

Update from



**tide**

**In Scotland**

**Welcome from the  
tide team in Scotland!**



**For those of you who may be reading this and are unfamiliar with who we are, tide (Together in Dementia Everyday) are a UK wide involvement network for carers and former carers of people with Dementia. We are funded in Scotland by Life Changes Trust and wanted to take this opportunity to update you all on what's been happening recently for tide in Scotland.**



**What's New?**

**July has been a very busy month for us in Scotland; we have released dates for the Carer Development Programme in August and launched our new fundraiser Coffee For Carers.**

# Virtual Coffee Morning Catch Up's and Get Togethers

One of our key aims as an organisation is to connect carers with each other and enable people to share experiences as carers of those with dementia. There are a range of ways to connect available to our members and our virtual Coffee Mornings and Get Togethers are just a couple of options on offer to all members.

## Scotland Coffee Mornings Tuesday at 10.30am

Join us on Tuesday mornings for a relaxed chat with our team in Scotland and other member of tide. Our Coffee Mornings are friendly, informal and attended by current carers, carers of those who are in residential care and former carers so are open to all.

We use zoom for this and can help you get set up and started if this is new to you.



## National Coffee Mornings Fortnightly Wednesday at 10.30am

In addition each fortnight we hold a National Coffee Morning with members from each of the four nations. Come along for a chat with carers from across the UK.



If you would like to come along to either of these events please visit our [event page](#) or send an e-mail to [carersconnect@tide.uk.net](mailto:carersconnect@tide.uk.net)

# Monthly Focus Groups

**Do you care for someone? Do you often feel isolated, unheard or alone in this experience? Are you looking for support, information or advice from other unpaid carers?**

**At tide, we believe that lived experience of unpaid carers is the most important thing in shaping what is offered to those who care for someone. We have several focus groups for you to meet and connect with other carers who share similar experiences. These groups offer a safe space for you to have your voice heard or simply listen.**

## Young Onset Dementia Carers

**1st Tuesday  
7PM-8PM**

## Former Carers

**Last Wednesday  
4PM-5PM**

## Residential Carers

**2nd Tuesday  
1.30PM-2.30PM**

## Home Carers

**2nd Wednesday  
7 PM-8PM**

**Rare Dementia Carers  
Group**

**3rd Wednesday  
2.30pm-4pm**

**Male Carers  
Group**

**2nd Thurs  
2.30PM-3.30PM**

**The Practical Carers Group**

**1st Wednesday  
3 PM-4PM**

**Living Grief and Bereavement Group  
Monday 23rd August  
1-3pm**

**The purpose of the group is to offer connection for carers and a safe space to talk about your experiences of living grief and bereavement. Please register your place at this [session here](#)**

**After registering, you will receive a confirmation email containing information about joining the meeting.**

**To book onto any of these events go to [www.tide.uk.net/events](http://www.tide.uk.net/events) and click on 'Monthly Focus Groups'  
To find out more about joining in in any of these events please contact [carersconnect@tide.uk.net](mailto:carersconnect@tide.uk.net)**



# Carer Development Programme

## Introduction to tide

- Meet other members
- Learn about what we do
  - How you can be more involved with us
- See what we can do to support you

You can now watch recordings of intro to tide [here](#)

## You Can't Pour from an Empty Cup

- Self Care and Self Compassion
- Taking the first steps to doing something for you
- Some practical hints, tips and suggestions to help you "Fill your Cup"

## Getting Your Point Across

- Phone Call or Meeting Toolbox
- Tips for Negotiating Effectively
- Safe, Constructive ways to Question
- Your Right to be Involved, Participate and Feedback
- Complaining Effectively

## Living Grief and Bereavement

- Trigger points where you may feel feelings of grief and bereavement
- Unspoken thoughts and feelings
- Advice from other carers who have experienced this
- Hints and tips in supporting you with these feelings



We have released dates for August for the Carer Development Programme. Please check our events page at [www.tide.uk.net/events](http://www.tide.uk.net/events) and click on 'Carer Development Programme'



# Intro to tide Pro

**Are you an organisation or project who works with or supports carers or former carers of people with dementia? Would you like to find out more about tide and what we can offer to the carers you support as well as compliment the work you are already doing?**



**If so please get in touch about our Introduction to tide Pro sessions. These are delivered at the moment online via zoom and can be adapted and delivered to suit a variety of days, times and settings.**



**They are ideal for any staff and team meetings or development days you have coming up where you would like us to virtually come and speak to several staff members at the one time or they can be done on a one to one basis if you prefer.**



**If you are interested in finding out more or discussing a bespoke plan for your session please get in touch with Amanda McCarren, our Head of tide Development and National Lead for Scotland on [Amanda@tide.uk.net](mailto:Amanda@tide.uk.net)**

# Restoring Relationships

## The Recovery of Love, Family & Connection

**tide has created two Recovering Relationships toolkits, one for families and relatives and one for care home staff and managers. These toolkits are for anyone who knows someone living in a care home in Scotland or for anyone who works with care providers in Scotland.**

**Evaluating the toolkits and how they are working in practice is a vital part of the project and we would appreciate you taking a few minutes to complete this evaluation form for us. Your feedback will support the continued development of the toolkits as well helping future phases of the project. If you would like to speak to someone personally about the toolkits then please contact the project lead, Amanda McCarren at [Amanda@tide.uk.net](mailto:Amanda@tide.uk.net) and she will be happy to follow up with you**

**Evaluation form: [www.surveymonkey.co.uk/r/57XGJTF](https://www.surveymonkey.co.uk/r/57XGJTF)**



**You can download the toolkits for Families & Relatives and for Staff & Managers via our website**

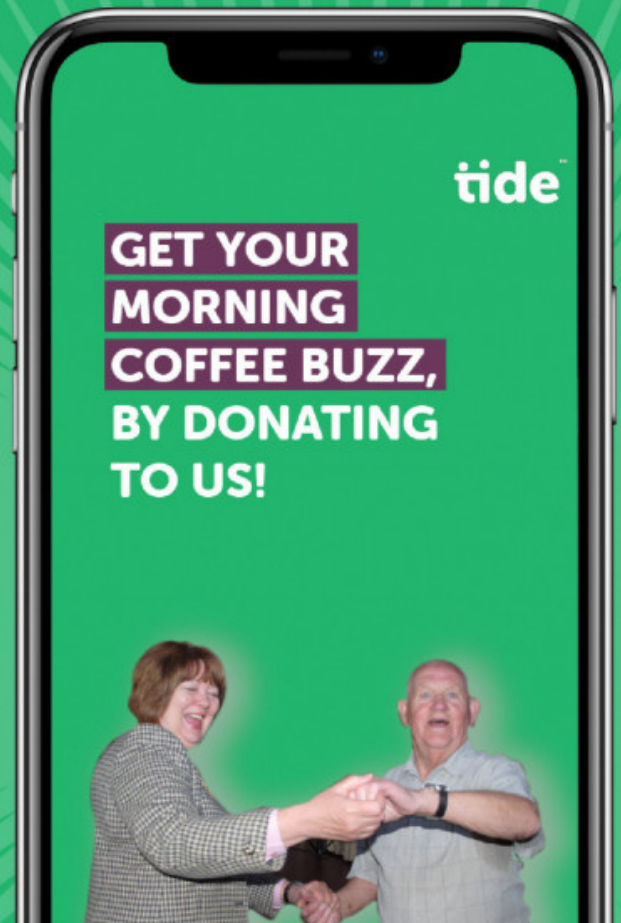
# HELP US RAISE MONEY!

 SHARE

 LIKE

 COMMENT

#COFFEEFORCARERS



## We're raising funds and we need your help! Here's how you can get involved:

1

Share the link to our [donate page](#) with your work colleagues, friends, family and local community.

2

Share the link to our donate page on your social channels! You can:

- Post on your own Facebook or share in a local group
- Share the link on Twitter (tag us @tide\_carers) & WhatsApp
- Share a photo on Instagram and tag us @tidecarers (You can download the poster below on our website)
- Use the hashtag #CoffeeForCarers

3

Fundraise with us and try your hand at baking, a bike ride or a sponsored walk. There are plenty of ways to support us, why not add fundraising to your activities?! Order a [fundraising pack](#)



**Give carers a  
break**

**Donate the cost of  
your coffee**

Z z z



**Without your donations  
tide wouldn't be able to  
fund the work we do.  
Help us continue to be  
here for family carers of  
people with dementia.**

**Donate to our fundraiser  
at [www.tide.uk.net/  
coffeeforcarers](http://www.tide.uk.net/coffeeforcarers)**

[Download Poster](#)

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# Carer's Spotlight

**The carers on our network are what make tide. We love to hear your stories and so do other carers across the UK. Your stories inspire us and many others. If you want to submit a story for our Carers Spotlight or for our website please contact [Rebecca@tide.uk.net](mailto:Rebecca@tide.uk.net)**

## Anne's Story



**So where do i start.... Right at the beginning to set the scene for how it all ended! My mum was an amazing, a strong independent woman, who in the space of a year, 1965, lost her mum and dad to illness, her career ended and she gave birth to me, she was left alone in the world and then chose to take on the care and responsibility of her mentally and physically disabled brother as well without a second thought for herself....so the first journey began, mum gave all of herself to look after me and uncle Joe,**

**4 cleaning jobs to keep our heads above water financially whilst I was at school, i will admit it was grim at times, poverty, stress and constant anxiety with the caring role for her, it took its toll on her long term mental health, there were times me and mum would 'escape' by walking for miles until it was safe to come home when Joe had calmed down from a delirium.**

**This all took its toll on mum and at 8 years old i took on my first caring role as mum developed agoraphobia, uncle Joe was already housebound and i became mum...the roles reversed and my childhood changed. I will say at no time did i ever feel anything but love and warmth throughout my life, this was my normal and i had everything I needed i was given everything she had to help me flourish, and become the rounded and caring woman that i am today, she taught me to respect everyone equally and look after nature and the animal kingdom.**

**We had a wonderful family unit, it was all just so difficult at times but we formed an amazing bond that would last for eternity. Sadly uncle Joe passed away when i was 16. We began to flourish after the shock, I got a job, hobbies and friends, mum found friends i guess we were living for the first time and carefree... we were inseparable just like sisters, she met the love of her life again, they had parted when she was just 18, I met my now husband and life began.....**

**Fast forward to 2007, mum had married her sweetheart, sadly he passed away in 2002, but they had a nice if short life together, this was another long difficult caring role for all 3 of us until his passing. Mum and me began again to live a new era of both our lives along with my husband and his amazing support to us both. We lived across the road from each other, never far away from one another. We went on holidays, we partied and we had fun shopping days out, i stayed over a few nights a week to keep her company. My career was doing great, we were all safe, happy and content.**

**Then mum was diagnosed with heart failure, it was challenging and worrying but didn't have a huge impact, fast forward to 2011, mum often met me for lunch and one day at the office was the first sign of dementia, I met her but no usual hugs or smiles, she had bought me a random scarf and said I feel really odd Anne, I cant remember buying this or getting here... and so the dementia journey began.**

**It was so hard, month by month I lost another little bit of mum, she was aware of it at times, she would ask me will you think of me sometimes when im gone, or what's happening to me? She unknowing to me wrote me out 3 birthday cards for the years after she had gone...so very thoughtful and hard to do... Please don't put me in a home she would plead, I never would i promised, that promise got very difficult to keep but I managed it..... it all went downhill with many steps down, her heart condition got worse, her memory and anger management got worse, she had TIAs, hallucinations, we made memories though, day trips instead of holidays, I learnt to drive to get us around safely, there were days folk tutted at us in the supermarket at her behaviour, they had no idea that I was dealing with an adult version of an afraid and confused toddler, no idea mum was scared and confused, they judged us without knowledge of how we got to where we were.**

**Mums deliriums were increasing, she forgot my birthday, my name and was afraid of me at times as she didn't recognise me... I left my career and my life behind on hold , hubby looked after the pets and home whilst still working full time, I seen him for breakfast and dinner only. Our final 2 years of this wonderful life's journey began, I became her best friend, daughter and carer, I don't really like that title, I did this for and out of love, it never crossed my mind not to do it in part as repayment for the love I'd been given as a child and as an adult and also because she would have done it for me. She would throw her dinner at me often, we had lockdowns to stop her escape I'd sit in front of the door until the delirium passed and tea and biscuits would sooth another difficult evening.**

**She ended up in hospital due to a heart failure event, it was awful, they restrained her by sitting on her to sedate her, I took her home 3 days later against their wishes covered in bruises from head to toe, no understanding of a delirium due to unfamiliar surroundings no dignity... i will never know what she endured in that stay, but i nursed her back to health and we shared another 18mths together. I often had to call the police when I was out with her, she suddenly didn't recognise me, started screaming I was going to hurt her, where's Anne? she would call out...**

People started to wonder if I did know her, I can laugh now at it when the police drove us both home and by then she wondered what the fuss was about as the delirium passed... it got worse, my life became a daily struggle to keep her safe, fed and alive, that was all I was living for, my friends, the good ones were supportive from afar and the others I never seen again! My husband was my rock. The stigma of mental ill health remains and it has no place in this day and age. We hardly slept when she was ill with her heart disease, then she got Nora virus in winter of 2016 but pulled through, but she never ate well after that, the dementia had taken a step and it was to be the final miles in the 52 years journey we had taken.

Her CPN and social worker popped in, her GP then told me one day when i said she needs palliative care, yes she does, well done your doing a grand job and left. Mum and me spent those 2 years in her house, no carers as she threw them all out, only me and my husband were allowed to care and support her, it was just us and lots of love, we made amazing memories, good and bad lol..... but all very special, 24/7 willing her to have a good day, and she did have a good morning or afternoon and they were special..... I had to beg her gp in a surgery sit in in her final week to provide palliative care, she got the hospital bed in her house on her last 5 days with palliative care carers coming in to wash and change her, she was on the morphine driver for last 36hrs before she passed, nobody told me before this started id no longer be able to communicate, we never got to say goodbye, i sang her favourite hymn to her for the last few hrs whilst lying next to her on the bed.

I have not and will never regret a moment of these special years with mum, you can never buy back time and make those memories again, love stays in your heart for ever, but i lost a part of me the day mum passed. I was and still am broken, thrown out the caring bubble on my knees with no title, feeling I'm not needed and afraid of the future and without a career.



**We need better government support, financial support, quicker decisions on self directed care funding, NHS awareness on dealing with dignity with dementia patients and palliative care packages put in place at diagnosis to walk with you and the dementia patient on this journey as they rightly do currently for cancer patients.**

**Carers, current and former please look after yourselves, remember what an amazing job you have done, and how much our loved ones appreciated it, they just didn't have the words to express it at times.**

**Our friends at Age Scotland Dementia Training are hosting a dementia learning day in September. tide will be involved in the session on Empowering Carers so come along and support our carers!**

## **Dementia: Making a difference in your community -a national day of learning**

**Dementia: Making a difference in your community.**

**A national, online learning event hosted by Age Scotland's dementia training team, exploring what we can all do to create, empower and effect change.**

**Monday 13th September 9.30 – 4pm\***

**\*Participants can attend for all or part of the day.\***

**Programme to be shared with participants shortly, along with details of workshops.**

**[BOOK NOW](#)**

# Join Us!

**Are you a carer or former carer of someone with Dementia? Are you are interested in finding out more about tide please visit our webpage on [www.tide.uk.net](http://www.tide.uk.net) and click the join us button – it couldn't be easier**

**Are you a professional working with carers or former carers of people with Dementia? Please join our network too and you will receive regular information and updates on tide and what we are doing which you can pass on to your carers**

**Or alternatively, if you would like to find out more about any individual aspects of tide in Scotland then please contact our National Lead for tide in Scotland, Amanda McCarren at [Amanda@tide.uk.net](mailto:Amanda@tide.uk.net) and she will be happy to talk to you**

**tide**<sup>TM</sup>

together in dementia everyday

**Find us**



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