

Dementia Carers and Covid-19

In Wales, approximately 42,000¹ people are living with dementia and it is most common in older people. One of the at risk categories for people during the COVID-19 pandemic, identified by the Welsh Government, is people over the age of 70 which comprises a high number of people living with dementia and their carers.

At tide (together in dementia everyday), we are acutely aware that carers of people living with dementia were already feeling socially isolated as a result of their caring role before they were asked to stay at home as part of the government guidance.

As identified in the Welsh Government Dementia Action Plan for Wales, (2018-2022), social interaction for people living with dementia and their carers is vital to encourage a general sense of well-being for anyone living with dementia. This is reflected in what tide is being told as our carer members have been reporting a greater degree of vulnerability not only for the people they care for but also for themselves.

As part of tide's COVID-19 response, we have designed activities to ensure that we reach more carers at this time and we are committed to keeping them connected, well informed and enabling them to continue to use their caring experience to influence policy, research and practice during this pandemic.

We have established a COVID-19 Hub on our website with a list of our involvement activities, research opportunities and resources that many carers of people with dementia will find useful. Click [here](#).

In addition to the COVID-19 Hub, we also ran a survey at the start of the self-isolation period to ask carers what services and information they would like tide to provide at this time. Specifically, one of the questions that was asked in the survey was: "Have the government restrictions brought in for Covid-19 affected you more than usual?"

The information in this report reflects what was captured in response to the online survey question and in addition to this, conversations and emails that tide has received over the past six weeks from carers in Wales.

For ease of reading, the feedback has been grouped under the emerging themes. We hope that this evidence will inform the National Assembly for Wales' Health, Social Care and Sport Committee about the issues affecting carers of people living with dementia at this difficult time.

¹Dementia: <http://www.wales.nhs.uk/healthtopics/conditions/dementia> [Accessed: 13.05.2020]

Visiting restrictions in care homes

Two tide members whose partners are in care homes found the use of technology as a positive way to keep in touch. Others found that devices such as Ipads were of no use to them as the person they care for was in the later stages of their dementia:

I “can’t visit my husband in his care home. Staff are very good (at) getting his favourite food for him. (I) Can’t talk to him as he can no longer converse. He wouldn’t use Skype it would confuse him”.

One carer was frustrated as she lives by the care home in Anglesey where her husband resides but was worried that waving or talking through a window may cause additional distress and unrest. In addition to this, two carers said that they were concerned their husbands would not recognise them when the restrictions are lifted.

Tide has offered support to carer members with being able to use Zoom including videos and guides and has also offered digital equipment to carers through Digital Communities Wales.

Correspondence from Welsh Government & information

Carers reported that they did not really understand what the ‘vulnerable person’ letter they received meant and said it was impossible to stay away from the person with dementia if either person were shielded. The carers wanted more guidance on how the legislation could be upheld but are using their own commonsense.

Some carers were a little confused as to what they were allowed in terms of exercise and if they were permitted to leave their homes at all. One response to the online survey from carers in Wales and discussions on Zoom meetings also reflected that carers accepted that adhering to guidelines was the best way to stay safe:

“Have received letter saying I have to stay in for 12 weeks which is daunting but it’s for the best”.

Carers reported their frustration on having to explain the ‘lockdown’ situation continuously:

“As a 24/7 carer for my 74 year old wife it gets very strenuous. Unable to make her understand the covid 19 situation”.

Tide responded to by adding information on legislation to the website in a resources section under the Covid-19 hub. The information is updated as and when it is issued.

Paid care

One carer spoke about his frustrations with a lack of PPE with paid carers coming to support his wife; putting their own life and the lives of him and his wife who is living with dementia in danger. The carer was aware it was not the fault of the care worker but that either social services or the care provider should have dealt with this. This was raised by the carer with Social Services and their GP.

“As recently reported the distribution of PPE especially within social care has been a ‘shambles’...”

Another carer had to learn to support her mother in new ways doing things like washing her and her hair, she said:

“I no longer get any respite as I’ve suspended the twice weekly carer visit as it was not essential”.

Some carers have been opting not to use external care services due to lack of PPE and the increased risk of external people in their homes. This is putting an added strain on them at this time as their own mental health is suffering from self-isolation and they have no respite.

Tide was able to respond to this by notifying Public Health Wales and Social Care Wales and being offered the names of the person responsible for PPE in each local authority. The carer’s wife has also now had a revised letter from the GP to state that she is “extremely vulnerable.

Shopping

Carers reporting that the shopping arrangements were not well thought out by the supermarkets and were not always helpful.

One carer in Powys had to stay up until 3am to get a shopping slot which was for a fortnight's time.

Another carer in North Wales reported that it was:

“not easy to get a slot for food delivery”. This had caused a considerable amount of stress.

A carer in North Wales was told that her local Sainsbury's could not deliver her shopping to her even though she is over 70 and living with someone with dementia. Eventually, after having to take this to the Older Person's Commissioner, she was able to resolve this. She did however note that she was unhappy about the waste of carrier bags as some bags only had one item in them and it was really bad for the environment. She emailed to tell tide:

“I eventually managed to get registered with Sainsbury's but can only do click and collect as most considered a vulnerable person. It is so frustrating”.

Carers reported that shopping was one activity that would previously get them out of the house but it is no longer safe to take the person they are caring for along. They are still managing by using convenience stores but they are often overpriced:

“I can still risk leaving mum for 30 minutes while I nip down to the local shop or to surgery for prescription”

Carers did also report however, that a good feature of some supermarkets is that once a slot has been booked, it is possible to add or amend their order up to 2 days before it arrives.

With the use of Zoom, tide has been able to connect carers to share their experiences and offer suggestions to these common problems. Discussing which supermarkets have served their needs best and how best to get a delivery slot.

Loneliness

Carers in North Wales reported that they felt very lonely in the evenings when the person they are caring for has gone to bed and when they have been in the house for most of the day (this was noted at a time when exercise was restricted to once per day):

“The night is long and services for us to use are mainly in the day time”

Another carer who responded to our online survey just simply stated: “It’s a very lonely life”.

I am “Unable to provide distraction for my mother (vascular dementia) by taking her out for coffee, meal, garden centre, seaside, etc. As well as missing her routine exercise and music classes. We are able to walk locally, and I fully accept the restrictions but mum's depression is getting worse and I don't know how to help”.

A former carer who had recently lost his wife said that the isolation felt particularly hard:

“I am finding the self-isolation depressing as I am having to deal with my bereavement and isolation. I fear for my mental health at times”.

Tide was able to respond to this by providing an evening quiz on a Monday where carers can connect and talk about their week but then are able to take part in a fun quiz to lift their spirits. A quiz is also provided on a Thursday morning.

In addition to the quizzes, tide is providing well-being sessions online and coffee mornings where carers from the four nations can meet up. All carers are offered catch up calls or Zoom meetings and are signposted to local services where they are available.

Recommendations

1. The voluntary sector in Wales is currently reviewing the services it delivers and when the best times are to provide services. The Assembly should encourage Welsh Government to urge the third sector to amend their service provision to reflect the needs of carers and people living with dementia that are now needed around the clock. Some of this work could be funded through the COVID-19 Response fund, the Sustainable Social Services grant and the Active Inclusion Fund managed by the WCVA.
2. The Assembly's Cross Party Group on Dementia are currently on hold due to the current crisis however, as highlighted in this report, people affected by dementia need support now more than ever. These meetings should reconvene as soon as possible.