, and was depressed. I had no one helping me".

"Support from local dementia charities, more funding from Social Services to cover my working hours, care agencies that are flexible enough to accommodate younger people and support them in accessing the community".



Impact on Relationships

80 % of respondents were caring for their partner.

The fact that YOD occurs in those of working age , means that in many cases, the partner/spouse of that person is still at a younger age. Therefore in contrast to those diagnosed with dementia much later in life, who may be cared for by adult children or other family members, the vast majority of those with Young Onset Dementia are cared for by their partner.

This brings with it , a myriad of difficulties, not least that a spouse/partner relationship is then replaced by that of a carer / cared for relationship with the accompanying issues that such a transition brings with it.

Respondents spoke about feeling the loss of their partner, or at least the partner that they had known, their marriage being replaced by a caring role and a feeling of loneliness at having to take on sole responsibility for decision making.

“Having 100% responsibility of everything and all under the shadow of having lost my spousealthough he's still here and requires a tremendous amount ”

“The balance of our relationship has changed dramatically - I have to make decisions alone instead of jointly but still discuss everything because he wants to be included in everything (just doesn't want to listen/can't remember the discussions ”

Carers spoke about a sense of grief and of mourning the loss of the relationship as it brought with it a sense of loss of the promise of a future together that they had imagined. Due to the average age of those diagnosed with YOD being in their mid 50's , many people of that age were making plans for retirement and enjoying more quality time together;they felt that the diagnosis had taken away the future that they had been planning with their partner and this was often a particularly difficult aspect of the diagnosis to come to terms with:

“Being only 53 when my husband was diagnosed, I feel we have missed out on that part of life when the children have left home and we can explore, holiday and generally re-connect. But on a more basic level, I have lost my husband- I can no longer chat with him about anything, I can't share my concerns, or share the joys, for example our daughter getting married. It is incredibly lonely even though we are together 24/7”

“A sense of losing someone who is a major part of your life ”

“Our lives have drastically changed, not what we had planned for our retirement ”

Another factor which contributed to feelings of loss and grief in some cases, was the fact that there were still children living at home and that the diagnosis therefore impacted not only directly on the spouse/partner but also on children living in the home; many were going through difficult teenage years themselves.

This added another dimension to the situation as the carer, is not only grieving the loss of the relationship they used to have with the person with YOD. They are also grieving for their children, for their loss of the other parent as they knew them and from the shift in dynamic of the whole family unit. Many respondents felt that their children had lost their father.

“Being the carer of someone with dementia is a long and lonely journey and it affects not only me but our children and the relationship of not only them with their father but also with me. Our daughter feels she has lost two parents to dementia ”.

“Specifically the impact on my school age children and trying to deal with everything that my husband used to do, the emotional toil on having your spouse suddenly gone ”

“My children have lost their Dad as they were only 12 and 16 at the time. I've lost my husband

These feelings of loss and grief are important to identify and acknowledge in not only carers/partners but also in children of those diagnosed with YOD. It is an area that is sometimes overlooked as often people equate grief and bereavement with death but anticipatory grief, particularly when someone has a diagnosis of YOD is important to be aware of and attuned to. The loss of a person as they were can be grieved. Sometimes there will be changes in the personality of the person living with dementia. They might not be able to have the same conversations as before, or do the things they used to love doing.

Carers often tell us that they grieve the relationship they had with the person they are caring for. They were previously a confidant, a partner, support. Carers of people with YOD often grieve for memories that have not yet been made.

Our team carried out a significant piece of work on Living Grief and Bereavement and produced resources for both carers and professionals which further explore this subject area, they can be found on our [website](#).



Financial Impact

As many people who are diagnosed with YOD are still of working age, there is often a far greater financial impact on the family than when someone of retirement age receives a diagnosis. Someone of working age will often still have a mortgage to pay and other debts and they may possibly still have dependant children.

There is also a knock on effect; that often their partner will consequently give up work to look after them as the disease progresses, causing even more financial hardship. Many respondents to the survey had never claimed benefits before and were completely unaware what they could claim or how to go about it. It was evident from the comments that much more information and signposting was needed. Some comments in response to this question included:

“(She was) initially off sick, then encouraged to retire early - also not supported to access full pension. I believe they were taken advantage of in their discussions with employers regarding pension rights, due to their ongoing and progressing dementia making their decisions vulnerable”.

“I wish somebody had told me I was due a Carer Needs Assessment. Also the nature of care available”

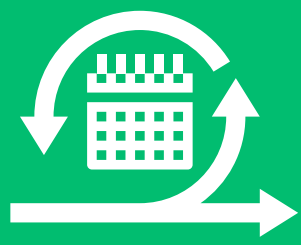
“I had no idea we could claim PIP or any other benefit for the first two years so we downsized and lived off savings. I feel very frightened of asking for help as I am afraid we will either run out of money or be dismissed because we are in a position to self fund at the moment. I fear that when this is over, I will have no money left for me. I get fed up with being told every case is different”.

Work was a topic that respondents also raised in the survey and the fact that many carers had to make a decision about retirement earlier than they had anticipated.

“A break, assistance. I've had to give up work now to care for my husband, financially it's a massive struggle as we are around £500 month worse off, it's not fair! I'm working by caring more hours than I ever did at work, families forced into this situation shouldn't be treated like this”.

“If they gave you information on benefits you may be entitled to and where to go for help because having had a weekly wage then going to 73 pounds a week is very daunting without having to deal with diagnosis you are scared you could lose everything house car etc.”

“I'm worried about the future. Partner going into care and losing benefits and paying for care and possibly returning to work as I'm still in my 50s”.



Impact on daily life

Many carers who responded to the survey spoke about the difficulties of daily life as a carer of someone of YOD. The fact that there were no age appropriate day services or groups in many areas specifically for those with YOD, meant that those living with the condition were often bored, frustrated and isolated which impacted on the carers. The carers were often looking after their loved one for 24 hours a day and were unable to get time to themselves.

There were many comments too about a lack of age appropriate respite care for those with YOD. This again meant that a carer didn't want to place their loved one in what they regarded as an unsuitable setting, so instead they struggled on and didn't take up respite care options. Many people commented that there needed to be more YOD specific services but also support groups for carers of those with YOD.

The survey responses offered some practical considerations about how to deal with some of the more difficult behavioural challenges:

"Health and social care agencies need to train staff on needs of those diagnosed with young onset dementia to realise that they have to reconfigure their services to be age appropriate"

Much more attention needs to be paid to those with younger onset dementia as it is in many ways far tougher as you are suddenly lumped together with the elderly who have had a quite different life experience".

"Support for under 65's is very limited and care homes are not tailored for that age group. Money is really difficult let alone if the sufferer is single and has a child under 18. A very hard time for all the family"

"Diagnosis has changed my life. I'm 57 and still working part time (can only do this as our two grown up kids are still at home). I still don't think there is enough support for younger people with dementia. Husband is now 56 and won't be eligible for respite for another 9 years!!"

A lack of age appropriate respite is something that is often raised and was commented on in the survey:

"Respite. Realistic training courses dealing with emotional resilience. A carers support group (I started one last year). Suggestions about practical aspects e.g. how to toilet someone when they are uncooperative and you have no additional help."

"There is nothing in our area for support for people diagnosed with Young Onset Dementia. This causes me stress as we both feel alone with this."
"I needed time away from him"

"Support worker for 1:1 activities. He was a keen cyclist enjoyed motorcycle and motorsport. I needed guidance and support,. I desperately needed respite but could not let him go into an older person's home".

Conclusion

As the survey responses have shown, caring for someone with Young Onset Dementia brings with it a set of challenges that in some cases is common to anyone caring for a loved one of any age with dementia. Practical issues, regarding support, benefit considerations, the emotional impact and the sense of anticipatory grief often felt as a loved one no longer recognises partners and family members.

However for those caring for someone with a diagnosis of YOD these challenges can be greater. Many of those people are the partners of the person they are caring for and they are coming to terms with a future that looks distinctly different for the one they had planned out. They are often at an age where they are planning for their retirement or how they will enjoy more frequent travel after years of work; often also stepping in to care for grandchildren. These carers are therefore not only coming to terms with a diagnosis for their loved one, but the loss of the future they were imagining. That is often very hard to come to terms with, when they feel still quite young and with many years and plans ahead of them.

There are many people who are still working when they receive this diagnosis and as a result of the diagnosis have to give up work. Their partner often has to give up work too and the financial impact of this can be enormous. Mortgages, loans, car payments, supporting children through university are often still huge considerations for those diagnosed with YOD and their partners and families. It can signal a huge lifestyle change as often they are not able to access pensions and may have little knowledge of the benefits' system. When carers of people with YOD finally access benefits, they still may not have enough money coming in to meet all the financial obligations.

The pressure on the family can be enormous and can also affect children, who may struggle to come to terms with the diagnosis of their parent and the often resulting change in their relationship.

Many respondents to the survey spoke of a lack of support and access to help and information. Whether that is a lack of practical support, such as a key worker assigned to the family or a lack of opportunity to undertake counselling as a family, through to no support groups available specifically to carers of those with YOD. For others, there was a feeling of that there weren't age appropriate activities for their loved one to participate in, suitable day care facilities, and respite or long term care options.

This lack of available support and suitable services then placed an added burden on carers, who often didn't want the person they care for to be placed in what they regarded as unsuitable surroundings, so as a result there was very little respite for the carer, either on a daily, weekly or longer term basis which then added to the carer stress and burnout and resulted in poor carer mental health.

It appears that so much more needs to be done to address the needs of carers and families of those diagnosed with YOD. From more awareness of YOD, to a faster diagnosis time, through a Young Onset Dementia pathway to include specialised advice and support for carers with age appropriate activities/day care and respite/long term accommodation for those diagnosed.

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