

Tide: The power of connection

The UK-wide charity tide (together in dementia everyday), brings together carers of people living with dementia to share their stories – as experts by experience – to influence positive change. Their work not only connects people to talk about key issues but it enables carers to gain the knowledge, skills and confidence to share their voices with key decision makers in Health and Social Care.

Jenie, a carer from North Wales who uses tide's services, explains: 'My partner's diagnosis was stressful, the resultant anxiety and "living bereavement" caused me to lose confidence in my ability to cope.

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Meaningful engagement with carers like Jenie, means that the charity has been able to provide public bodies, including the Senedd, Welsh Government and Public Health Wales invaluable insights into the challenges facing carers, whilst simultaneously offering recommendations on how they can improve services and legislation.

The importance of capturing real-life experiences and relaying them to policy makers cannot be underestimated as it sheds light on widespread problems.



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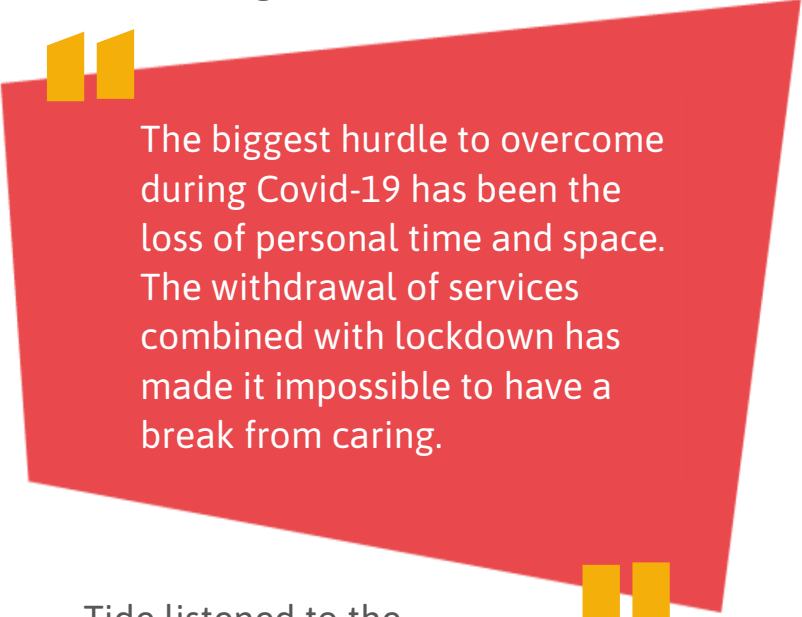
Jenie

Approximately 42,000 people live with dementia in Wales,¹ most of whom are older people. With WHO identifying the over 70s age group as one of the most 'at risk' categories during the Covid-19 pandemic, people living with dementia and their carers have been forced to make uncomfortable changes to their already challenging lives.

Before the global pandemic, staying connected and the ability to interact socially were always cited as vital by tide members, because being the carer of someone living with dementia often brings isolation and loneliness. Furthermore, social interaction was recognised as crucial in the Welsh Government's [Dementia Action Plan for Wales](#) (2018-2022). Carers also talk to tide about having little time for themselves, and to interact with other people in a similar situation. Feeling part of a collective voice is often a lifeline.

At the start of 'lockdown', tide surveyed its members to see how staff could adapt their ways of working to ensure carers continued to feel included and connected and to find out the best way to engage with them. Carers like Jenie reported a greater degree of vulnerability in both themselves and in the person living with dementia: 'the biggest hurdle to overcome during Covid-19 has been the loss of personal time and space. The withdrawal of

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Tide listened to the voice of carers and responded by creating a [Covid-19 Hub](#) on its website to ensure everything it offers is in one place. The Hub brings together important health and social care information from around the UK, offers carers the opportunity to take part in consultations and research and shows the ongoing social activities that members can take part in.

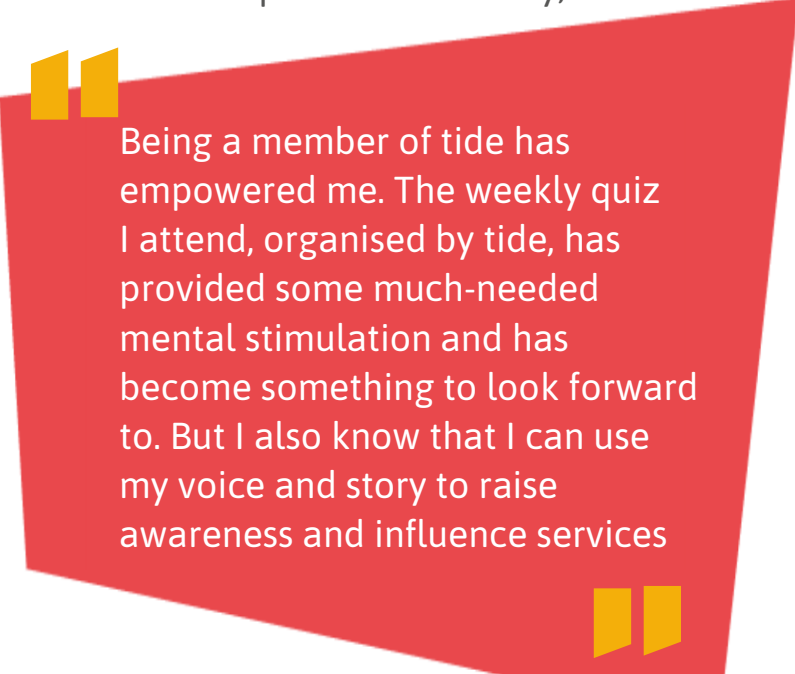
Modules from the Carer Development Programme now take place via Zoom as do coffee mornings, quizzes, thematic discussions and webinars. Recognising the additional strain carers are under at the moment and their limited availability, tide uses these social sessions to tease out any issues that carers are facing to ensure, where appropriate, that they are taken forward using the correct channels.

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

Carers have complained of survey fatigue and tide recognises this time as an opportunity to give back to its members, therefore the quizzes and coffee mornings are not only a bit of fun in dark times but they provide immediate relief for carers and flag up ongoing concerns.

According to Jenie, these social activities offer multi-faceted positive experiences for carers: 'Being a member of tide has empowered me. The weekly quiz I attend, organised by tide, has provided some much-needed mental stimulation and has become something to look forward to. But I also know that I can use my voice and story to raise awareness and influence services'.

Carers only use these opportunities to vent about the challenges they face for example, but also provide each other with advice. Shopping is a case in point. While it had once been one of the few activities that would get carers out of the house, since the outset of the self-isolation period, it has morphed into a stressful experience for many;



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including one carer staying up until 3am for a shopping slot in a fortnight's time or being forced to buy all goods from an over-priced convenience store.

Clearly, a dual challenge has emerged for the charity: in continuing to support service users who are already vulnerable to life's everyday challenges, while also responding appropriately to the fact that a great number will be in the high-risk group for Covid-19 complications.

Similarly, during lockdown, tide recognised that there were carers who had similar experiences across the UK so it connected carers from Wales in four nations' coffee mornings and focus groups; one area being carers of people with young onset dementia. It is through these social activities that tide staff were also made aware of the increasing problem carers had of staying in touch with loved ones in care homes.

While some tide members had found digital technology such as zoom and skype a useful way to stay connected, other members reported not having the digital literacy skills to do this. This is particularly important when caring for someone living with dementia as carers worried that the person they cared for may not remember them when they were next able to meet.

Tide partnered up with Digital Communities Wales to find out about its services and to notify its members of

the free equipment they can access and training they can undertake. Carers on the network were offered training in digital storytelling as this is the way carers may have to share their experiences in the future with less reliance on face to face sessions.

Tide has also been able to provide Public Health Wales and Social Care Wales with evidence that the lack of Personal Protective Equipment (PPE) offered to care staff was creating significant concern and stress for carers, leading to some refusing to use external care services. For many, this also meant, for the first time ever having to carry out personal hygiene tasks for the person they care for. This

has contributed further to the carers' anxiety and in some cases impacted on their mental health. In addition to this, tide was able to feed back this issue, along with many other challenges when responding to the Senedd's [Health, Social Care and Sport Committee's Inquiry](#) into the impact of Covid-19.

Tide recognises the unique challenges that being a carer of someone living with dementia brings; challenges that are amplified during these unprecedented times. Tide welcomes you to [join](#) them in their campaign for a brighter future and to ensure that carers of people living with dementia in Wales have a stronger voice.

To learn more about WCVA's Health and Social Care work, email Sally Rees, National third Sector Health & Social Care Coordinator, on: srees@wcva.cymru

For more information about tide and its services go to: www.tide.uk.net



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