

Tide – Together in Dementia Everyday

.....
A Mixed-Methods Evaluation





Contents

Summary.....	3
Outcome 1 – Connectedness & Self-Efficacy.....	5
Outcome 2 – Self-Development.....	6
Outcome 3 – Influence & Policy.....	7
Detailed Analysis – Outcome 1.....	8
Case Study 1 – Alison’s Story.....	12
Detailed Analysis – Outcome 2.....	15
Case Study 2 – Ray’s Story.....	18
Detailed Analysis – Outcome 3.....	22
Case Study 3 – Natasha’s Story.....	26
Living Grief & Bereavement.....	29
Conclusion.....	32
Evaluation – Self-Efficacy.....	35
Evaluation Process.....	37
Acknowledgements.....	40



Summary

The tide network is a UK-wide network of carers, former carers and practitioners first established in England, following the Carers' Call to Action campaign (2015). In 2017, tide established a dedicated network of carers and former carers of people with dementia in Scotland, funded by Life Changes Trust.

"It seems to me that once the Alzheimer's/Dementia diagnosis is given, the carer is left to pick up the pieces as best they can, deal with the emotions and upsets along the way, find the legal and financial paths through a minefield and also deal with the general day-to-day problems of life as well. With the help of the tide organisation, I am coping better, feel more prepared and don't feel as isolated or inept." *tide member*

Significant findings

- 1 Carers **value** being members of tide in Scotland.
- 2 Becoming a member of tide can be **life-changing** for carers.
- 3 Membership of tide has **increased substantially** in recent years, indicating both a need and demand for tide in Scotland.
- 4 tide Board & staff are **committed** to the development of tide in Scotland.
- 5 External stakeholders value tide and believe that tide's presence in Scotland is much **needed**.



Learning

In December 2018, the University of the West of Scotland was asked to complete an independent evaluation of the impact of tide in Scotland. The evaluation ran from **January 2018 to April 2021** and used a mixed-methods approach. The evaluation provides evidence of the positive impact of tide, some of the challenges faced and areas for further development.

The evaluation was structured around the 3 core outcomes of tide in Scotland, and this section is a summary of the key findings:

Outcome 1:

Carers of people with dementia report increased connectedness to others, a greater sense of self-efficacy and feeling part of a collective voice.

Outcome 2:

Current and former carers will gain confidence, knowledge and new skills that will increase their ability to influence positive changes in policy, commissioning and services.

Outcome 3:

Development of policies, research, education, commissioning and services will be more responsive to carers' needs by the inclusion of the voice of carers through the tide network at local, regional, national and international levels.



Outcome 1

'Carers of people with dementia report increased connectedness to others, a greater sense of self-efficacy and feeling part of a collective voice.'

What does the evidence say?

- Carers who become members of tide experience increased feelings of connection to others and feel part of a broader community.
- Carers, tide staff and external stakeholders believe tide is very much needed in Scotland and that tide is an important part of the dementia landscape in Scotland.

"I don't think I would be mentally strong at this stage of mum's dementia ... if I hadn't met tide." *tide member*

What were the challenges?

- Engaging with a demographic who do not have the time to spare – even though they want to (how do you involve carers who are so stressed and with so little time to themselves?).
- How to include carers who were in employment and unable to attend events during the day.
- The evaluation used the General Self-Efficacy (GSE) Scale to help measure the impact of tide on carers' feelings of self-efficacy. The GSE scale has been used successfully by other researchers to measure the impact of carer involvement on self-efficacy. However, it is possible that a tool created specifically to measure self-efficacy for carer activism might produce different results. No such tool exists at present.



Outcome 2

'Current and former carers will gain confidence, knowledge and new skills that will increase their ability to influence positive changes in policy, commissioning and services.'

What does the evidence say?

- Engaging in tide's carer development programme can have a transformative impact on carers' lives.
- Carers supported by tide to share their stories and experiences have seen their confidence and skills increase as a result.
- Participating in tide's Carer Development Programme can not only equip carers with new knowledge and new skills but can also help carers rediscover existing knowledge and skills and share with others.
- The tide team adapted to a new digital way of working during the pandemic and carers appreciated being able to participate online and at times that suited them.

"At the carers' day, we could, if we wanted, share our story, it was just such a lovely, lovely feeling. To have the confidence to get up there and do it. I wouldn't have without the support [from tide]." tide member

What were the challenges?

- The carer development programme was originally designed for face-to-face delivery. Adapting the programme to meet government guidelines and to reflect changes in carers responsibilities during Covid meant that some elements of the programme were removed in order to streamline them for online delivery. New content was also added, however, such as managing feelings of isolation during 'lockdown'.
- Capturing evidence of carers' ability to influence at local and national levels became more challenging for tide, as carers focused on caring for loved ones during the pandemic.

Outcome 3

'Development of policies, research, education, commissioning and services will be more responsive to carers' needs by the inclusion of the voice of carers through the tide network at local, regional, national and international levels.'

What does the evidence say?

- Through tide, carers are supported to have their voices heard at local, regional, national and international levels.
- Alongside supporting individual carers, tide is mobilising the collective experiences of carers in order to influence policy makers and bring about positive change.
- Both individual member carers and the network as a whole have had clear impacts when it comes to making policy and services more responsive to the needs of carers.

"I've been on TV, radio, newspapers, speaking to government, joined groups... I'm very clear in saying that I would never had the confidence then to do that if it wasn't for tide." *tide member*

What were the challenges?

- Building a nation-wide platform for carers in Scotland was both ambitious and courageous and its development was affected by changes in organisational structure.
- Building relationships of trust with external stakeholders in a complex and competitive environment took time, tenacity and diplomacy.
- Developing carers' confidence to tell their stories and speak in front of different audiences took time and trust. Finding suitable opportunities to speak was impacted by Covid.
- Ensuring carers voices remained visible at a time when they were impacted by an increase in carer responsibilities was challenging.



Outcome 1

Detailed analysis

- Carers told us they had felt lonely and isolated before joining tide. Becoming a member of tide gave carers opportunities to make new connections and establish new friendships, but the interim report highlighted the difficulty in measuring a direct link between tide and any improvement in feelings of isolation.
- Some members have made “lifelong” friends through tide. For others, simply being part of a network of carers and sharing links, advice and support online has enabled them to feel part of a broader community.

“I feel more hopeful, feel more in control and feel more positive about the future because I know there’s other people that feel the same as me.” *tide member*

- Carers spoke with real warmth and affection when talking about tide staff and described how they have come to feel personally supported by them. This was exemplified during Covid-19, when carers appreciated being able to connect with other carers through tide’s online coffee meetings and workshops, and especially when there was the option to join at different times in the day, at evenings and weekends.
- Online sessions gave carers a sense of connection across the UK, not just to other carers in Scotland. By developing online sessions, tide have been able to reach carers who may otherwise not have been able to participate in face-to-face workshops or other national events.

“A lot of dementia services don’t allow you to talk about the difficult things in life when you’re looking after someone with dementia. In fact, I would say you were made to feel guilty for being sad.” *tide member*

What did we find?

Participants felt that:

- tide is a much needed and important part of the dementia care landscape in Scotland.
- tide provides a forum for “carer activism” in Scotland and has created a space where carers can express a shared voice on key issues that affect them.
- tide provides a space where carers can give voice to their inner experiences, especially experiences that are difficult and which (carers felt) may not appear compatible with the idea of ‘living well’ with dementia.
- The network is a forum in which carers could be themselves and can talk openly in the presence of other carers about what life as a carer is like. Being able to be open and honest is a much a needed opportunity for carers to express themselves.
- The tide network in Scotland has grown since 2017 and increased significantly since the first lockdown (see Fig 3) highlighting the demand for such services. From March 2020 to January 2021, membership of tide in Scotland increased by 96%.
- The shift to online delivery meant that tide’s programmes were accessible to more people, and were able to deal with a wider range of issues and topics that were relevant to carers. The tide network created focus groups that covered the following areas identified by carers, and have continued to expand to reflect the topics of concern for the network (see Fig 1).

Fig 1. tide Themed Focus Groups



- With 90,000 people living with a diagnosis of dementia in Scotland, there are carers and former carers of people living with dementia in every local authority area in Scotland. Tide now has members in each area, and membership continues to grow.
- Unpaid carers and former carers of people with dementia continue to contribute almost £14 billion per year to the UK economy¹ and tide’s network of carers continues to grow through events, campaigns and social media.

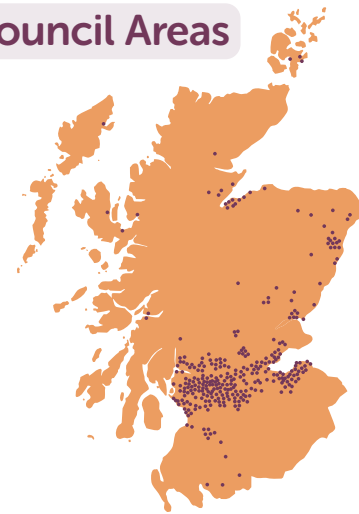
¹ Source – Alzheimer Society



Fig 2. Coverage of Membership across Council Areas

Top council areas

Council area	No. of members
Glasgow City Council	52
South Lanarkshire	26
Edinburgh City Council	20
Highlands	16
Fife	15



What did we learn?

- The evaluation highlighted the challenges involved in measuring carers' feelings of 'self-efficacy'² when it comes to dementia activism.
- Whilst the evaluation found strong evidence that being a member of tide can increase carers' confidence, the impact of self-efficacy proved more difficult to pin down.
- Carers described themselves as either "determined", "stubborn" or "change agents". Carers also described how becoming members of tide has helped them to be more assertive in their dealings with housing, healthcare or social care practitioners.

What does this mean?

- There is currently no reliable tool available for measuring self-efficacy for dementia activism. Our attempts to measure carers' feelings of 'general self-efficacy' indicates that these remained very stable during the period, despite all carers experiencing profound changes in their day-to-day lives, and in particular during the Covid-19 pandemic.
- It is possible that, without the support of tide, some of these carers may have experienced significant decreases in their self-efficacy but there is no way to reliably measure this.

What action will tide take?

- tide will work with researchers to develop tools that can better measure self-efficacy for dementia activism. This will help to demonstrate the impact that being a member of tide can have on self-efficacy and may help with future evaluations.

² Definition and model of self-efficacy is included on page 35.



What did we learn?

- Some carers felt a loss of connection to tide and to others in the network, over time, particularly if there were changes to their carer responsibilities or work commitments. Changes in staff, for example, could result in carers feeling separated from established connections.
- Changes in circumstances, such as 'former carers' (or anticipating becoming former carers) could result in carers questioning whether they wanted to remain in the tide network, and about what place they wanted dementia to play in their (post) carer lives.
- Carers, as a population are the one of the most heavily impacted (and time constrained), and the methods of engaging with carers needs to be flexible, adjusting to different times of the day, evenings and weekends to enable them to balance care, work and family responsibilities.

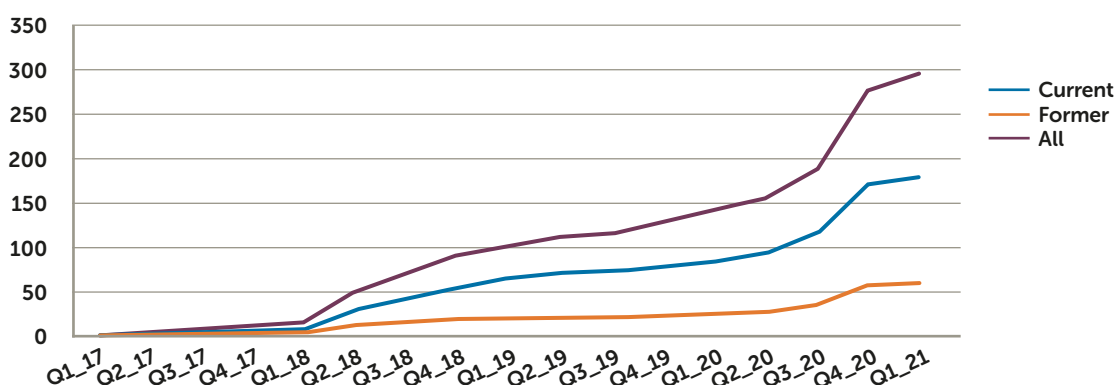
What does this mean?

- Continuity is important to the network and could be maintained by creating a more sustainable operating model that can deliver a mixture of digital services and one to one services, retaining strong connections, in a way that works for staff, carers, former carers and key stakeholders.
- Greater use of the Tide Advisory Group, or volunteer carers or former carers will enable and empower carers to have a sense of purpose and longer term commitment to tide, and increased continuity.

What action will tide take?

- Develop a new sustainable operating model that creates a balance of skills that can provide support, develop carers, influence policy and practice and enable a strong voice for dementia carers for the UK, including Scotland.

Fig 3. Increase in Membership Since 2017 (in Scotland)





Case study 1

Alison's story

Alison³ is a retired Registrar who lives with her husband in East Lothian. Alison worked as a Registrar for over 20 years and "loved" her job, as it gave her contact with people during some of the happiest and the saddest times in their lives.

"I've always been, I suppose, you would call a 'people person'. I was always meeting new people."

Name	Alison
Age	55–64
Gender	Female
Ethnicity	White
Self-Efficacy Score	35/40
Social Support Score	81/84
Z Score (Self-Efficacy)	0.84
Z Score (Social Support)	0.81

- In 2014, Alison's husband started developing symptoms that were eventually diagnosed as signs of early onset dementia – Alison's husband was 60 years old at the time.
- Alison continued to work during and after her husband's diagnosis but found the demands of work and caring increasingly difficult to manage, especially as the family was not entitled to any social care support.
- By May 2016, Alison found the juggle too difficult, and she felt she had no choice but to leave her job much earlier than planned and care for her husband full time. Leaving her job was something that she felt was "expected" of her by the care system.
- Leaving a job she loved had a profound impact on Alison's wellbeing and her sense of who she was. Looking back on it, Alison said, "I didn't realise how much of me I lost."
- Alison heard of the tide network in January 2018, at a meeting organised by Dementia Friendly East Lothian, where she met people from tide and other charities.



³ The carer has consented to using her real name, as she is comfortable about telling her story openly.



What changed for Alison?

- Through involvement with these organisations, Alison agreed to be part of a group of carers who organised a one-day event “By Carers, For Carers”, which enabled her to use her professional skills in a different way.
- She agreed to share her experience as a carer at an event being held in East Lothian in May 2018. The opportunity to share her experiences of being a carer felt exciting and represented “something for me”.
- Whilst Alison was experienced in public speaking – having presided over marriage ceremonies sometimes with more than 100 guests in attendance – speaking about being a carer was something altogether new.

“Conducting a marriage ceremony is from a basic script with additional words usually chosen by the couple. These are a whole different ballgame. These are from here (the heart). And, yes, they can be emotional ... it’s a different type of presenting.”

- The tide network offered training and support to Alison (and other carers speaking at the event) as part of tide’s Carer Development Programme.

“.....none of the information we got at diagnosis, none of the information I got ... was there ever any mention of tide.”

- As a result of taking part in tide’s Presenting to Influence workshop, Alison was able to connect with the other carers at a deep level. This gave her confidence that her story was important and needed to be told.



What difference did tide make to Alison?

- Through the workshop, Alison was able to create and present her story 'Losing Me and Finding Me' in May 2018. Her involvement in influencing work started to snowball and she received speaking requests for other events, including from the Scottish Trade Union Congress and at other carer's events as well as invitations to take part in filming work for projects highlighting carers' experiences.
- Alison started "Speaking to Influence" by joining with other members of tide at the Scottish Government's Cross-Party Group on Dementia and in helping to recruit new tide staff.
- Alison established close connections with other carers in tide. During her participation in the Dementia Congress in Brighton, for example, she and four other carers presented to over 700 delegates and they banded together to form a new informal group of carers, called 'The Disruptors'.
- Alison knows that she may not see some of these carers face-to-face, yet she remains in touch with them through tide's closed Facebook pages.
- Alison has also become more active in her local community and has become involved with a local charity, Our Community Kitchen.

"I was going probably down the road of shutting myself away. Absolutely shutting myself off from the world, because I wasn't coping. There are still days I don't cope. But ...the difference is, I now know where I can go to get support, where I can go for a hug."

- Through tide, Alison has become more connected to other carers and to her wider community. Yet, this does not stop Alison from feeling lonely and isolated at times. Rather than withdraw inwards, Alison feels that being a member of tide gives her space for comfort and support from other carers.

Outcome 2

Detailed analysis

- The Carer Development Programme offers services and resources to support and facilitate carers' growth in the network. Members can participate in various training and educational sessions.
- The 'Welcome to tide' session introduces new member carers to the network and to other carers. 'You Can't Pour from an Empty Cup' focuses on self-care and compassion and emotional well-being.

"Carers are not good at looking after themselves I believe that respite, along with the carer learning how to develop emotional resilience are both vital to ensure that caring for someone with dementia helps carers to survive the trauma and ensure dementia does not claim two casualties. Your Empty Cup session is powerful and I frequently recommend it to dementia carers." *Session attendee*

- Carers reported that this was a valuable service in helping to recognise that they are not alone in their difficult feelings.
- 'Living Grief and Bereavement' introduces the concept of grieving while the person for whom one is caring is still alive and is discussed further in Case Study 4.

"Some of the darkest and saddest feelings I have experienced were discussed in an open and honest way." *Session attendee*



- 'Getting Your Point Across' focuses on communication and supports carers in planning for meetings with professionals and being able to advocate for themselves and their loved ones.

"...great to hear about your rights and to feel empowered..."
"straightforward practical advice..."

- Many of the carers we spoke to described how they had lost their confidence during their caring journeys. Whilst carers had often led successful working lives, increased social isolation and having to give up work had left some carers feeling disconnected from their former selves. Whilst carers were highly motivated to share their stories and to influence change, they often felt daunted by this prospect.

What did we find?

- The personalised support provided by tide, combined with opportunities to acquire new knowledge and to speak in new environments, enabled carers to take their first steps towards sharing their stories and their personal experiences in public forums (see Case Study 2, for example).
- One of the key factors in increasing carers' confidence was the ability of the Carer Involvement Leads to identify opportunities for carers to share their stories in forums where carers were likely to receive positive feedback.
- Tide staff were acutely aware of how carers' confidence was damaged by the caring journey, and of the importance of re-building carers' confidence gradually and through a sustained process of personalised support.

"I wouldn't be the person I am today or doing the job that I do, had I not been involved with tide and giving me that clear voice to be open and honest and really talk about the difficult things... a lot of dementia services don't allow you to talk about the difficult things in life when you're looking after someone with dementia."

- A second key factor was enabling carers to prepare for their first experiences of sharing their stories, by participating in tide's Carer Development Programme (CDP). Working with other carers in learning how to build personal resilience and tell their own story can have a transformative impact on carers and their routes into influencing.



- Due to Covid-19, delivery of tide's CDP has moved entirely online. In response to requests from members, tide has added several focus groups which meet monthly including Practical Caring, Young Onset Dementia, Living Grief and Bereavement, Rare Dementias, Care Homes, Care at Home and Male Carers.

What did we learn?

- Whilst some carers missed the opportunity to participate in the workshops face to face, overall carers appreciated the flexibility that participating online could provide, including the ability to use 'closed captions' and subtitles for those members with sensory or hearing impairments
- Alongside developing carers' confidence and skills, these sessions have provided opportunities for carers to develop their abilities to cope with challenges that may have been made worse by the pandemic, including techniques for fostering resilience and for regulating sleep.

"Tide did a workshop around sleep and it was very, very good... one of the things that a lot of dementia carers talk about is the lack of sleep, you know because the person with dementia might not sleep at night, might be up half the night and how exhausting that can become. That's what happened to me, ... I understand how sleep deprivation is used as a form of torture..."

- Prior to Covid-19, tide had encountered a number of challenges in rolling out the Carer Development Programme across Scotland. Changes in staffing led to tide's CDP being delayed. As one staff member explained, "because we've not had that rolling programme, it's been quite hard to then get people excited for it." Developing tide's online and hybrid delivery of the CDP is likely to be crucial in broadening access to the programme, especially during the pandemic.

"It's not just about carers arriving and having to speak or do something that they don't feel comfortable. It's the preparation ahead of time. So it's being supported, the training, public speaking, that kind of empowerment, growing in self-confidence." *External Stakeholder*



Case study 2

Ray's story

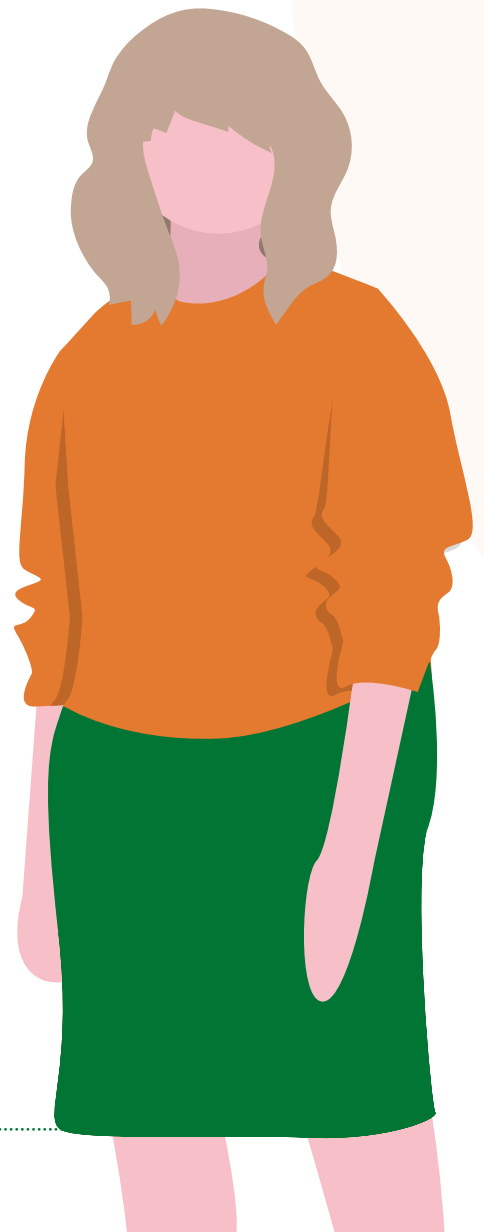
Ray⁴ lives in the West of Scotland. She describes herself as “confident”, “strong” and (at times) “stubborn”, with a strong sense of fairness and a commitment to social justice. Ray met her husband when they were both in their early twenties.

Name	Ray
Age	55–64
Gender	Female
Ethnicity	White
Self-Efficacy Score	34/40
Z Score (Self-Efficacy)	0.66
Z Score (Social Support)	-1.48

Ray described the long, difficult and traumatic process through which her husband eventually came to be diagnosed with a rare form of dementia in 2017.

They married and were able to successfully navigate the Protestant- Catholic divide that was prevalent in Scotland at that time.

- Ray started to notice changes in her husband's behaviour and personality as far back as 2012. These changes were difficult to spot at first, because Ray's husband had become skilled at masking the difficulties he was having in his day-to-day life.
- As time went on, however, his symptoms became more severe and easy to spot. He was initially misdiagnosed as having a “nervous breakdown”, so it was not until 2017 that Ray managed to get a formal diagnosis.
- During these five years, Ray fought hard for her husband to be referred to a specialist neurologist and felt she often had to “take the lead” in managing input from different agencies and organising her husband's care. Both she and her husband fought hard to access Self Directed Support, yet this was something the local authority were never able to put in place.



⁴ The carer has consented to using her real name, as is comfortable about telling her story openly.



What changed for ray?

- Following a stay as a psychiatric inpatient (between 2017- 2018), Ray's husband was eventually discharged home, still with limited support. His condition was terminal, and Ray knew that her husband wanted to live his final days at home, surrounded by his family. Without proper support from the local authority however, it became impossible to provide care at home safely. Ray's husband was admitted to a local hospice where he passed away in February 2018.

"... that left me with a lot of guilt. You know, was it my fault that he never got care? ... I was never rude, and I was never aggressive I was simply asking for help [and] not getting it...the system is so broken."

- The trauma of these years had a deep impact on Ray and continues to affect her. Her commitment to advocating for her husband resulted in her being labelled as "trouble" by some in the local authority and she constantly felt the need to stay "two steps ahead" when advocating. Not being able to care for her husband at home left Ray with intense feelings.

"You learn to have so many faces, so many people silencing, that you lock it all away. So I'd be driving to work with tears tripping me. And I would be driving home from work with tears tripping me. And then I would have to paint my smile on going in the door."

- Ray's struggles with the health and social care system played an important role in how she came to be involved with tide in Scotland. Ray found tide in 2017, before the network established a formal presence in Scotland. Ray was searching for sources of advice and support for carers of people with dementia and, before coming across tide, had struggled to find places where she could talk openly and honestly about her experiences.



What difference did tide make to Ray?

- Becoming a member of tide meant that she was able to be “honest” about her experiences and to talk with other carers about sensitive, difficult and emotional things. Ray believes carers need to talk about such things with each other and to share them with policy makers, if things are to improve in Scotland.

“... my whole belief is if we don't talk about difficult things and difficult journeys, how is the government ever going to give more funding, if they think everything is a bed of roses and everybody is 'Living Well?'”

- Ray describes the impact that being a member of tide has had on her as truly “life changing”. In May 2018, around a year after joining tide, Ray began a new career as a Project Coordinator offering advice and support to other people affected by dementia.
- The knowledge and skills that Ray acquired through tide, including through tide's Carer Development Programme (CDP), helped give her the confidence to embark on this new career path.

“...without learning all the new skills and being allowed to use them, I wouldn't be in the profession I'm in today.”



- Prior to joining tide, Ray had no experience of public speaking or other forms of influencing work. Yet, through participating in tide's CDP and associated workshops, she told us how she was able to build her confidence and her skill set.
- When the Evaluation Team returned to interview Ray (in October 2020) she told us that the Project Coordinator job had ended, but that she had started a new job – as one of tide's Carer Involvement Leads.

"I didn't know, you know, that I could stand up there in front of how many hundreds of people – I do now... And I'm not afraid to open up. It gives you freedom."

- She told us that her first-hand knowledge and experience as a carer – combined with the training and skills acquired through tide's CDP – puts her in a unique position to build empathy and trust with other carers in the network.
- Transitioning from being a member of the network to being one of tide's regional Involvement Leads is, she explains, another exciting next step in her on-going journey in dementia, and taking control.

"I'm beginning to find out who I am and where I'm going to go with my life, and what I'm going to do. Whereas before ... I just couldn't see past the state that I was in... I've now got aspirations and career goals."



Outcome 3

Detailed analysis

- Carers are passionate about improving the lives of other carers in Scotland. Many carers described difficult, challenging and traumatic experiences and were keen to ensure their voices were heard by policy makers and others to help bring about positive change.

“We’ve got some strong-willed people round the table [at Cross Party Groups]. And tide, their presentations are meaningful, so they seem to have found a stature now. And it’s recognised that the good work that they do and they’re listened to and yeah, I think it’s a huge difference from when we first went in.” *External Stakeholder*

- Carers often had preferences for how they wanted their voices to be heard. Some carers were keen to focus their energies at local and regional levels, whereas others were more focused on raising awareness and campaigning at national and international levels.
- Whether carers wanted to influence change at local, regional, national or international levels, being members of tide has helped them to achieve their goals. Support from tide ranged from guidance on how to set up and facilitate a local carer group, through to supporting carers to present at national and international conferences.

“Whenever someone from tide speaks, it is quite an emotional experience for the person who’s listening in the audience. It’s a challenge back to the audience, especially to those professionals in the room.” *External Stakeholder*

- External stakeholders said that tide is making a notable impact in Scotland. Since coming to Scotland, tide has had to navigate a complex landscape and establish connections and working relationships with the Scottish Government and with organisations already established in Scotland.

What did we find?

- tide has developed a network and key relationships across Scotland, co-ordinated by the Carer Involvement Leads, and Head of Tide Development and National Lead in Scotland.
- tide have established key relationships at a local level and national level, working with key partners at the Scottish Government, Alzheimer Scotland, About Dementia and Age Scotland on delivering joint projects and webinars on Human Rights and a Carers Link and Learn series.

Locked In, Locked Out Webinar hosted by tide in December 2019 (Comments from Panel Member and carer): "Thank you for giving me the opportunity to share my experience and organising the webinar it was brilliant. I was really nervous as I haven't done anything like that before but I'm very glad I did it and I think it will help my confidence too."

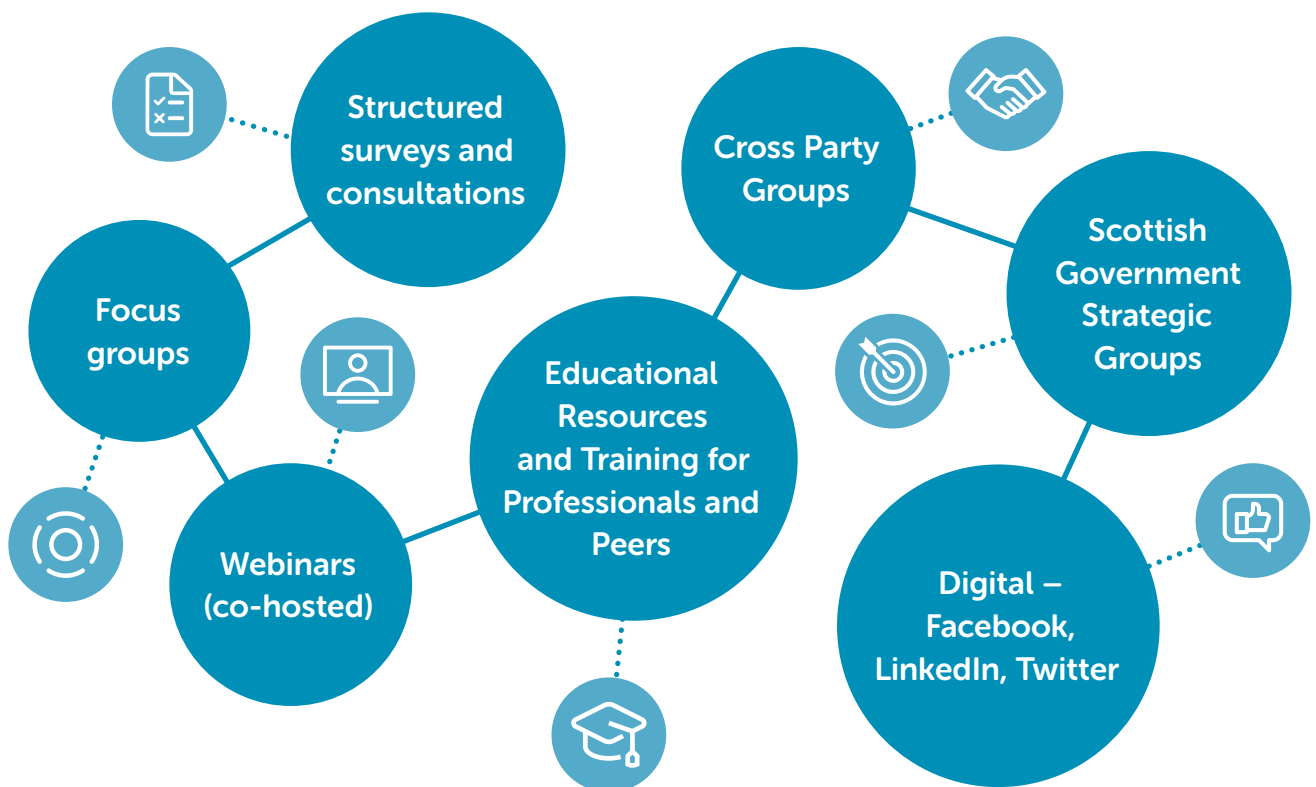
- Alongside supporting individual carers to have their voices heard, we found clear evidence that tide has been able to successfully mobilise the collective experiences of carers in order to influence policy making and practice in Scotland.
- Carers, tide staff and external stakeholders all highlighted tide's work on Living Grief and Bereavement as a key example of this and as something that is likely to have a significant and long-lasting impact in Scotland (see Case Study 4).





"I feel that tide are a positive force and when they turn up to the cross-party meetings and go to policy events and meetings with the Scottish government, they're bringing the voice of carers....they're also coming with a growing number of partnerships and relationships with other organisations that have approached tide." *External Stakeholder*

- Becoming a member of tide can clearly help carers to have their voices heard at a local, regional and national level (including UK).
- Carers contribute to local and national policy work through a variety of mechanisms, ensuring the 'voice of carers' is representative of the wider network. These include:



- Examples of this contribution are;
 - Tide submission to the recent review of Adult Social Care by Derek Feeley
 - [Tide manifesto](#) and priorities for recent 2021 parliamentary elections
 - Contribution to Scotland's Dementia Covid-19 Action Plan
 - Scottish Government Commissioned Restoring Relationships project, which created [two toolkits](#) to support families, relatives of people living in care homes during the pandemic and the staff members who work there.
 - Locked In, Locked out webinar tide hosted in December 2019 on the then current restrictions placed on indoor visiting in care homes.



What did we learn?

- All carers have their voice heard, through a variety of mechanisms, not just public speaking. However, it is the minority of membership that have been more active on an individual or direct influencing level to date, with the majority of network members focused on being part of a community and sharing insights collectively.
- As tide's membership continues to develop, it is important that the network reaches carers from diverse backgrounds and that tide helps to ensure that a diverse range of voices and experiences are being heard at local, regional, national and international levels. Monitoring diversity within the network in Scotland may be one route to achieve this.

What does this mean?

- Diversity and inclusion are key values for tide in Scotland but the current membership is predominately female and white. Further effort is required to determine ways of addressing potential unconscious bias and ensuring the network include cultural diversity.

What action can tide take?

- Tide have carried out significant work in Greater Manchester with our Dementia Dekh Bhaal project and will leverage key learnings from this work, with involvement of BAME stakeholders and staff, to inform future projects in Scotland.
- In the post-pandemic world, tide will continue to build connections with other organisations and promote the Scottish tide perspective. As one key informant said, "tide need to be better known and they need to swamp social media with the Scottish tide perspective."



Case study 3

Natasha's story

Natasha lives in East Scotland and works in Retail Management. She describes herself as "funny, friendly and "headstrong".

Natasha's mother was diagnosed with early onset dementia in 2014, although she started experiencing symptoms two or three years beforehand. Natasha's mum was in her mid-50s at the time, and she described getting an accurate diagnosis for her mother as a "fight" during which she often struggled to be heard.

Name	Natasha
Age	25–34
Gender	Female
Ethnicity	White
Self-Efficacy Score	30/40
Social Support Score	72/84
Z Score (Self-Efficacy)	-0.04
Z Score (Social Support)	0.31

- Motivated by her experience, Natasha set up a social media site dedicated to raising awareness of early onset dementia. On the site, Natasha shares hers and her mother's experiences and helps to signpost carers to sources of information and support. As she says, "it's been a good experience because it's coming out of something that's so bad".
- Natasha first heard of tide towards the end of 2017. She had started attending meetings of the Cross-Party Working Group on Dementia, having been told about the group by her MSP. Natasha had not shared her experiences at the meetings until she met one of tide's Carer Involvement Leads, who was the first to encourage her to speak.

"I felt like the doctors just weren't really listening to our side of the story... once she was diagnosed, there's a lot of 'Oh, there's not much for her because we don't cater to people of your mum's age' ... Nightmare, an absolute nightmare."





What changed for Natasha?

- Natasha met with the Carer Involvement Lead again after the Cross-Party meeting, and made the “no brainer” decision to join the network. Since joining in December 2017, Natasha has been “very active” in tide.

“I think I’d been to two or three Cross-Party Groups before that and I used to sit at the back thinking, ‘I’m just a carer, I shouldn’t be here, I don’t have anything to say’.... and I had to ask [the Carer Involvement Lead], ‘Do you think I can speak?’ and she was like, ‘Yes!’ and she just like pushed me up...”

- Whilst she sees herself as “headstrong”, Natasha does not think of herself as a “naturally confident person”, especially when it comes to public speaking and speaking to professionals. Through her involvement with tide, Natasha feels that she has become a more confident person. Seeing the positive impacts that sharing her story can have has been a big part of growing that confidence.

“... it’s made me a more confident person in terms of knowing that it’s ok to kind of give my opinion in a room full of professionals... knowing that they will respect your opinion, they’re not going to just shoot you down straight away... it’s opened my eyes to the impact that carers can have on change.”

- When we returned to interview Natasha in 2020, she told us how she had been working to raise awareness of the impact that the Covid-19 pandemic was having on carers and on people with dementia living in care homes.

What difference did tide make to Natasha?

- Natasha’s mother developed Covid-19 and was hospitalised early in the pandemic; thankfully she recovered. Natasha told us how this was a very difficult time, and she had several “mini-fights” with professionals to find out what was happening and to be able to see her mum. Natasha felt that her expertise as a carer was being overlooked by health and social care staff during the pandemic, so she decided to campaign.



“... we created a survey to put out to the family representatives ... it was that kind of knowing that ... real life stories do matter but we have to back it up with evidence... I've learned all that from tide ... that the gathering the information is just as important as real-life stories, you need to kind of marry them together.”

- To make her voice heard, Natasha joined a new Facebook group to help raise awareness and harness the support of other carers. She also became part of the key steering group that managed to secure meetings with senior policy makers in Scotland – including the Cabinet Secretary for Health & Sport, the Chief Nursing Officer for Scotland and the National Clinical Advisor for Ageing & Health. To influence these policy makers, Natasha knew she would need to arm herself with evidence and with personal stories. Below she describes how she did this through the Facebook group.
- Natasha feels that her confidence to engage with policy makers at this level has in large part come from the advice, support and encouragement that she has been able to draw upon through tide.

“I would never had the confidence then to do that if it wasn't for tide... they can direct me and go, 'Well maybe try this avenue.' 'Have you heard of this group? Or, you should maybe ask these questions in your next meeting.'”

- Natasha told us how she has already achieved some notable wins through her recent campaigning work. She told us how she has found influencing policy and practice to be a gradual process, where change is achieved step-by-step rather than all in one go.
- As a result of working through tide to influence policy and practice in dementia, Natasha is currently considering a career change, and regularly posts updates to her own social media channels, campaigning on issues that are important to her family and dementia community.
- Natasha is a member of the Tide Advisory Group and is key to providing insight to the senior team and Board on what matters to young carers.

Case study 4

Living grief & bereavement

The Living Grief and Bereavement project started in February 2019. The idea for the project came about as a result of conversations between tide's Carer Involvement Leads in Scotland and tide members.

- Grief and bereavement are widely thought of as emotions people experience when someone close to them dies. Yet, both Alison and Ray described how they experienced feelings of grief, loss and bereavement whilst their husbands were still alive. Rarely, however, did professionals in dementia care seem to understand and to appreciate this. The following statement is included in the Bereavement Charter, which was influenced by the work that was designed by tide and is recognised as a key resource across a number of stakeholders, and has been used to create new resources.
- Speaking with others in the network, tide's Carer Involvement Leads came to realise that such feelings were common amongst carers, yet many felt unsupported in dealing with them. So in 2019, tide in Scotland began to draw upon the knowledge and expertise of the membership to raise awareness of this issue and influence change.
- During 2019, tide organised an online survey of the membership and conducted a series of focus groups, during which members could share their experience of living grief and bereavement in a safe and supportive environment.
- Members responded positively both to the survey and to taking part in group discussions. The experiences of carers that were highlighted through the survey and the focus groups were captured in a series of outputs, including a video and two information booklets.
- The first booklet is aimed at carers and seeks to reassure them they are not alone in having these difficult feelings. The second booklet is aimed at practitioners and seeks to educate them on the carer experience.

"Good bereavement care is a human right grief and bereavement can begin before death and can be lifelong."





“...carers don't only feel the effects of grief when the person dies, it's an ongoing daily loss in your life. ... the things he has lost, the things I have lost, and the things we've both lost as a couple.”

- Both booklets were launched at the 2019 National Dementia Congress. Members Ray and Alison participated in the launch and have shared their experience of living grief through a series of talks – before, during and following the formal launch.

“...we launched at the UK Congress and the people who were in that room, they're all kind of like “Yeah, why's nobody talking about this?”

- Since the launch, tide have produced a series of video and audio recordings of carers' experiences of living grief and bereavement and these, along with the booklets, have been made freely available within tide's online story bank – <https://www.tide.uk.net/resources/grief-bereavement/>

What do we know?

- The work on living grief and bereavement is having a positive impact on carers as well as on policy makers and senior managers in Scotland.
- Through tide, carers in Scotland have been able to take part in sessions designed to help them visualise, accept and process the difficult emotions of living grief and bereavement – including informal online catch-ups and an arts-based session, organised by tide and delivered in Glasgow by an arts therapist. Through these, tide has helped to create space where carers can meet, connect and learn from each other's experience of grief and loss.

“... was really, helpful because it helped me to identify what was happening for me and why I was kind of thinking and feeling the way that I was about stuff.”



- Most of the external stakeholders who took part in the evaluation were familiar with tide's work on living grief and bereavement and valued how tide had helped to raise awareness of this important issue in Scotland. These interviews suggest that tide's work on this issue has been instrumental in helping to put tide 'on the map' in Scotland.

"Losing someone while they're still alive is one of the topics that tide explicitly and brilliantly raises ... All of those very complex feelings tide discusses under the umbrella of living grief resources. And we direct ... people to those all the time."

What did we learn?

- The approach that tide took to identifying the work on Living Grief and other practical and emotional issues that carers are facing on a day-to-day basis, was successful and is being used for other co-produced resources.
- As part of the living grief and bereavement work, tide have been actively involved in shaping A Bereavement Charter for Children and Adults in Scotland, which was launched in April 2020. Contained within the Charter is clear recognition that grief can begin before death.
- The tide network in Scotland continues to work with the Bereavement Charter Group to promote the Charter in Scotland. Carers' stories and experiences will be included in a new resource on Anticipatory Grief, being developed by NHS Education for Scotland.

What does this mean?

- Carers' stories will be shared with the SIGN Guidelines for Dementia Review Group (in May 2021) and discussions are underway to publish a book on living grief and bereavement which will serve as a best practice guide for professionals.
- *tide is developing a training session on living grief and bereavement, which will be aimed at professionals working with current carers as well as with former carers of people living with dementia.*

[A Bereavement Charter for Children and Adults in Scotland \(April, 2020\)](#)



What did we conclude?

Outcome 1

'Carers of people with dementia report increased connectedness to others, a greater sense of self-efficacy and feeling part of a collective voice.'

- The evaluation identified areas of genuine social value from the work undertaken by tide in Scotland, by demonstrating that carers reported increased feelings of confidence and of emotional connectedness to others as a result of their engagement with tide.
- tide has created a network of staff, carers, former carers and professional carers who were committed to the network in Scotland and felt comfortable and confident to share their life stories and experiences. This enabled tide to work with key partners to co-produce material that is aimed at raising awareness of local and national practices, and developing new skills.
- Our attempts to measure carers' feelings of self-efficacy using the General Self-Efficacy (GSE) scale indicates that self-efficacy remained stable during the period, despite carers experiencing profound changes in their day-to-day lives brought on by the Covid-19 pandemic. There is currently no validated tool for measuring self-efficacy for dementia activism. However, the General Self-Efficacy (GSE) Scale has been used successfully by other researchers to measure the impact of carer involvement on self-efficacy (please see our Rapid Review for further details of these studies).



Outcome 2

'Current and former carers will gain confidence, knowledge and new skills that will increase their ability to influence positive changes in policy, commissioning and services.'

- The evaluation identified areas of genuine social value from the work undertaken by tide in Scotland, by highlighting how being a member of tide could lead to increased confidence, development of new skills and new applications of existing skills amongst carers.
- External stakeholders highlighted the value that tide brings to the dementia community in Scotland. There is evidence of this work continuing in key projects in Scotland that will enable members of tide to have a platform for change. Tide provided some early indication of key partnership work that has started for 2021, including Restoring Relationships Toolkits with the Scottish Government.
- tide in Scotland could prioritise the development of local tide Groups. Whilst we found evidence of member carers establishing local support groups, these appeared to be independent of tide and not a conduit for delivering the Carer Development Programme. Establishment of local tide groups could be led by member carers with guidance and support from tide staff.
- Memorandums of understanding and other formal agreements should be used to encourage other organisations to refer carers to tide.





Outcome 3

'Development of policies, research, education, commissioning and services will be more responsive to carers' needs by the inclusion of the voice of carers through the tide network at local, regional, national and international levels.'

- The evaluation identified areas of genuine social value from the work undertaken by tide in Scotland, to increase carers ability to influence positive changes in policy, commissioning and services. This is highlighted in Case Study 4.
- tide should support member carers to create 'personal development portfolios' that summarise and showcase the contributions they make to dementia policy and practice in Scotland. Creating e-portfolios that showcase carers' development and influencing work would provide important evidence of 'experiential prior learning' that carers can use to pursue additional (e.g. professional level) training and development.
- tide may benefit from monitoring the social and demographic profile of its growing membership in Scotland, in accordance with its ongoing efforts to ensure the network provides a safe and inclusive space within which carers from a diverse range of backgrounds can connect with each other. tide will invite member carers from diverse communities (e.g. BAME, LGBTQI+) to lead the development of special interest groups and themed working groups within the overall network.



Evaluation process – Self-efficacy

This section summarises the main activities that were conducted as part of self-efficacy evaluation for Outcome 1; whether tide members find themselves having a greater sense of self-efficacy as a result of being involved with tide

Albert Bandura describes self-efficacy as the belief in one’s own ability to successfully accomplish something. It tells us that people generally will only attempt things they believe they can accomplish and won’t attempt things they believe they will fail.⁵

All Member Carers who participated in the evaluation were asked to complete a validated instrument known as the General Self-Efficacy (GSE) scale. These measurements were analysed and interpreted alongside qualitative interview data – where carers talked in-depth about their perceived ability to manage difficult situations and affect positive change.

The GSE scale is a validated tool designed to measure the extent to which a person holds optimistic self-beliefs in their ability to cope with a variety of difficult demands in life. The scale is comprised of 10 items and the person’s response to each item is scored between 1 and 4, depending on the extent to which the person agrees with the statement presented (i.e. 1= Not At All True; 4 = Exactly True). The lowest score a person can receive on the scale is 10 and the highest score a person can receive on the scale is 40. The GSE scale has been used by other researchers to measure the impact that participating in advocacy based education and peer support may have on carers’ feelings of self-efficacy (see our Rapid Review for further details).

Determining Efficacy Judgements⁶

Performance Outcomes

“Positive and negative experiences can influence the ability of an individual to perform a given task. If one has performed well at a task previously, he or she is more likely to feel competent and perform well at a similarly associated task” (Bandura, 1977).

Verbal Persuasion

“Self-efficacy is influenced by encouragement and discouragement pertaining to an individual’s performance or ability to perform” (Redmond, 2010).

Vicarious Experiences

“People can develop high or low self-efficacy vicariously through other people’s performances. A person can watch another perform and then compare their own competence with the other individual’s competence” (Bandura, 1977).

Physiological Feedback

“People experience sensations from their body and how they perceive this emotional arousal influences their beliefs of efficacy” (Bandura, 1977).

⁵ Bandura, A. (1977) Self-efficacy: Toward a unifying theory of behavioural change. Psychological review, 84, 191–215

⁶ Source – The Pennsylvania State University



Self-Efficacy Questions

- *Do you feel like you can handle problems if you are willing to work hard?*
- *Are you confident in your ability to achieve your goals?*
- *Do you feel like you can manage unexpected events that come up?*
- *Are you able to bounce back fairly quickly after stressful events?*
- *Do you feel like you can come up with solutions when you are facing a problem?*
- *Do you keep trying even when things seem difficult?*
- *Are you good at staying calm even in the face of chaos?*
- *Do you perform well even under pressure?*
- *Do you tend to focus on your progress rather than getting overwhelmed by all you still have to do?*
- *Do you believe that hard work will eventually pay off?*

Evaluation process – Self-efficacy judgements

The theory of self-efficacy introduces the idea that the perception of efficacy is influenced by four factors; mastery experience, vicarious experience, verbal persuasion and somatic and emotional state.⁷

Further investigation is required to look at developing methods of measuring self-efficacy that are more reliable and can demonstrate the value of tide services in improving feelings of self-efficacy. Tide are planning to do further work on investigating ways of measuring the 4 judgements of self-efficacy.

⁷ Pajares, F (2002) Overview of Social Cognitive Theory and of Self-Efficacy



Evaluation process

This section summarises the main activities that were conducted as part of the evaluation and provides an overview of each activity.

The rapid review of the literature

The evaluation team conducted a 'rapid review' of the published literature. The review explored what outcomes we can expect by enabling carers of people living with dementia to engage in advocacy-based forms of peer support. There was evidence to suggest engaging in advocacy-based forms of peer support can increase feelings of well-being. However, there was a dearth of evidence to suggest such activities either reduce feelings of loneliness or lead to changes in policy and practice. Findings from the review were used to revise Outcome 1.

The theory of change workshop

In February 2019, the evaluation team facilitated a 'theory of change' workshop with tide staff. Theory of change is a structured approach to understanding how desired changes may be brought about. It involves describing and visualising a sequence of events that are expected to bring about change. Theory of change is a 'bottom up' approach where the beneficiaries of change have a role in planning how change will be happen.

Initial interviews with member carers

From October 2019 to November 2020, the evaluation team conducted interviews with nine tide carers members. The interviews ranged from 50 minutes to 1 hour, 31 minutes and explored carers' experiences of diagnosis and post-diagnosis support, how carers came to be involved with tide, their involvement, and the impact that being a member of tide has had on their lives. Carers were also invited to complete a pre-interview questionnaire.

The pre-interview questionnaire asked carers to identify their age, gender and ethnic backgrounds as well as provide an indication of their current caring responsibilities. Carers were asked to complete two validated instruments that are designed to measure carers' feelings of self-efficacy (Instrument 1) and social support (Instrument 2).



Follow-up interviews with member carers

From October 2020 to January 2021, the evaluation team conducted follow-up interviews with member carers to explore carers' experiences of being members of tide since their initial interviews, with a particular focus on their experiences during the global pandemic.

Follow-up interviews lasted between 44 minutes and 1 hour, 41 minutes and most were conducted approximately 1 year after the initial interview.

Member carers were asked to (re) complete the pre-interview questionnaire. This provided information on caring commitments and the number of tide workshops that member carers had participated in, since the initial interview. Carers were also asked to complete Instrument 1 (which measured changes in carers' feelings of self-efficacy) and Instrument 2 (which measured changes in carers' feelings of social support).

Interviews with external stakeholders

Between March 2020 and December 2020, the evaluation team conducted in-depth interviews with 11 external stakeholders. These stakeholders tended to be senior executives and managers from both the public sector (e.g. the NHS) and the third sector (e.g. charitable organisations) whose professional work brings them into contact with tide or with issues to do with dementia in Scotland on a regular basis. The aim of these interviews was to explore stakeholders' views and experiences of tide and to explore their ideas and suggestions for how the network can develop in Scotland. These interviews lasted between 28 minutes and 1 hour, 5 minutes and, due to the pandemic, were all conducted online.

Interviews with tide staff

Between April 2019 and October 2020, the evaluation team conducted in-depth interviews with key members of tide staff. The aim of these interviews was to explore staff's experiences of working for tide and their suggestions for how the network could be best developed in Scotland. These interviews lasted between 47 minutes and 1 hour, 26 minutes. The majority of the interviews were conducted face-to-face, prior to the pandemic.



Service data

In March 2020 and in March 2021, the evaluation team collected service-level records from tide. These contained details of the total number of carers in the network, as well as regions where carers lived and whether members reported being current or former carers. The evaluation team also received copies of feedback that tide had received from members (e.g. after carers had taken part in tide's workshops). In addition to these records, tide staff also completed pro-forma designed to capture key information and key documents relating to tide's work on Living Grief & Bereavement.

Our approach to data analysis

Data from the interviews were mainly analysed using Framework, which is an approach developed by Natcen in the UK. Service level data was input in Microsoft Excel and analysed using a mixture of pivot tables and graphs.

Strengths and limitations of the research

One of the main strengths of the evaluation was that the team were able to work closely with tide for an extended period (January 2019 – April 2021). Whilst the evaluation team remained independent throughout, this enabled the researchers to develop good working relationships with tide staff and tide members and to develop a deep level understanding of what the network is seeking to achieve in Scotland. A second strength of the evaluation is the extent to which we were able to develop a 360-degree perspective on the network, by gaining insights into how tide is experienced by member carers, tide staff and by external stakeholders.

One of the main limitations of the evaluation was the limited number of member carers who took part in the evaluation. Despite concerted efforts on the part of tide and the evaluation team, recruiting members to the evaluation proved to be highly challenging. We had hoped to follow a cohort of 15–20 member carers during the evaluation, but were only able to recruit nine members. All the members who took part in the evaluation identified as White-UK and all except one identified as Female. If we had been able to recruit a larger cohort of member carers and recruited carers from non-White ethnic backgrounds, this may have affected our findings.



Acknowledgements

We would like to acknowledge the insight, wisdom and generosity of all the member carers, tide staff and stakeholders who participated in this evaluation. It has been a privilege to learn from you, and without your involvement, this evaluation would not have been possible.

The evaluation team:

Dr Nick Jenkins is a Senior Lecturer in Sociology & Social Policy at the University of the West of Scotland and he leads the evaluation team. He has previously worked with a range of advocacy groups in dementia, including Dementia Alliance International and the Scottish Dementia Working Group.

Dr Karen Monaghan is a Research Assistant in the School of Education and Social Sciences at the University of the West of Scotland and is a member of the evaluation team. She works in the arena of health and social justice and her area of expertise is in the intersection of stigma and mental health policy implementation.

Dr Beverley Young is a Senior Lecturer at the University of the West of Scotland and a member of the evaluation team. She is the Post Graduate Research Lead within the School of Health and Life Sciences. As a registered nurse, Beverley has 15 years-experience of caring for people living with dementia within a community hospital.

Michael Smith is a PhD student within the School of Health and Life Sciences at the University of the West of Scotland and is a member of the evaluation team. He has a background in health psychology, with a research focus on assessing appropriate housing options for people living with dementia.