

# The tide is turning for carers

**Anna Gaughan** explains how a growing UK-wide network, tide – together in dementia everyday, is ensuring that the expertise of carers influences dementia policy, research and practice

**C**reated by carers for carers, our UK-wide involvement network, called tide – together in dementia everyday, gives all carers of people with dementia the chance to recognise that they are the experts at what they do. Hosted by Life Story Network, it helps them to see that they can use this first-hand knowledge and expertise to influence changes, locally and nationally, in how dementia care and support is designed, commissioned and delivered.

One of the many strengths of the tide network is that it does not provide direct support services to people affected by dementia and so its members can give completely impartial and independent feedback based solely on their lived experiences as carers. Their direct experience must be used as a litmus test to measure whether policies are actually making a real difference in the day-to-day lives either of carers themselves or the people they are caring for.

## Our aims

Working with former and current carers, supported by our advisory group, tide has developed the following aims:

- challenge the perceptions of carers of people with dementia in society
- campaign for better support for carers of people with dementia
- influence government, legislation and policy
- speak on behalf of people who can't speak out for themselves
- provide carers of people with dementia with the tools and support to help themselves and others

- educate people, organisations and the public on the essential role that carers of people with dementia perform
- connect carers of people with dementia with other carers of people with dementia – a truly unique UK-wide involvement network.

Over the past 18 months the tide team has been working tirelessly to get the carers involvement network firmly established. Our membership has surged by 300% over the period, which has culminated in securing funding from the Big Lottery Accelerating Ideas Programme for a phased roll-out of tide across the Liverpool and Manchester city regions. It has enabled us to recruit two carer engagement leads, as well as continue our work in creating a bespoke personal development programme that will equip carers with the knowledge, skills and confidence to participate as equals in any event or engagement process. Such investment in personal development is helping us to achieve our aims.

For example, our members are exercising an influence on government, both in terms of legislation and policy. As part of the Prime Minister's Challenge on Dementia 2020, they helped to design the citizens' engagement process, which will report to ministers and the programme board on whether the policy is having the desired effect.

Additionally, members were particularly influential in helping to redraft the Dementia Action Alliance's "I" statements, which have been updated to reflect developments since they were

first drafted seven years ago. Following a consultation led by Alzheimer's Society, they have been turned into "WE" statements with an equal focus on the needs of carers and people with dementia.

## Sharing experience

Another example is given by two of our members, Janis Cottee and Shahid Mohammed. On completing just one of the modules of our carers development programme, they opened the UK Dementia Congress (UKDC) in Brighton last year and shared their caring experiences in a compelling, impactful and constructive way with 700 delegates. With support from one of our carer engagement leads, they were able to recognise how the lack of care and support afforded to them potentially infringed both their human rights and those of the people they care for.

Janis Cottee's words afterwards are instructive:

*I felt validated. After having felt so isolated, exhausted and angry over the lack of humanity shown to both Richard and myself, the tide team made me feel totally included, and the feedback to my speech gave me validation for the anger I had felt. I came away from Congress hopeful that things will change for people with dementia and their carers; and on a personal level, because tide gave me that opportunity, I feel more confident and determined to do whatever I can to move that forward.*

Also reflecting afterwards, Shahid Mohammed said opening UKDC had felt "extremely empowering." He added:

*Having cared for my mum I knew how important it was for me*



*to share my experience at Congress – that was huge in itself – and also because some people from BAME communities and religious groups may not be able to talk about dementia. Sadly, mental health conditions and dementia are still hugely stigmatised in my community (as there isn't a word for dementia in many south Asian languages), and crucially mainstream dementia services are still not meeting their needs. The tide team supported me leading up to Congress, during and afterwards, and I was able to discuss my speech with them.*

Both carers acknowledge that, with investment in their personal development, they have become more confident and are more actively involved in influencing policy. Janis was among the carers who took part in creating the "We" statements and had, with my involvement as tide chief executive, an instrumental role in making certain that the new statements were explicitly linked back to the relevant human rights legislation.



**Shahid Mohammed speaking at UKDC 2016**

Shahid continues to be active in raising awareness of dementia across the south Asian communities in Rochdale as well as being involved in a new work stream on black, Asian and minority ethnic communities led by Public Health England.

Another one of our carer members, Tracy Shaw, was invited to participate in the Liverpool Radio City Talk programme (listen on the link <http://tide.uk.net/radio-city-talk>) to speak about the experience of caring for her mother, who has dementia. Supported by tide, Tracy spoke about the challenges and frustrations of trying to navigate the health and care system. She stressed that "caring for someone with dementia changes your life immeasurably" and highlighted the impact of this on her own career along with the sense of loneliness and social isolation felt by many carers.

### Widening influence

We aim to educate people, organisations and the public on the essential role that carers of people living with dementia perform. We have been working with partner organisations to find opportunities for carers to share their expertise. So far, in partnership with Yorkshire & Humber Dementia Clinical Network, carers from tide have contributed to three webinars (view them at the link <http://tide.uk.net/carers/webinars>):

- The importance and diversity of carers of people living with dementia
- The importance of nutrition
- Delirium and dementia.

We have also been extending the reach of tide beyond England into the rest of the UK. In February, we secured just under £1.4m investment from the Life Changes Trust to establish tide in Scotland, where we will be collaborating with existing organisations and networks which are already making a difference, such as Dementia Engagement and

Empowerment Project (DEEP) and National Dementia Carers Action Network (NDCAN).

Anna Buchanan, director of the Life Changes Trust dementia programme, said:

*In Scotland we want to empower those who look after friends or relatives living with dementia to have a bigger say in the issues that affect their lives, with support from a network of like-minded people, who have had similar experiences. tide acts as a catalyst to bring about positive attitudinal and behavioural change in how, as a country, we recognise, value and involve carers of people living with dementia.*

In partnership with Carers Outreach and Bangor University's North Wales Dementia Network, we organised events in Anglesey, Gwynedd and Conwy to encourage carers to respond to the consultation on the Welsh Government draft dementia strategy, "Together for a Dementia Friendly Wales". We are now working with partner agencies to build on this momentum to extend the network across Wales.

### Understanding what works

Finally, we are committed to understanding "what works" and sharing this learning across the UK and beyond. So in addition to undertaking our own self-evaluation, we have commissioned Arc Research and Consultancy to undertake an independent evaluation of the impact and outcomes tide is achieving.

We have accomplished a great deal in a short time, but there is much still to do. We are committed to building and strengthening tide, enabling us to achieve much needed cultural change, where carers of people living with dementia are fully involved and their contribution is resourced, valued and respected. We look forward to the day when they are treated as equals alongside professionals.

■ Anna Gaughan is chief executive of Life Story Network

## PERSPECTIVES



By Paola Barbarino

### The global plan on dementia marks the start of a new era – but we have a lot of work to do

■ Paola Barbarino is CEO of Alzheimer's Disease International

As the new CEO of Alzheimer's Disease International (ADI), I am honoured to be joining the global fight for the prioritisation of dementia at such a key moment. In May, I had the privilege to witness the adoption of a global plan on dementia by the World Health Organization (WHO) in Geneva, where ADI called for governments around the world to commit serious resources to this plan.

As I step into my new role, the facts are stark. Someone in the world develops dementia every three seconds. In many countries as few as 10% of these individuals receive a diagnosis. The stigma attached to dementia is still a global problem.

Of the 194 governments who are members of the WHO, less than 30 have developed substantive policies on dementia, and fewer yet have allocated funding to implement change.

The global plan is the result of 10 years of hard work by Alzheimer associations worldwide who have advocated through ADI for a global response to the dementia crisis. It is a great opportunity to change the face of dementia from one of stigma and aversion, to one of inclusion and action. We have seven targets including: greater coverage of diagnosis, care and treatment, encouraging awareness and dementia friendliness, enabling research and addressing dementia locally by developing national plans.

This is a great step forward. In Geneva, it was heartening to hear so many open statements of support – 30 in all – from the nations represented in the room. Some of these statements contained important observations; many adopted the language and numbers that ADI and its members have been using for years in the dementia community. But, without doubt, we need many more voices to be added to ours to turn words of hope into practical actions that will improve the lives of people living with dementia and their care partners, encouraging attitude change and sharpening efforts to identify new treatments and, eventually, a cure.

By 2018, the global cost of dementia is expected to exceed a trillion US dollars but funding for prevention and diagnosis, drug development and public health is woefully insufficient. My main priority for the coming years will be to lead, help and support our members in the call for every government to develop – and crucially to fund and implement – a national plan on dementia which includes the views of all those affected. We will continue to ask for 1% of the total societal cost of dementia to be invested in research.

Alzheimer associations are ready to act, and this will be a key focus of World Alzheimer's Month in September. We will be strengthening our relationships with the WHO and governments, and enhancing our support for associations in every country to empower and raise the voice of those living with dementia, training more care partners and health professionals to provide support, involving the public in risk reduction and prevention, and advocating effectively for a visible, monitored and funded response to the global plan.