**June 2022 Newsletter**

Welcome to our June newsletter, we have some updates about what has been happening at tide, information about some upcoming events as well as some other opportunities!

**Parliamentary Event: The Carers Experience**

We hosted a parliamentary event to support the Front of Mind (https://www.tide.uk.net/tide-front-of-mind-campaign/) campaign. We were delighted that these 5 carers were able to join us and represent tide and the interests of those affected by dementia. We believe carers are experts by experience and, as such, deserve to have a say in the policies that affect them.

We asked 5 carers to speak a little about their experience coming to Westminster with tide. We understand the idea of approaching MPs or campaigning can be intimidating at first. But carers deserve to have their voice heard and an equal seat at the table.

We feel it's so important to involve current and former carers in events such as this. It's vital we value their lived experience. Policy-makers have such insight to be gained from listening to carers about their thoughts, feelings and experiences.

"People need to hear authentic stories and that each one is different," says Roger.

You can read about their experience and what they had to say on our website.

Find out more (https://www.tide.uk.net/tide-members-share-their-experiences-at-parliament/)

**\*\* We launched our Policy Influencing Toolkit!**

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You may have seen we have launched our policy influencing toolkit. To aid our Front of Mind campaign, Incisive Health developed a toolkit to help you gain a better understanding of the parliamentary landscape and influence dementia policy and practice.

It's packed with useful information, advice, tips and workbooks for you to feel confident in campaigning!

Download the Toolkit (https://www.tide.uk.net/policy-influencing-toolkit/)

**\*\* Alzheimer's Disease International**

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Head of tide Delivery, Sarah, and Training and Products Manager, Micheal headed to ADI 2022 to promote the valuable work tide does.

They spoke about our Carer Development Programme (https://www.tide.uk.net/projects/carer-development-programme/) and our training for dementia professionals (https://www.tide.uk.net/about-us/tide-for-dementia-professionals/) . This training is carer led, co-produced and tailored to for the health & social care sector, It aims to improve the quality of life for people with dementia. We have a range of training modules aimed at supporting the best level of care possible for those with dementia. You can find out more about tide training on our website (https://www.tide.uk.net/about-us/tide-for-dementia-professionals/) .

Sarah delivered a fantastic talk about the work tide has done to engage carers in influencing policy and practice and create real positive change. We have so many stand-out examples of inspiring tide members making a real difference to not only their own lives but other carers lives!

You can download Sarah's presentation on 'Engaging Carers of People with Dementia to Influence Policy, Practice and Legislation' below.

Download Sarah's Presentation (https://mcusercontent.com/6d828bc801ad2aeef09fd76ad/files/bf012a80-42d0-cfbe-cf79-e75497169c42/ADI\_2022\_Presentation\_Sarah\_Merriman.pptx)

Ruth Eley, tide Co-Founder and Chair, shares her experience meeting with Rhun ap Iowerth following on from our joint campaign with Roche: Front of Mind which is calling for improved diagnosis rates and a proper dementia pathway.

Following an approach by Mary Mitchell (one of our Tide Advisory Group members), a group of five carers from North Wales, along with our Chair of Trustees Ruth Eley, met with Rhun ap Iowerth on 27 June. He is the member for Anglesey of the Welsh Senedd and the shadow health and care minister.

The carers told their stories to highlight the difficulties that unpaid carers experience, particularly during and after getting a diagnosis, when they are often left to their own devices with little advice on where to get further information or help. They also highlighted the difference across North Wales in the extent and quality of services, depending on where you live - a familiar story to many.

We also raised the potential role of hospices in providing high quality respite care for people with dementia and family carers, based on the real experiences of one of our local carer members. Rhun was especially interested as he is a member of the Cross-party group on palliative and end of life care. Ruth was also able to highlight the difficulties for voluntary sector organisations in the current climate: warm words about how wonderful we are do not pay the bills! We all felt listened to and are confident he will use our discussions in his role to influence policy in relation to unpaid carers.

**Are you a carer living in Scotland? Don't miss our training events with Age Scotland!**

The next session is about self-directed support (https://www.tide.uk.net/training-with-age-scotland-self-directed-support/) and is on July 7th at 10.30AM-12PM.

We are also hosting training on the following topics:

Power of Attorney (https://www.tide.uk.net/training-with-age-scotland-power-of-attorney/)

Welfare Benefits (https://www.tide.uk.net/training-with-age-scotland-welfare-benefits/)

You can book via our events page

Book Now (https://www.tide.uk.net/training-with-age-scotland-self-directed-support/)

We're very proud of tide Trustee, Clarissa Giebel, for being nominated for the North West Coast Research and Innovation Awards for her research project into dementia social care and the impact of COVID 19.

Clarissa and the team at Liverpool dementia have done so much fantastic work looking into community and care homes during the height of the pandemic

A research opportunity for carers...

My name is Nusrat Nadir. I am a PhD student at De Montfort University, Leicester. I would like to interview family carers to seek an understanding of the experiences of a person with dementia who have/had admissions to ICU during the last five years in the East Midland region. Participants can choose to have an online interview conducted by telephone and/or using Micro Soft Teams or by face-to-face, in a location of their choice.

There has been very little research on the experiences and understanding of care for people with dementia who are admitted to ICU. We know that, during the COVID-19 pandemic, few people with dementia were admitted to ICU’s due to the strict triage systems. Eliciting the experiences of family carers will contribute to knowledge in this field which may help other families affected by dementia in the future.

If you are interested in taking part or would like more information, please contact me.

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