

Dementia in Scotland



**Alzheimer
Scotland**
Action on Dementia

Winter 2022 – Issue 105



Winter Edition

We all need somebody to *lean on*

We're here for you this winter and always.



Alzheimer Scotland
Action on Dementia

Prevent.
Care.
Cure.

We want to reassure you that Alzheimer Scotland will remain here for you this winter:

Winter Essential Fund

- Part of the 'Time for You' initiative

Our Winter Essentials Fund aims to provide an additional helping hand of support for you over the coming winter months. If you live in Scotland and are a person with dementia or an unpaid carer of a person with dementia you can apply for a grant of £50. It could help buy warm clothing, electric blankets, hot water bottles, or help meet travel costs to attend a local group or visit your loved one if they are in a care home. This is a little helping hand for you – however that looks. For full details of the criteria and how you can apply, please visit www.alzscot.org/timeforyouwinter



Warm spaces

We know that rising energy costs are a worry for many people. All of our 24 Dementia Resource Centres will be providing extra groups and sessions where possible, providing people with a warm space and company. This might be with additional Tea & Blether sessions or more Coffee Catch Ups where a warm welcome and a hot drink awaits. Remember our Centres are also open when no groups are running so do drop in for a cuppa and a chat. To find out more about how we can help, and what's on at your local Dementia Resource Centre, please go to our website at www.alzscot.org/drc



Alzheimer Scotland 24 hour Freephone Dementia Helpline

Our Helpline is there for you day or night, whenever you need us. Our highly skilled team will offer a listening ear and emotional support, provide information and will signpost on to other supports if necessary. Call on 0808 808 3000. You can also contact our Helpline team via email on helpline@alzscot.org



24 HOUR

Dementia



Alzheimer Scotland
Action on Dementia

Helpline

Freephone 0808 808 3000
Email helpline@alzscot.org

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Welcome

Welcome to the winter edition of Dementia in Scotland magazine.

We know how difficult the winter months are for the people we support, particularly with the current cost of living crisis and rising energy costs. We want to reassure you that we remain here for people living with dementia and their family carers across Scotland. You'll see to the left of this page some of the ways in which Alzheimer Scotland is providing support this winter. This includes our Winter Essentials Fund which offers grants of £50 to people with dementia and unpaid carers. This fund is part of our 'Time for You' initiative which launched in February last year as a way to offer much needed breaks for carers. We are delighted to announce that we will be relaunching 'Time for You' in 2023.

Our team at Brain Health Scotland launched their schools programme 'My Amazing Brain' in October. Aimed at 8-12 year olds, the programme is the first of its kind in the UK and highlights the fact that it's never too early to start thinking about brain health. Find out more on p14.

Another exciting development is our new Student Research Programme which will fund studentships for projects on dementia and brain health in

Scotland. The programme offers research students the invaluable opportunity to work with people living with dementia and carers. You can read more about this on p15.

Without our amazing fundraisers and supporters, we would not be able to provide the level of support that we do. I had the great privilege of meeting fundraising stalwart Nick Gardner recently, and the pleasure of attending the wonderful annual Crystal Ball at Prestonfield House in Edinburgh – I am always impressed by the imaginative and innovative ways in which people raise funds. I want to thank our staff, volunteers, fundraisers and supporters who help Alzheimer Scotland make sure nobody faces dementia alone.

Henry Simmons

Henry Simmons, Chief Executive



We would like to hear your thoughts on Dementia in Scotland magazine. If you have any questions or comments, get in touch with the Editor, Caroline Russell, by email: crussell@alzscot.org

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www.alzscot.org/news/sign-up-for-enews

East Ayrshire programme for carers knocks it out of the park

At the start of Dementia Awareness Week, our team at Kilmarnock Dementia Resource Centre launched a highly successful programme for carers. Funded by the Scottish Government, the programme was developed after asking carers what kind of activities or sessions would benefit their health and wellbeing.

The first activity was a 'football memories' session delivered by Kilmarnock Community Sports Trust. This included watching archive footage of matches and looking at trophies and memorabilia. For those a little less interested in the 'beautiful game', alternative sessions provided holistic therapies such as massage, aromatherapy, and meditation to help them relax. The Trust invited participants to their monthly sessions held at Rugby Park, as well as an outing to Hampden Park. Football memories allows people to share their thoughts and memories on the different games and build on friendships. One carer said:

"I can be myself and talk openly to others. Football memories helps as it is a common ground for all of us and it's a good day out."

Other activities included monthly yoga sessions, which helped promote calmness and relaxation.

Participants loved these sessions and would leave feeling refreshed and relaxed. Our 'afternoon tea' ran for 6 monthly sessions.

We decorated our dementia friendly café like an old tearoom with flowers, china teacups and plates on the tables, and

played old time music in the background. Our guests left with a bunch of flowers from the table after enjoying an afternoon of delicious food, great music, and friendly chat.



Memories unlocked for veterans through reminiscence project

Helensburgh veteran Martin served in the Royal Navy for over 25 years. When he was diagnosed with dementia a year and a half ago, he started visiting his local Dementia Resource Centre in Helensburgh. Realising his strong personal ties, Alzheimer Scotland contacted the local Royal Navy base to ask for help connecting him to his past.

Reminiscence therapy can be a powerful tool for people with dementia. Many daily conversations rely on short term memory – like sharing recent anecdotes and discussing current events. This can often be hard for people with dementia though, and many will find it easier to recall things from their long-term memory. Using keepsakes like photos, letters, or journals can prompt conversations, and sharing happy or interesting memories can improve wellbeing, reduce stress, and provide enjoyment.

With visits from current servicemen building his confidence, Martin soon felt comfortable

enough to share his full collection of memorabilia. Then, with the help of Alzheimer Scotland staff, Martin created a collage of a Royal Navy anchor out of cap tally ties – ribbon from a sailor's cap. This piece of art has been on tour around the local area, including Faslane naval base. Accompanying the anchor is a notebook, inviting others to share their own stories. You can also share experiences on social media using #MilitaryMemories.



***"It has been a real honour to be part of Martin's journey. Many ex-military personnel struggle to talk about their past and Martin's courage to share his life stories in our sessions has encouraged others to open up. The Royal Navy is always happy to help the local community, we are so grateful for their support."** – Rebecca Morrow, Community Activities Organiser.*

Post Diagnostic Support Link Worker Rebecca talks about her role

The role of a Post Diagnostic Support (PDS) Link Worker is to support people who have received a dementia diagnosis (and their families) to understand the illness, maintain community connections, meet other people with dementia, and help them with future planning and decision making. Rebecca Macdonald joined Alzheimer Scotland in June 2022 as a PDS Link Worker and shares her thoughts on the role:

"I have a degree in psychology from Strathclyde University. While I was studying there, I did some voluntary work with people with dementia who were in hospital – organising dementia cafes, and visiting them, I loved it.

"I was working in a role that helped to keep young people safe, monitoring them online and looking for signs of self-harm, bullying or violence. Although I enjoyed the job, I always wanted to work with older adults. I saw the PDS Link Worker role advertised,

"Making someone's day just by chatting to them, being able to do that is just an amazing feeling. Even the smallest thing we do for someone can make a big difference to their lives." – Rebecca

and everyone I talked to about it said, 'that's your dream job!'. My personal experience was a key factor in applying for the job. My Grandpa had cognitive impairment and had lived with us for 4 years. I've always enjoyed the company of older people and hearing their stories, so it was lovely spending time with him. With that experience and my previous voluntary work in the hospital, I knew I had to apply, and I was delighted when I got the job. Every day is different, I could have two or three home visits, meeting the person with dementia, their family and carer, taking the time to have a chat and listen and find out what is important to them. Even the smallest thing we do for someone can make a big difference to their lives. I could be in the community mental health team between visits typing up my case notes. I might be following up on referrals or speaking to GPs or other professionals. Other days, I could be calling carers, helping them arrange respite or getting them connected with carers centres and groups. I'm really enjoying my role and working with Alzheimer Scotland, and I hope to continue making that difference to the lives of people with dementia and their families."



250 referrals for our Digital Dementia Advisor!

With a myriad of digital products available, it can be hard to find the right pieces of technology at the right time. A Digital Dementia Advisor can demystify the tech and help you make the most of consumer technologies to support greater independence, health and wellbeing. Our Digital Dementia Advisor for Edinburgh, Kathy Wiles, has recently hit the milestone of 250 families referred since her role was established in 2019.

For people like Sophie*, who is Power of Attorney for her friend Anna*, this service means peace of mind. Speaking about Kathy's assistance setting up a GPS system she said,

"Anna has always been a free spirit and she wants to remain independent for as long as she can. For

"It is important that we don't focus on the technology, but on the person. What does that person enjoy doing? Getting out and about? Managing around the home? Then the digital technology is presented as a tool to keep those things going." – Kathy



both of us, there was a bit of a fear and a reluctance around technology because we weren't sure what to do. Kathy was so very patient, walking us through the different options and helping us decide what was best. She gave us such a lot of time when she came to set up the system and was very knowledgeable. For me, it's provided peace of mind and I feel confident that I could contact Kathy at any time if I wasn't sure about something. I'd encourage anyone, even if you're not a 'techie' to embrace the service!"

**names have been changed*

Campaigning groups have their say on Scotland's new dementia strategy



Our two Active Voice campaigning groups represent the voices of people living with dementia and unpaid carers of people with dementia within Alzheimer Scotland. The Scottish Dementia Working Group (SDWG) was formed in 2002 and recently celebrated an amazing 20 year anniversary. The SDWG is made up of people living in Scotland with a diagnosis of dementia who are passionate about campaigning and bringing about change. The National Dementia Carers Action Network (NDCAN) also marked an important milestone in 2021 – a remarkable 10 years of campaigning. NDCAN's members are all either current or former carers of someone with a dementia diagnosis, and they work tirelessly to raise awareness of the issues impacting the lives of carers.

Both groups exist to improve the lives of people living with dementia, their families and carers, and over the years their members have been involved in influencing policy and practice in order to help achieve this aim.

At the end of September this year, the Scottish Government launched a consultation process for their 4th National Dementia Strategy. SDWG and NDCAN members have inputted to the three previous strategies and of course wanted to have their voice included in this fourth strategy. Alzheimer Scotland held a series of informal meetings for people with dementia and carers to share their experiences and their opinions to help shape this new strategy. These meetings were held both in person and online to give as many people as possible the opportunity to take part. SDWG and NDCAN members played a key role in hosting these meetings, talking to people in locations such as Inverness, Alloa, Livingston, Dundee, and Glasgow, ensuring local people with lived experience of dementia could have their say on this important subject.

"We welcome the opportunity to feed in our experiences to the fourth dementia strategy. But we cannot forget the many people who already shared their experiences in consultations for the first three dementia strategies. Opening up and talking about painfully difficult times is not easy."

- The Scottish Dementia Working Group



Fair Dementia Care campaign update

Our Fair Dementia Care campaign, which launched in 2019, seeks to end the inequalities faced by people living with advanced dementia who we believe are treated differently in our current system to those with other life limiting illnesses. We continue to make this case and have provided Scottish Government with a further legal view on the duty of the NHS to provide the opportunity for an assessment of individuals with advanced dementia health care needs, which we believe is not being provided currently. We await a response to this and will keep our members and supporters updated.

"We hope this strategy will include the outstanding commitments from the three previous strategies. Those commitments mattered then, and they matter now. We mustn't lose all that work in searching for the new 'story'. NDCAN look forward to contributing to the conversation."

All of the feedback that was given at the meetings will help form a collective response from Alzheimer Scotland which will be shared with the Scottish Government. Alzheimer Scotland would like to thank everyone who took the time to come along to the meetings and share their thoughts, as well as the local Dementia Advisors and Link Workers who facilitated the meetings.

ndcan

National Dementia Carers
Action Network

**Are you an
unpaid carer
or former
unpaid carer of
a person with
dementia?**

The National Dementia Carers Action Network (NDCAN) is open to anyone living in Scotland who has experience of caring for someone living with dementia. By joining NDCAN you are adding your voice to carers of people with dementia across Scotland to make sure dementia carer issues are heard. You will be part of influencing the future of dementia policy and strategy in Scotland and making things better for the people who come after us.

Find out more at
www.alzscot.org/ndcan or
get in touch by email at
activevoice@alzscot.org



Are you a person with dementia?

The Scottish Dementia Working Group (SDWG) is open to anyone living in Scotland who has a diagnosis of dementia. The more SDWG members we have, the louder the voice of people with dementia in Scotland will be. The only requirement for membership is that you would like to meet other people with dementia to discuss things that really matter to you.

Find out more at **www.alzscot.org/sdwg** or get in touch by email at **activevoice@alzscot.org**



the scottish
dementia
working group

'With your help, we can be somebody to *lean on*'

Our 2022 Winter Fundraising Appeal

Our winter campaign this year focuses on the Every Voice Community Choir, and two of the choir members, Tony and Angela Worthington. Tony was diagnosed with vascular dementia at the age of 77, and they both became involved with Alzheimer Scotland after visiting their local Dementia Resource Centre in Clydebank. Tony, a former MP, joined the Scottish Dementia Working Group (SDWG) as he was passionate about campaigning and influencing policy. Then, having enjoyed watching the choir perform at the Dementia Resource Centre, he and Angela both decided to become members.

The song of choice for our winter campaign is Bill Withers' Lean On Me. The lyrics speak volumes, and the Every Voice Community Choir belt it out loud and proud.

Tony says:

"I have friends through Alzheimer Scotland who really understand, from other people living with dementia and carers, a wonderful Dementia Advisor who supports us both, an incredible choirmaster and campaigning peers who believe as passionately as I do that the inequities people with dementia face should end, and end now. We are connected, and for that we feel lucky."



In the last year, we have supported people with dementia, their carers and families through:



8,000

calls taken by our 24 Hour Freephone Dementia Helpline



20,000

people living with dementia attended activities to improve their physical, mental, and emotional wellbeing



3,706

community groups organised by our Community Activity Organisers for people living with dementia and their carers



22

Dementia Resource Centres across Scotland

The Every Voice Choir

The Every Voice Community Choir was created as a therapeutic activity for people living with dementia and their carers by our team in West Dunbartonshire. Led by choirmaster Bryan Marshall, the fortnightly rehearsals have brought laughter, joy and friendship to its members. Established in 2016, the choir has performed at Christmas concerts, appeared on BBC television show 'Make a Wish', and performed at the Edinburgh Festival. Choirmaster Bryan was nominated as one of BBC Scotland's People of the Year in 2021.

"Angela and I are both members of the Alzheimer Scotland Every Voice Choir – ironic since I'm not a singer! Positive attitude prevails!" – Tony



Jess Bruce,
Communications and Campaigns Lead said:

"It's been a privilege to work with Tony, Angela, choirmaster Bryan and all the members of the Every Voice Community Choir to tell their story for this year's winter appeal. The choir is such a great example of the close-knit peer bonds that are formed in our community activity groups up and down the country, which I think shines through when they perform. We'd like to thank everyone who helped put this campaign together, and a particular thanks to Tony and Angela for being so welcoming, and so open."



To view Tony and Angela's story, watch the Every Voice Choir perform 'Lean On Me', and find out how you can support our fundraising appeal, visit our website at leanon.alzscot.org or scan the QR code.

Our Brain Health & Dementia Resource Centres

Our Dementia Resource Centres (DRCs) are designed to be friendly, accessible environments for everyone to enjoy. They offer people living with dementia, their families and carers, information, advice or support, as well as a wide range of local groups and activities.

We now know that potentially up to 40% of dementias are preventable, and by protecting our brain health today, we may be preventing dementia in the future. That is why our goal is to transform all of our Dementia Resource Centres into Brain Health & Dementia Resource Centres (BHDRCs).

2022 has been an exciting year for us as we have now opened four of these Centres.

Dementia Awareness Week in June saw the opening of our very first Brain Health & Dementia Resource Centre. Situated in Mill Road, Alloa, the Centre was made possible due to the efforts of our volunteers and fundraisers. It offers support for people with dementia, their families and carers, as well as providing day care and a range of person-centred and therapeutic groups.

The Centre also has a drop in facility for anyone interested in finding out more about brain health and risk reduction – this has been extremely well received by the public.

Our second Brain Health & Dementia Resource Centre opened in Edinburgh on 21 September – World Alzheimer's Day. Situated at our existing office at 160 Dundee Street, it offers a central spot in the capital for anyone looking for support and advice on brain health and dementia. Early October saw our third opening of the year when our existing Centre in Kirkcaldy was reopened as a Brain Health & Dementia Resource Centre following a wonderful refurbishment.

Our Annual General Meeting for members on 11 November was the perfect opportunity for the opening of our fourth Brain Health & Dementia Resource Centre at our Glasgow office at 81 Oxford Street. We were delighted to be joined by Dementia Dog Uno who, along with Lord Provost Jacqueline McClaren, together pulled the ribbon to officially open the centre. Thanks to Uno and owner Anne for making the moment so special.



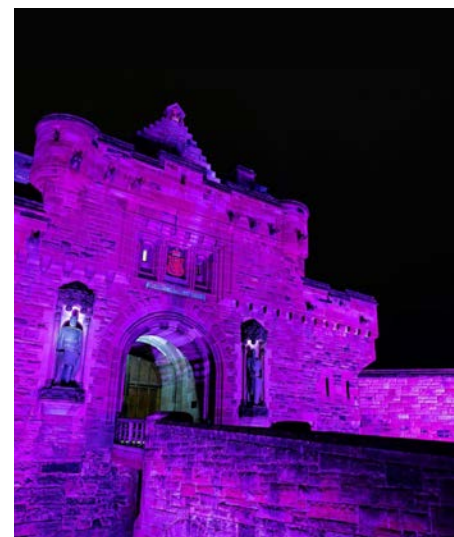
Our next Brain Health & Dementia Resource Centre will open in Perth in 2023. If you are interested in finding out more about brain health, visit our Brain Health Scotland website where you can find a wide range of information and resources.

www.brainhealth.scot



World Alzheimer's Day

Wednesday 21 September was World Alzheimer's Day and we were thrilled to see the iconic Edinburgh Castle illuminated in purple for the occasion. The castle looked absolutely stunning, and it was a great way to raise awareness of dementia.



Alzheimer Scotland's Annual Conference 2022

It was wonderful to have our first in person conference since the COVID-19 pandemic. Held at the Edinburgh International Conference Centre (EICC) on 5 September, we were delighted to be joined on the day by over 300 attendees. The Conference theme was 'Prevent, Care, Cure' and we had a range of speakers and presentations on each of these three key areas. Each session was opened by a member of either the Scottish Dementia Working Group (SDWG) or the National Dementia Carers Action Network (NDCAN) – keeping the voice of lived experience at the heart of the event. A highlight of the day was the Every Voice Community Choir who joined us in the morning and provided some uplifting songs to get the day started. If you were unable to attend this year's conference, the videos from the day which contain all presentations are still available to watch on our website.

www.alzscot.org/conference22

Main plenary session 2
'Innovations in care'
Introduced by Barry & Margaret Northedge,
Scottish Dementia Working Group (SDWG)

Alzheimer
Annual Conf
Prevent.



Alzheimer Scotland
Annual Conference 2022
Prevent. Care. Cure.

A Global Ultra Odyssey for Amazing Audrey

*Have you ever run a marathon?
How about 100k?*

In 2013, at the age of 50 years old, Audrey McIntosh took on both within 48 hours and in the sub-zero temperatures of the Antarctic. But this was just the beginning of Audrey's adventure as she challenged herself to run a 100k in each of the most unique climates the seven continents have to offer. Here, Audrey talks about her incredible journey:

"I am an ordinary person. I'm a mum and wife and I work full-time. Running is my passion and I have always loved a challenge. I am also passionate about supporting charities and often use my running to fundraise.

"When I decided to enter the Antarctic Ice Marathon and Antarctic 100k in 2013 to mark my 50th birthday it was a great opportunity to fundraise. At the time my family were experiencing the impact of dementia first hand through my uncle and I decided I would use the race to raise funds for Alzheimer Scotland. Before I knew it, I was in the Antarctic. Both races went well, and I was the first Scot and only the 3rd women to complete this double feat. This inspired me to continue to take on extreme running challenges to raise more funds, including races in the North Pole, the Atacama Desert, The Namibian Desert, and a frozen steppe in Mongolia.

"In 2017, I resolved to complete a 100k ultra-marathon on each of the remaining six continents and to make each one as extreme, hard, and as challenging as I could."



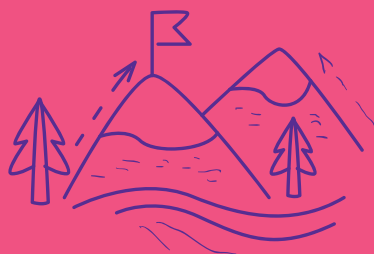
"Each expedition was self-funded, so I had to save up. In June 2022, I completed my final race making me (to my knowledge) the first person to run an extreme 100k ultra-marathon on all seven continents.

"This journey has been at times sad and poignant. My uncle passed in 2018 aged 73. I've heard many stories from people and families affected by dementia. I've also learned a lot about how dementia is regarded in other countries. It has been important along the journey to remember why I have done it and to honour the memory of loved ones. It has also been uplifting knowing and seeing the work that Alzheimer Scotland does and knowing that I have helped to fund projects. I am proud that the funds I have raised have made such a difference in the community."



Congratulations Nick!

We would like to say congratulations to Nick Gardner who won 'Endurance Fundraiser of the Year' at the Just Giving Awards 2022. Nick, from Wester Ross had set himself the target of climbing all of Scotland's 282 Munros over 1200 days. He was motivated to take on this epic challenge for his wife Janet who has vascular dementia and osteoporosis. Nick reached the summit of his final Munro in August 2022 and raised over £100k for Alzheimer Scotland and the Royal Osteoporosis Society. An incredible achievement – thank you.



Scotland's Memory Walk 2022

Thank you to everyone who took part in this year's Memory Walk. Held over the weekend of 16-18 September, it was the perfect opportunity to walk in memory and in honour of a loved one. 'Memory Walkers' could choose their own route and a distance that was challenging to them.

To date, over £71,000 has been raised – an amazing amount. We look forward to seeing you again for Scotland's Memory Walk 2023!

Scotland's
MEMORY WALK
16-18 September

Thank you!



Brain Health Scotland launch 'My Amazing Brain'



On 31 October, at the National Museum of Scotland in Edinburgh, our team at Brain Health Scotland launched their exciting new schools programme – 'My Amazing Brain'. The team were joined by over 100 primary school children from across the capital who were given the chance to learn fun facts about brain health, take part in hands-on activities and get a close-up look at a real-life brain.

'My Amazing Brain' aims to empower young people with the knowledge they need to protect themselves against future disease. It focuses on five vital areas – healthy eating, rest and relaxation, staying active, spending time socialising, and keeping brains injury free. The key message of the programme is that it's 'never too early' for people to start thinking about keeping their brains healthy.

Backing the campaign is professional rock climber Dave MacLeod who has a keen interest in sports science. He said:

"Brain health was once associated with older people, but we now know the value of raising awareness much earlier. Good sleep, nutrition, mental agility and protection from even mild injury all make a huge difference – whatever age we are."

The programme, which is the first of its kind in the UK, consists of a range of free brain health teaching resources aimed at 8-12 year olds, and is now available to every school in the country. The materials, which are aligned with the Curriculum for Excellence, can also be used by club leaders outside of school as well as parents. The programme has already attracted interest from other countries and the Brain Health Scotland team hope the initiative can be extended throughout the UK and overseas.



Brain Health Scotland Programme Coordinator, Joanna Crispell said:

"Research shows that up to 40% of dementia cases are linked to factors we can influence, such as obesity, physical activity and loneliness. This is about inspiring young people to find out what they can do to keep their brains in peak condition – and helping them set up good habits early in life."

Alzheimer Scotland's Student Research Programme

In November 2022, Alzheimer Scotland launched a new Student Research Programme. The programme, which is supported by the Scottish Dementia Research Consortium (SDRC), will fund studentships for projects on dementia and brain health in Scotland.

In its first year, the Alzheimer Scotland Student Research Programme will fund two MRes (Master of Research) projects relating to the themes of 'living with dementia' and 'diagnosis'.

The programme differs from other funding schemes in that it will offer more than a financial contribution. Successful applicants will have the

opportunity to work with Alzheimer Scotland staff and have access to a wide range of expertise from our networks – helping them develop their research communication skills. As always, the voice of lived experience is at the heart of everything we do, and members of Alzheimer Scotland's two campaigning groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) will be part of an independent panel helping

to select which projects are funded. The students will work with the groups throughout the course of their project, gaining invaluable insight, knowledge, and experience from people living with dementia and carers. Find out more at www.sdrc.scot



Time for You fund update

When we launched our Time for You fund on Valentine's Day this year, we had no idea just how successful it would become. The fund offered grants of up to £300 to unpaid carers of people with dementia. Carers could apply for funding for short breaks, for hobbies, or to buy a new piece of technology – something that would make a difference to their lives. It was also a great

opportunity to connect with carers and signpost them to some of our other services. A total of 1192 grants were given out and the fund closed in July, however we are delighted to announce that the Time for You fund will be reopening in early 2023. Keep an eye on our website www.alzscot.org for details.



Time For You Carers Fund



**Alzheimer
Scotland**
Action on Dementia

Ideal gifts for
your loved ones
or treat yourself!

Support people living
with dementia this
Christmas!

Shop a range of gifts
from carefully selected
partners

Visit
alzscot.shop



Visit **www.alzscot.shop**, scan the QR code
or call us on **0131 243 1453** (Monday to Friday 9am – 5pm)
All profits go towards helping people living
with dementia here in Scotland

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