



## Annual Review 2021/22



**Alzheimer  
Scotland**  
Action on Dementia

**Prevent.  
Care.  
Cure.**

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# Introduction



**David  
McClements**  
Our Convener

*David McClements*

In this Annual Review, we take a look at some of the work we have done over the last 12 months, as well as reflecting on what we did as an organisation to maintain our support for people with dementia, their families and carers during the challenging times of the COVID-19 pandemic.

There are some wonderful examples of innovative projects taking place across Scotland that have made a real difference to the lives of many people, and I hope you enjoy reading about them.

It is a privilege to work with our Board of Trustees, and I would like to take this opportunity to thank them all for giving their valuable time, knowledge, skills and experience to Alzheimer Scotland in this way. I would also like to thank our Chief Executive, Henry Simmons, for his excellent leadership, with invaluable support from the senior management team. Everyone who works or volunteers for the organisation plays a vital part in our aim to make sure nobody faces dementia alone, and I thank you for all your hard work.

Over the last year there has been an increased focus on brain health and dementia prevention, with the first of our Brain Health and Dementia Resource Centres opening in Alloa. This is an exciting development and I look forward to seeing more opening in the future.

Finally, I would like to say how grateful I am to all of our supporters, including our amazing fundraisers and those who have donated to us over the years. Thank you.



**Henry  
Simmons**  
Our Chief Executive

*Henry Simmons*

This is our first Annual Review since the COVID-19 pandemic and our thoughts are with every person who lost a loved one, and to this day the many people who are grieving and attempting to recover from the trauma experienced by our community. As part of our process of recovering, we are setting a vision for the future that will move us forward with hope. Our new vision for the organisation is based on the aims of Prevent, Care and Cure. This builds on, and complements, our fundamental aim of making sure nobody faces dementia alone. You can read more about this on pages 6/7.

The support and services our staff and volunteers deliver across Scotland is truly inspirational. The way we adapted and reimaged our support in response to the pandemic crisis is a testament to the passion and commitment of our people. Thank you to them all.

We are delighted to bring you some the highlights from our work in 2021/2022 - with the launch of four Brain Health & Dementia Resource Centres, the development of our Time for You fund, and a number of community events, we have been able to continue, and indeed extend, our support for people with dementia and their carers.

It was wonderful to host our first in person Annual Conference since the pandemic, with over 300 delegates from across the dementia community in attendance. It was an immense privilege to share our 'Prevent, Care, Cure' vision and key work with such an engaged audience, with the voices of those lived experience opening up each session with their own unique contribution.

As always, we are humbled by the volume of people who support our work - climbing, running, walking, dancing - we are never short of amazed at the range of events people undertake to fundraise for this charity. We simply could not deliver on our work without your invaluable support and I thank each and every person who supported Alzheimer Scotland across the year.

# The COVID-19 pandemic

**2020/21 were difficult times for us all, but especially for the dementia community. Our staff and volunteers responded to the challenges faced and we would like to thank them for their hard work and commitment.**

The COVID-19 pandemic undoubtedly had a disproportionate impact on people living with dementia, their families and carers. There were both direct and indirect harms caused by the pandemic and the public health restrictions that were put in place to prevent the spread of the virus, and the existing gaps in our health and social care system meant that people were not prepared for the devastation that the pandemic inflicted on so many lives.

## WHAT WE DID

### Alzheimer Scotland's 24 hour Freephone Dementia Helpline

Our Helpline continued to operate 24/7 throughout the pandemic. It is often the first point of contact for people living with dementia, carers, family members or friends, as well as people who are worried about dementia. Over the course of the pandemic, our dedicated Helpline team provided information, signposting, and emotional support to callers, taking over 15,000 calls, and providing over 1,964 hours of support – the equivalent of 82 consecutive days.

From hearing the traumatic experiences of our callers who had loved ones in care homes, our Action on Rights team was established through Scottish Government funding. Dedicated to supporting the implementation of the Scottish Government's 'Open with Care' guidance, they worked to ensure that families had meaningful contact with their relatives living in care homes.

The stress and distress that the dementia community faced was immense – from being unable to visit loved ones in care homes, to carer stress exacerbated by the loss of key services and respite, to the cognitive decline and acceleration of symptoms in people with dementia and the untimely deaths of so many people. To help people cope, we created our National Counselling Service, supporting people across Scotland who are either living with dementia or caring for someone with dementia.

### Day services

Like so many other services, we had to close our physical doors in March 2020 when the country went into lockdown. We knew how vital our support was and we were committed to continuing this as much as we possibly could. We quickly established a range of online groups, made wellbeing calls, and introduced other forms of support – like our volunteer befriending project helping people engage in therapeutic activity in their own homes. It was so important to us that people still felt connected to and supported by Alzheimer Scotland. When restrictions were easing, we reimagined and redesigned our day services. Shorter sessions for less people meant we could give a more person-centred approach. Our frontline staff know the people we support so well that they were able to place people with shared interests or existing friendships into 'bubbles'.

### Post diagnostic support

There is no doubt that receiving good quality support after a diagnosis can make a huge difference to the life of a person with dementia and their family. From understanding the illness and managing symptoms to planning future support, post diagnostic support can be transformative. Every person in Scotland with a dementia diagnosis is entitled to one year's post diagnostic support. Despite the severe restrictions enforced by the pandemic, Alzheimer Scotland Dementia Post Diagnostic Support Link Workers delivered support to over 5,760 people with dementia and their carers. They held 2715 digital peer support groups, digital cafes and online one to one support sessions. They also made 10,101 referrals or contacts with other professionals.



Between the beginning of lockdown  
on 23 March 2020 until the end of March 2021,  
Alzheimer Scotland provided:

**49,236**  
therapeutic interventions  
(excluding post diagnostic support)

**This includes:**



**2,357**  
wellbeing home  
visits to help reduce  
social isolation,  
support wellbeing,  
and reduce carer  
stress and distress



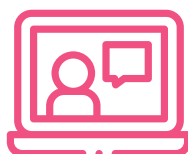
**6,338**  
responses to  
enquires



**5,016**  
online groups  
which have  
been attended  
by people with  
dementia and  
carers



**3,030**  
activity packs  
to support people  
with home activities



**6,925**  
video calls



**30,804**  
telephone calls  
where support  
was provided

# Our Vision – Prevent, Care, Cure

Our new vision is based on the aims of Prevent, Care, and Cure, and compliments and builds on our fundamental aim of making sure nobody faces dementia alone.





**Alzheimer  
Scotland**  
Action on Dementia

**Prevent.  
Care.  
Cure.**



Brain Health and Dementia  
Resource Centre, Alloa

## Prevent

The Prevent theme reflects the recent innovations and work we have been doing in terms of creating a new brain health and dementia prevention model through the work of Brain Health Scotland. As part of this move towards a greater prevention focus, we will gradually introduce the concept of Brain Health and Dementia Resource Centres to provide basic brain health information and self-assessment opportunities.

The Brain Health Scotland team will also lead the way in developing brain health services, delivering a school's programme, sports initiatives, tackling key areas of inequality in our system and developing our approach and understanding on issues such as women's health.

In June 2022, we opened our first official Brain Health and Dementia Resource Centre in Alloa. The centre provides support for people living with dementia, their families and carers, and anyone interested in finding out more about brain health. Alzheimer Scotland fundraisers and volunteers worked tirelessly to raise the vital funds to create the space, which provides day care and a range of person-centred and therapeutic groups that cater for both the person living with dementia and their carer. The centre, which has a drop in facility for people to find out more about reducing risks and getting support, has been extremely well received by the public. Our goal is to transform all our Dementia Resource Centres into Brain Health and Dementia Resource Centres.

## Care

Our Care theme has two key areas of focus: The direct provision of support services for people with dementia and their families, and our ongoing campaigning to fight to improve the rights and quality of care for people with dementia, their families and carers. The voice of lived experience is at the centre of everything we campaign and fight for, and we work closely with the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) to deliver this.

Our frontline care services consist of the services we fund and provide in local communities, and those that are commissioned by local Health and Social Care Partnerships. Our locality and post diagnostic support teams work hand in hand to deliver our main face to face frontline services across Scotland – reaching a significant number of people living with dementia each day.

Over the past 12 years, Alzheimer Scotland has developed and delivered a world leading innovative model of post diagnostic support based on our Five Pillar Model, delivered by an ever-growing number of skilled Link Workers. We now have over 100 Link Workers enabling our post diagnostic support service to have the capacity to support several thousand people each year.

Our National Support Services team encompasses the 24 hour Freephone Dementia Helpline, the Action on Rights team, the National Counselling Service and our Active Voice campaigning groups. The team are at the forefront of hearing from the dementia community about the issues that are directly impacting their lives.

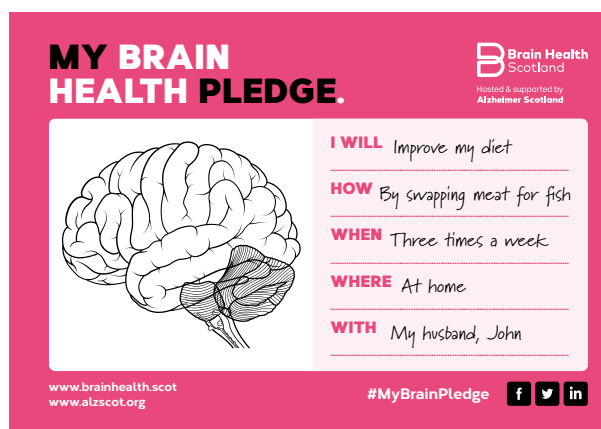
## Cure

Our work on Cure is intended to raise the profile, public understanding, and support for our work in research. For over ten years we have supported and funded an exceptional group of highly skilled, world leading academics that form the Executive of the Scottish Dementia Research Consortium (SDRC).

Our research engagement supports prevention, care, and cure of dementia. High quality research is crucial to Alzheimer Scotland and to Scotland in the pursuit of excellence in responding to dementia. It drives innovation in policy and in practice and provides the evidence base for everything we do as an organisation. Our contribution to building the research infrastructure can bring greater investment to Scotland's dementia research community.

# Prevent

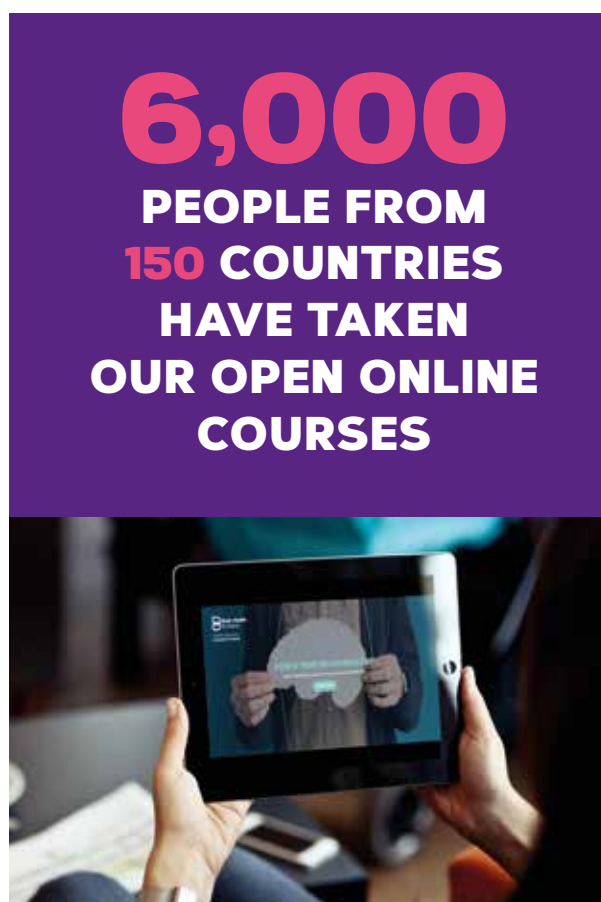
**We know that potentially up to 30% of dementias are preventable. By protecting our brain health today, we may be preventing dementia in the future.**



## My Brain Health Plan

There are many positive steps we can all take throughout our lives to protect the health of our brains. In March 2022 we launched the online quiz 'My Brain Health Plan' to provide a quick and easy way for everyone to take personal actions that are meaningful for them.

By answering a few quick questions about their life and routine, users can then find top tips tailored to them. This advice can then form a framework to set a series of Brain Health Pledges – commitments to make positive changes for better brain health.



## A global movement

Inspiring people to understand how to protect brain health across communities is key to our mission. That's why we place free, open, and accessible education programmes at the heart of our activity. In 2022 we worked with former elite athletes and expert researchers to launch our second open online course 'Sport and Exercise for Brain Health'.

## Building a national picture

To understand the priority areas of risk to tackle, we need high quality data that can help us paint a picture of the Scottish population. We carried out the first National Risk Factor Surveillance Report, surveying a representative sample of 1000 adults aged 30-59 to understand how common certain brain health risk factors are across the country. We found that for women, the most common risk factors were – social isolation, being overweight, not getting enough sleep, feeling stressed, and exposure to air pollution. For men the most common factors were – social isolation, being overweight, not getting enough sleep, exposure to air pollution and drinking too much.

Data like this supports our work in targeting specific interventions to improve the nation's brain health. It also gives us a good baseline against which to measure the success of future risk-reduction programmes.



## Brain health services

We continue to work closely with several NHS boards to establish the first wave of 'demonstrator sites' for brain health services. These brand new clinical services will deliver accurate risk profiling, earlier disease detection and put in place personalised prevention plans.

In preparation for these new services going live we completed the Scottish Cognitive Clinics Census to understand in detail the current landscape of clinical services on offer and how they may differ around the country. We also led a collaborative team of 17 academic, clinical, and 3rd sector contributors across nine institutions to publish a report 'The Scottish Brain Health Service Model: Rationale and Scientific Basis for a National Care Pathway of Brain Health Services in Scotland' to share our vision for a comprehensive brain health approach that could be replicated around the world.

## A strategy for Scotland

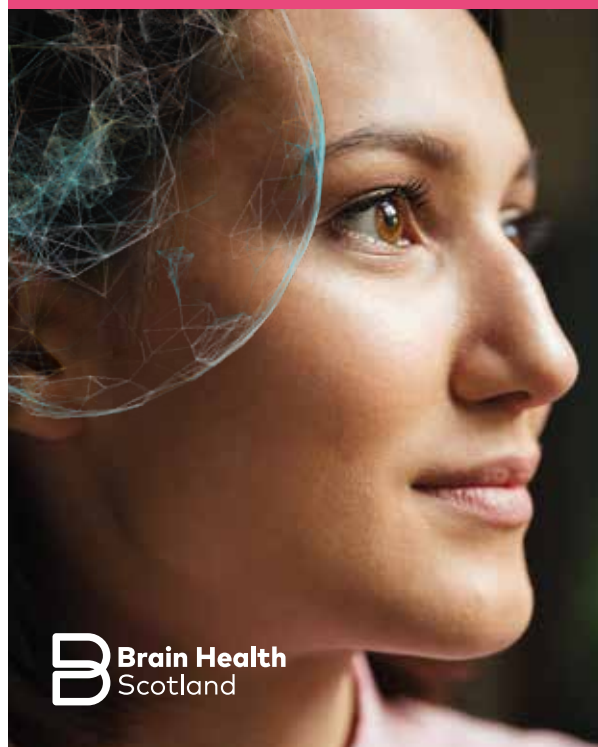
Coordinating this growing brain health movement and providing a solid foundation for the national commitment to improving brain health requires clear direction and purpose. This year saw Scotland take the lead on a world first, a national brain health strategy. The strategy features four core commitments – awareness raising, targeted engagement, establishment of open access services for personalised prevention, and a system for disease and risk factor surveillance. The approach described will transform the way we assess and protect brain health, and bring new opportunities for risk profiling, disease detection and early intervention to place Scotland at the forefront of the global effort to promote brain health and prevent dementia.

Visit [www.brainhealth.scot](http://www.brainhealth.scot) for more information.

**MOST COMMON  
RISK FACTORS FOR  
WOMEN: SOCIAL ISOLATION,  
BEING OVERWEIGHT, NOT  
GETTING ENOUGH SLEEP,  
FEELING STRESSED, EXPOSURE  
TO AIR POLLUTION.**

**MEN: SOCIAL ISOLATION,  
BEING OVERWEIGHT, NOT  
GETTING ENOUGH SLEEP,  
EXPOSURE TO AIR POLLUTION,  
DRINKING TOO MUCH**

National Risk Factor  
Surveillance Report 2022



# Care

**As well as campaigning for greater improvements and transformation within our health and social care system, we continue to provide as much direct frontline support as possible in order to make sure nobody faces dementia alone.**

Our frontline support consists of services that we fully self-fund and services that are commissioned, in most cases by local Health and Social Care partnerships. We aim to offer a blended approach across localities to ensure we achieve the best possible synergy between self-funded and commissioned services. We also fund investments that will support change within our NHS, such as the National Dementia Nurse and Allied Health Professional (AHP) Consultants and we benefit greatly from our committed AHP partners who contribute to our AHP Dementia Forum.

Alongside our frontline support, our National Support Services provide that vital additional back up, including our 24 Hour Freephone Dementia Helpline, Action on Rights Team, and National Counselling Service. Crucially our Active Voice Team sits alongside these core services and provides that direct voice of lived experience within the development of our practice, policy, and organisational strategies. You can read more about them on page 14.

## Dementia Advisors

At present we have 39 Dementia Advisors across Scotland. They support individuals, families and local communities and have a varied approach to local delivery based on local need and opportunities.

The Dementia Advisors continue to be one of our most significant areas of investment, their reach and contribution to supporting people is extremely effective. The light touch approach of our Dementia Advisors ensures they can respond to a high number of individual requests for support. They also provide an opportunity for ongoing support and involvement, fulfilling our goal of encouraging people to feel a long-term connection with us and creating that sense of security in knowing that we will be there to support them. Our Dementia Advisors also run a number of therapeutic groups, as well as carer support and education activities both within and out with our Dementia Resource Centres.

- We have 39 Dementia Advisors across Scotland.
- On average, each Dementia Advisor has received 113 referrals in the last year.
- 94% of referrals came from carers.
- In the last year, Dementia Advisors supported the delivery of 1242 groups within our Dementia Resource Centres including: 663 social groups, 307 therapeutic groups and 272 peer support groups.

## Dementia Resource Centres

All of our Dementia Resource Centres are fully funded by Alzheimer Scotland. Our quest to take dementia to the high street has continued this year. As part of our new aim of developing a brain health and dementia prevention platform, we have been gradually testing and introducing the concept of Brain Health and Dementia Resource Centres (BHDCRC).

We opened our first ever BHDCRC in Alloa this year, a development made possible due to an immense local fundraising effort by our volunteers. This received excellent feedback and we have followed on with opening a new BHDCRC in our revamped Edinburgh base, in our Oxford Street premises in Glasgow, and in Kirkcaldy. We now have 24 Dementia Resource Centres, and we will continue to increase this with our new property in Perth that will open in early 2023.

**We have 24 Dementia Resource Centres**

**4 of these are Brain Health and Dementia Resource Centres**

**We also have 1 Outdoor Dementia Resource Centre and 1 Virtual Dementia Resource Centre**

## Outdoor Dementia Resource Centre

One very new development has been the introduction of our Outdoor Dementia Resource Centre in the Highlands. This is in the early stages of development, but it is already offering people the chance to explore and make use of the therapeutic benefits that nature and our green spaces have to offer. Specifically designed to support people living with dementia, their families and carers, it enables people to enjoy and explore the outdoor environment. This innovative new resource centre is nestled on the grounds of Badaguish Outdoor Centre, where we offer a weekly programme of outdoor based therapeutic activities including ability cycling, bird box making, garden design and much more.

We have secured 7-year project funding to develop this resource and will receive almost £900,000 in start-up funding through The Heritage Lottery Fund (in partnership with Cairngorm National Park Authority). A small team are based at Badaguish and run the therapeutic programme, centred in, and inspired by the natural environment.



We are part of the NHS Green Health Prescribing initiative, and our vision is that we will work towards a clear referral process where people with dementia can benefit not only from our services but from the wider range of opportunities within the initiative. It is unusual to hear about funding initiatives like this being directed towards the older generation, and even less so to people living with dementia. This project gives us the opportunity to reimagine the environment of care and how we perceive dementia.

## Community activities and groups

Within our Dementia Resource Centres and across our communities, we have continued to fund and support people with dementia and their carers to come together in a very varied and high quality network of groups and activities. Many of these groups are based around specific activities such as music, or football reminiscence, with others around the concept of Dementia Cafes or fundamental peer support.

What they all do is allow the people connected to us to come together, to have a sense of belonging and a chance to engage in some form of therapeutic activity. Many of these groups also provide carer education and support, and again offer that vital connectivity that helps ensure people do not feel on their own.

**1242** groups within our Dementia Resource Centres

**2464** groups out with our Dementia Resource Centres

**3706** groups in total

**2616** individuals attended groups

**18000<sup>+</sup>** attendances, on average each person attends 7 groups

# Care

## Day services

All of our registered day services are commissioned in the main by local Health and Social Care partnerships. We have 17 registered services, and we are extremely grateful to those local partnerships who support our view that day services for people with dementia need to be very specialised, person-centred and delivered on a small scale. In a world where large economies of scale are the norm, we are delighted that our services are still being commissioned and supported. We aim to provide the highest possible quality of day care experience, ensuring that all our staff are trained and skilled in a range of meaningful therapeutic interventions and individual practice. The small scale nature of these services means our staff really get to know and understand each person and their family. We are able to work with that person's strengths and aspirations, and whilst most people using our day services will have a high level of need, our goal is to continue to ensure we help each person live well, continuing to prevent and minimise the most difficult symptoms of their illness. We want to ensure that sense of wellbeing and support is achieved by people not being on their own.

*"It is great to know my mum is being so well cared for and is supported to join in all the activities provided by the day care. It means I can have some time away without worry and this helps me by providing some much needed respite from caring for someone with dementia. Thank you so much for all you do."*

*"I like meeting people who have a similar experience to me, being able to talk to people who understand living with dementia. I enjoy getting out of the house and feeling part of a group again."*

Day service users

## Post Diagnostic Support Services

Since the very first National Dementia Strategy prioritised post diagnostic support in 2010 and highlighted the benefits of our Five Pillar model, we have been commissioned by many local Health and Social Care partnerships to deliver this service. This ensures people receiving a timely diagnosis are thereafter offered the highest possible level of support to help them live well with dementia. For many areas there has always been a challenge in having too few Link Workers and we were delighted this year to see the Scottish Government invest directly in this service in addition to what was already being commissioned. For a few years our Link Worker workforce had been around 80 people, with this increased funding we have been privileged to see that increase to around 110 Link Workers. All these new posts have been recruited and we hope this will soon start to make an impact on the waiting lists that have been developing due to a lack of funding. Many of these services are now commissioned through a tendering process and we have welcomed the opportunity to bid for these and new services as this is truly one area of practice that we have developed an exceptional level of skill, knowledge, and practice in, and indeed one we intend to continue to grow.

**By the end of 2022 we will have around 110 Post Diagnostic Support Link Workers across Scotland.**

**From October 21 to September 22, our Post Diagnostic Support Link Workers supported 7057 people with dementia.**

*"The Link Worker has been incredible. She is the place to go to for everything. She has helped with so many aspects for me and my wife."*

*"Having someone I could contact and speak to gave me confidence to deal with my dementia."*

Post diagnostic support users



## Alzheimer Scotland Dementia Nurse and Allied Health Professionals (AHP) Consultants

Another area prioritised in the first National Dementia Strategy was acute hospital care. In direct response to the needs of people with dementia and indeed staff in acute general hospitals, we agreed with the Scottish Government to fund a network of skilled Nurse and Allied Health Professional Consultants. There is now one in every NHS Board, funded by Alzheimer Scotland, the Scottish Government, and the Boards themselves. The purpose of these roles has been to lead the transformation of practice in general hospitals, to support the network of Dementia Champions and to support staff in hospitals to understand how they can look after people with dementia well. In more recent years their skills have been called upon to support specialist dementia hospital facilities. During the pandemic however, many of the Consultants played a pivotal role in supporting practice in care homes and helping implement guidance – making the very challenging restrictions and practices as dementia friendly as possible. There has never been a greater need and role for such a skilled group of practitioners, and we look forward to their ongoing support and contribution to ensure that the needs of people with dementia are understood and prioritised as the NHS recovers from the pandemic and tackles the mounting winter pressures.

## National Allied Health Professional (AHP) Dementia Forum

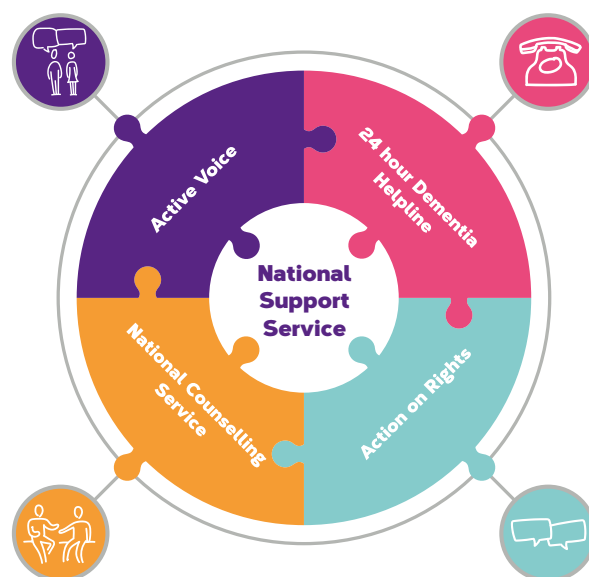
As well as the national Nurse and AHP Consultant Group we have also been extremely fortunate to have the support of a committed and dedicated group of AHPs. Established by our National AHP Consultant, who led the development of the 'Connecting People Connecting Support' AHP strategy, this group are helping to transform the engagement and understanding of what the various AHP professions can offer to people with dementia. Interventions such as the 'Occupational Therapy Led Home Based Memory Rehabilitation' and the value of practitioners such as dieticians, physiotherapists and speech and language therapists are all becoming much better understood, utilised and accessed as a consequence of this work.

We are extremely grateful to the individuals who make up the forum and support this work in a voluntary capacity, they are truly helping us improve the lives of many people.



# Care

Our National Support Services include our Freephone 24 hour Dementia Helpline, our Action on Rights team, our National Counselling Service and our Active Voice network. Together, they play a key role in providing both practical and emotional support, offering signposting and information, as well as campaigning, awareness raising and influencing policy and practice.



## Alzheimer Scotland's Dementia Helpline

Our 24 hour Freephone Dementia Helpline was established in 1989 and since then has supported thousands of people with dementia, their families and carers. The Helpline is staffed by trained volunteers and many of them have had personal or professional experience of caring for or supporting someone with dementia. The Helpline team provide information, signposting, and emotional support to callers. Open 24/7 and 365 days a year, the Helpline is a free and confidential service that can really help people facing stress and distress, as well as those who may simply be looking for information on dementia. Helpline volunteers can signpost callers to other Alzheimer Scotland services or other resources such as financial and legal rights services.

Between 1/10/21 – 1/10/22 the Helpline has received approx **8170** inbound calls and have spent in excess of **1,115** hours listening and responding to our callers.

**93%** of calls from carer

**5%** of calls from person living with dementia

**2%** of calls from professional working within dementia community





## Action on Rights Team

Our Action on Rights team was initially formed during the pandemic to support the implementation of the Scottish Government's 'Open with Care' guidance. Although the team continue to support people experiencing issues in relation to care home visiting, their remit has expanded to working alongside colleagues to support people living with dementia, their families and carers on some of the more complex issues such as complaints processes with Health and Social Care Services, hospital visiting and discharge, Power of Attorney and Guardianship, paying for care, welfare rights, Community Care Assessments as well as human rights and equality issues.

Since the team was established, they have been there to support staff and families, acting as mediators and advocates, providing guidance on interpreting legal frameworks, and ensuring people have the right information to challenge difficult decisions. Going forward they will continue to strive to reach the best outcomes for people living with dementia and their families.



## National Counselling Service

Our National Counselling Service celebrated its first full year of operation in 2022. There has been a huge demand across the country for counselling services, particularly in the aftermath of the COVID-19 pandemic. Our counsellors are highly skilled and use a variety of different methods including cognitive behavioural therapy (CBT), person centred counselling, and eye movement desensitisation and reprocessing (EMDR). The team meet weekly to allocate referrals, taking into account the individual needs of the person referred. Referrals to the team mainly come from Alzheimer Scotland frontline staff such as our Dementia Advisors and Post Diagnostic Link Workers.

Our counselling team have been able to help people with dementia, their families and carers come to terms with the impact that a dementia diagnosis can have. They have also been able to help people facing bereavement, financial stress, and anxiety. The feedback from people who have used the service has been overwhelmingly positive. We now have a dedicated member of the team who offers support to people with young onset dementia and their families, and we hope to expand the service further increasing our capacity to offer this much needed form of support.

### ACTION ON RIGHTS STATISTICS

**284** referrals in 2021

**165** referrals in 2022

**449** total referrals to date

### NATIONAL COUNSELLING SERVICE STATISTICS

**111** Number of referrals from June 21 – June 22

**21** Persons with dementia

**90** Carer/family member

**8** Average number of sessions attended

### GENDER OF REFERRALS

**27** Men **84** Women

Majority of referrals in the 50-59 year old age bracket

# Care



## Active Voice

Our Active Voice network campaigns both locally and nationally to improve the lives of people within the dementia community. Working alongside our members, people with dementia, their families and carers, our awareness raising and campaigning work is built around people sharing their lived experience. Local campaigning is so important because the decisions that most affect the lives of people with dementia, their carers and families are made locally.

Our two national campaigning groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) are committed to bringing about positive change for those whose lives have been affected by dementia.

### The Scottish Dementia Working Group

The Scottish Dementia Working Group (SDWG) is a national, member led campaigning and awareness raising group for people living with a diagnosis of dementia in Scotland. They are the independent voice of people with dementia within Alzheimer Scotland. In 2022, the group celebrated an amazing 20 years of campaigning. Over the last two decades SDWG members have worked tirelessly to campaign and raise awareness at both national and international levels.

When the country went into lockdown in 2020, the group had to adapt from being an active campaigning group who regularly met in person, to a group working exclusively online. They did this with great success. For 2021-22, the groups priorities are post diagnostic services, influencing policy and practice, research and brain health, equality and diversity, and tackling stigma.



### The National Dementia Carers Action Network (NDCAN)

At the end of 2021, the National Dementia Carers Action Network (NDCAN) marked an important milestone – 10 years of campaigning. Founded in 2011, the group was established to raise awareness and to campaign against the inequalities faced by people living with dementia, their families and carers. As the independent voice of unpaid dementia carers within Alzheimer Scotland,

NDCAN has gone from strength to strength over the last decade. Members continued their work digitally throughout the pandemic, and as we move back to a more 'normal' way of working, their priorities for 2021-22 are care homes, post diagnostic support, and workforce development. They also have a strong focus on research, continuing their work with their research subgroup, a collaboration with the Alzheimer Scotland Centre for Policy and Practice.



**Congratulations to both groups on their campaigning anniversaries and we look forward to working with you for many years to come.**





## Advocating and campaigning for change and equality

**Our policy and campaigning activity is underpinned by the ethos that people with lived experience are at the heart of everything that we do.**

Our Fair Dementia Care campaign was launched in 2019 following the publication of our 'Delivering Fair Dementia Care for People with Advanced Dementia' report. The campaign 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.

Delivering Fair Dementia Care for people with advanced dementia remains our most significant current campaign. We are determined to ensure that we bring about an end to the inequality that people with advanced dementia experience – the lack of equal access to the health and specialist nursing care that they need to meet the complex health care needs that arise in advanced illness.

They also face unfair charges for care in their own homes and in care homes for what we have demonstrated through our Fair Dementia Care Commission and Fair Dementia Care Report are unequivocally health care needs. It is our view that these needs should therefore not be paid for by the individual but by the NHS, and there must be an assessment to identify when someone with advanced dementia's needs change from social care to health care.

People living with advanced dementia are facing

**£50.9m**

in care costs every year.

**This needs to change.**



**Alzheimer  
Scotland**  
Action on Dementia

#fairdementiacare

## Getting as many people involved with dementia research as possible is vital in making progress towards a cure

– Research is hope.

### **‘Confident Conversations about Research’ programme**

The ‘Confident Conversations about Research’ programme is a partnership between Alzheimer Scotland and the NHS Research Scotland Neuroprogressive Dementia Network. The aim of the programme is to inform Alzheimer Scotland’s frontline staff about dementia research, the different types of research taking place, and who can take part in research. Staff will then have the knowledge and skills to confidently talk to people they support about research, the benefits of it, and how they can participate in it. The programme, which takes the form of in-person training sessions across Scotland launches in the autumn of 2022.

### **Join Dementia Research (JDR)**

Join Dementia Research (JDR) is a nationwide online and telephone service that makes it easier for people to register their interest in volunteering for dementia research studies. Anyone, with or without dementia, can register as a volunteer by visiting the JDR website. The service was launched by the National Institute for Health Research (NIHR) in partnership with Alzheimer Scotland, Alzheimer’s Research UK and the Alzheimer’s Society. Alzheimer Scotland are very proud to be part of Join Dementia Research which has been one of the most successful UK wide dementia research collaborations of its time. In the last 7 years, the number of people signing up has been remarkable, driven by a strong clear vision that enables people to take part in research. We continue to encourage as many people as possible to sign up and help deliver our shared goals for prevention, improved practice and treatments and ultimately find a cure.

### **Scottish Dementia Research Consortium and Scottish Dementia Research Strategy**

The Scottish Dementia Research Consortium (SDRC) brings together researchers, policy makers, healthcare professionals and people living with dementia across Scotland, and is open to anyone with an interest in dementia research. In 2021, the SDRC launched the first Scottish Brain Health and Dementia Research Strategy. Prepared by Alzheimer Scotland, the Scottish Dementia Research Consortium and Brain Health Scotland, the strategy sets the direction of travel for research in Scotland by defining key areas with strategic actions. Many countries have dementia plans or strategies, but Scotland is among the first countries in the world to develop a government sponsored, standalone research strategy for brain health and dementia. The overall aim of the strategy is to create an environment in Scotland to promote the conditions for the highest quality of brain health and dementia research, and the rapid implementation of research into practice.

### **Davos Alzheimer’s Collaborative**

In 2022, Alzheimer Scotland joined the Davos Alzheimer’s Collaborative (DAC), a programme led by the World Economic Forum (WEF) and The Global CEO Initiative on Alzheimer’s Disease (CEOi) that unites leading organisations worldwide. The Davos Alzheimer’s Collaborative is investing over \$700 million over 6 years to accelerate innovation in drug development and transform the way healthcare systems diagnose and treat Alzheimer’s for people across the world.

## **Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland (UWS)**

We continue to fund and support the Alzheimer Scotland Centre for Policy and Practice (ASCPP) at the University of the West of Scotland (UWS). The UWS centre has been leading the way in developing a deeper policy and practice understanding of current and emerging issues in health and social care science.

## **Alzheimer Scotland's Brain Tissue Bank**

Relaunched in 2021, Alzheimer Scotland's Brain Tissue Bank is based at the Alzheimer Scotland Dementia Research Centre (ASDRC) at the University of Edinburgh. The Brain Tissue Bank is able to accept donations of brain tissue from people with a diagnosis of dementia who live on mainland Scotland. Samples of brain tissue enable researchers to shed more light on how changes in the brain relate to symptoms of dementia. Donating brain tissue is a vital way of helping research into dementia.

## **New research programme**

We will be launching a new research program in collaboration with the Scottish Dementia Research Consortium, funding a series of studentships in dementia and brain health to actively contribute to Scotland's dementia research community. We want people with lived experience of dementia to be able to directly influence what research is funded. We will work with the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN) to decide on research priorities and to jointly select and award any funding to successful applicants. This will ensure the program is driven by the voice of lived experience and differs from other academic research. We hope to begin the selection process in late 2022, culminating in the studentships starting later next year.





## Campaigns & events

**Our campaigns and events are so important to us, not only to raise funds and awareness but to keep us connected with our members and supporters.**

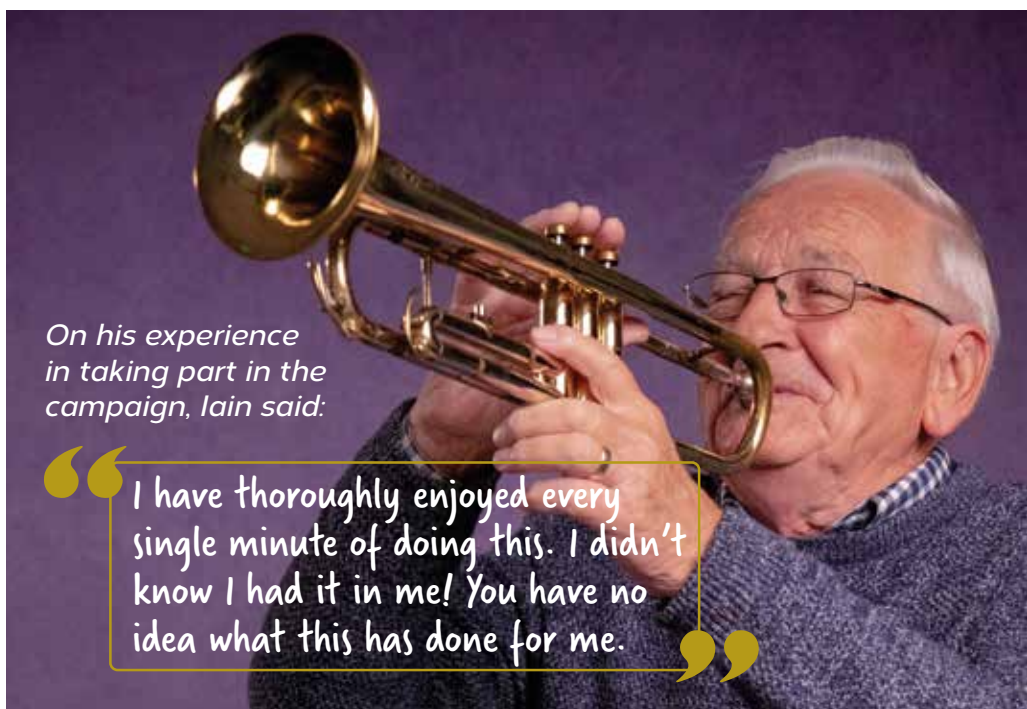
### **We believe a little bit of magic goes a long way**

Our 2021 winter fundraising appeal launched in late November and featured three of the people we support as our campaign 'stars'. Iain, Danny, and Danny's wife Catherine all shared their experiences of how the support they received from Alzheimer Scotland had changed their lives. Iain spoke about the impact that his local Dementia Advisor Karen had made and how it was often the small things that made the greatest difference. Danny and Catherine talked about their local Dementia Resource Centre and the support they had received there. Our strapline 'The little moments of magic make such a difference' really captured the spirit of the campaign.



*On his experience in taking part in the campaign, Iain said:*

“I have thoroughly enjoyed every single minute of doing this. I didn't know I had it in me! You have no idea what this has done for me.”



### **Dementia Awareness Week 2022**

The aim of Dementia Awareness Week is to raise awareness, reduce stigma and help improve the lives of people with dementia, their families and carers. In 2022, the theme for the week was 'Let's Prevent, Care, Cure dementia together'. Throughout the week there was a series of events including the opening of our Dementia Resource Centre in Alloa – the first of our centres to have a Brain Health Hub. Our Tea & Blether campaign ran throughout the week and encouraged people across Scotland to meet up, raise funds and get talking about dementia. We also asked people to send us pictures of themselves with their favourite mug for our #mugshot Twitter feed. On our website we shared stories of people with lived experience – people living with dementia and carers, as well as special content on the topics of Prevent, Care, Cure. At the end of the week, our Chief Executive Henry Simmons called on the Scottish Government to do more to address the inequalities and pressures on people living with dementia and their families.





## Annual Conference 2022

Over 300 attendees joined us at the Edinburgh International Conference Centre for our 2022 conference – our first in-person conference since 2019. With the theme of 'Prevent, Care, Cure', the day was an opportunity to hear from people with lived experience, Alzheimer Scotland staff, researchers, academics, and health and social care professionals. Opened by members of the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN), we were joined on the day by key speakers who spoke on the theme subjects of prevent, care and cure.

Lunchtime therapeutic sessions gave attendees the chance to try out a virtual reality headset or glass painting.



*"I have been to many conferences throughout my professional life of 30 years. This was one of the very best and I think it set out a clear and inspiring vision for the future (whilst rightly acknowledging past and ongoing challenges). The contributions from those living with dementia were especially inspiring, humbling and moving and I feel privileged to have heard their experiences first hand."*

Quote from conference attendee



## World Alzheimer's Day 2022

It was an incredibly proud moment for us all seeing Edinburgh Castle illuminated in purple to raise awareness for World Alzheimer's Day on 21 September.

This was the first time that the iconic castle had been lit up in purple for the event and it looked amazing.



We received some pro bono work from GoForth design agency, who also secured free billboard space in prime locations around the central belt. These included the steps at Waverley Station and Murrayfield Stadium.

To coincide, we ran a complementary social media campaign from 21-28 September. The campaign was a big success, receiving lots of engagement on our social channels.

# Innovations & initiatives

**There are so many creative ways that we can help support the dementia community and make that difference.**



## Time for You

Thanks to funding from the Scottish Government we launched the Time for You fund in February 2022, providing a simple way for unpaid carers to apply for up to £300.

Applications soon started flooding in, all assessed by a panel made up of people with lived experience who dedicated time to consider each application. It was important to us that the fund was flexible – support looks different for different people, so we asked applicants – what does time for you look like? This way we could make sure that the support given was meaningful to each individual applicant.

The impact has been far reaching with the fund supporting short breaks, new hobbies, getting fit, or enjoying precious time away with their loved one.

The benefits for many applicants extended beyond the grant too – we reached out to those carers who were struggling and connected them into Alzheimer Scotland's network of on-the-ground and digital community support.

The fund closed in August and has been an amazing success, and a chance for us to offer much needed support to almost 1,200 carers across Scotland.

***“It’s amazing how strangers care, I am so grateful as they have no idea how much they have helped. Thank you, Time for You.”***

Mrs Todd, recipient carer

**1192** grants were given out in total with 75% going to fund short breaks. 25% of applicants weren't able to take a short break as their caring role was 24/7 so the flexibility of the fund allowed us to extend the reach of the people we could help with different circumstances.

## Purple Alert

Purple Alert celebrated its 5th birthday in 2022. Launched in 2017, this community minded app was the first of its kind to support the families and carers of people with dementia during an immediate missing person search. Working in close partnership with Police Scotland, the app allows users to create a profile of the person living with dementia and share it with the local community.

Everyone in the area who has the app on their phone will get notified and can actively help with the search. The app is free and can be downloaded on both Android and iPhone.





## **ADAM** **About Digital And Me**

ADAM is Alzheimer Scotland's online platform that helps people to find the technology they need to live well at home. It holds an online catalogue of products that can be purchased from the high street or online retailers. What makes ADAM a fantastic tool is that all products featured on ADAM are tested by people living with dementia and their families as part of a project called Dementia Circle. Families can therefore find out more information about each product including set up time, price, where to purchase, and reviews from real families who have tried out the product before. ADAM complements our face to face support, acting as a trustworthy website for frontline workers and Digital Dementia Advisors to look at with families and identify tailored digital solutions to meet their needs. Over the coming year a focus for the Dementia Circle will be helping test out the therapeutic benefit of virtual reality for people living with dementia.



## **Dementia Friends Scotland**

During the COVID-19 pandemic, we developed the Dementia Friends programme to be delivered online, which lets us connect with organisations with offices around the country. Demand for our face-to-face sessions has increased as people come back to the office environment. We have also restarted engagement with schools, universities, and colleges across Scotland. Since the start of 2022, we have delivered around 75 online and 60 face-to-face sessions – raising our profile and sharing information about our support services. We are developing a programme around Dementia@Work, engaging with the Scottish Dementia Working Group, the National Dementia Carers Action Network, and the University of the West of Scotland to support and build the programme based on their insight and experience. We hope to launch this in the new year.



**Alzheimer  
Scotland**

**Virtual  
Resource Centre**

## **Virtual Brain Health and Dementia Resource Centre**

Thanks to the generosity of donors to our 'virtual brick' campaign we were able to officially open the doors of this innovative service on World Alzheimer's Day, September 2021. The centre is designed to offer people with dementia, their families and carers free, online access to many of the features of our traditional Dementia Resource Centres without the barriers of distance, costs of travel and restrictions of opening times. People with lived experience have been at the heart of its development ensuring that families visiting the site will have an inclusive and dementia friendly experience. Since its launch, a major 'virtual build' has been underway to create different rooms that can mirror the look and feel of our physical Dementia Resource Centres. This virtual centre will also become a valuable tool to enable families in rural and remote areas of Scotland to connect into new forms of support, such as livestreamed events on brain health, interactive sessions and increased access to professional and peer support for those with rarer forms of dementia.



## **Dementia Dog**

Dementia Dog is a collaboration between two charities – Alzheimer Scotland and Dogs for Good – that seeks to empower families affected by dementia to live with more confidence, independence and joy. Dementia Dog offers a range of services from one-to-one Community Dog therapy interventions, online group doggy bingo sessions, to training and placing life changing Assistance Dogs to support families living with earlier stage diagnosis of dementia. Dementia Assistance Dogs are highly trained with full public access rights. They can help with a range of tasks to prompt daily routine such as fetching medication pouches. This year the team have been excited to resume face to face activity following the restrictions of the pandemic. This includes reopening its Assistance Dog service to welcome applications from families in Scotland. To date, the Dementia Dog project has placed ten dogs in Scottish homes and is now currently training a new dog to place with a family over the coming winter months.



# Your support



## Scotland's Memory Walk 2022

We are celebrating the success of our 2022 Scotland's Memory Walk campaign after an emotion packed weekend which saw supporters taking part across the country and beyond. The event took place in September, and so far the campaign has raised almost £70,000 from 520 registrants.

Fundraisers paid touching tributes to their loved ones through their walks - one supporter Sophie joined Memory Walk for the first time and successfully climbed Ben Lomond in memory of her mother Lesley, who sadly died aged just 66 after being diagnosed with dementia.

Another walker, long term supporter Megan, paid tribute to her grandmother for her sixth Memory Walk, tracing the steps of her grandmother's life through North Lanarkshire. Megan passed her former home, place of work and completed her walk at the cemetery where she is buried.

We look forward to Memory Walk returning in 2023 to unite more families and friends together to raise awareness of dementia and enjoy fundraising in memory and honour of their loved ones.



## Tea & Blether

Our brand new campaign 'Tea & Blether' followed the format of a coffee morning event with a Scottish twist. This fundraising initiative gave people the opportunity to host their own coffee mornings to raise funds and awareness for people living with dementia, their families and carers in Scotland. Supporters may recognise the name Tea & Blether as Alzheimer Scotland have a history of hosting small scale coffee mornings across our Dementia Resource Centres.

This was a chance to bring these much loved gatherings to a national audience. Coinciding with Dementia Awareness Week, Tea & Blether took place between Monday 30 May and Sunday 5 June 2022. The campaign raised over £20,000 in its first year and we look forward to Tea & Blether returning for Dementia Awareness Week 2023.





***“Sadly, this is an illness on the increase and Alzheimer Scotland relies on charity in order to provide vital care, support and research. I know first-hand how traumatic it is to care for a loved one, and the more money that goes to this cause, the sooner a cure can be found. Therefore, if you’re thinking about fundraising, please go for it!”***

Nick Gardner



## Our amazing fundraisers

As we emerged from lockdown, despite the economic challenges everyone faced this year, support for our third-party events has continued to be positive. From all over Scotland our supporters have taken part in marathons and 10ks, walked thousands of miles and climbed Munros, swam and skydived their way to raise funds for us. Some supporters even went beyond that extra mile.

In 2020, for his 80th birthday, Nick Gardner from Wester Ross set himself the challenge of climbing every Munro in Scotland over 1200 days. Nick’s motivation is for his wife Janet who was diagnosed with Alzheimer’s disease and osteoporosis.

Throughout his challenge, Nick continued to spread the word of Alzheimer Scotland and The Royal Osteoporosis Society. He has become a hill climbing celebrity, meeting and climbing with people from all over the world.

Nick completed his epic challenge in August, raising over an incredible £100,000 for Alzheimer Scotland. As well as receiving international media coverage he has also won a Just Giving award for Endurance Fundraiser of the Year.



June 2020 saw supporter Ross MacNamee begin his yearly fundraising challenge. His first was to climb Ben Nevis with friends, he then followed this up by completing the West Highland Way in 2021 and again in 2022. His inspiration and motivation to set himself these goals is his mum Angie who was diagnosed with vascular dementia and young onset Alzheimer’s Disease when she was just 40. Despite only being a young teenager, Ross adjusted in order to care for his mother during a difficult and uncertain time. **Ross said:**

***“At times when caring for my mum with Alzheimer’s I’ve felt helpless because there is genuinely nothing you can do except to make life as comfortable as possible. Doing something like this makes you feel you’re giving something back, and you get a bit of comfort from it.”***

# Your support

## Our corporate partners

We would like to thank all our corporate partners who have supported over the past year. We have welcomed new partnerships with Fosters Funerals, Topps Tiles, The Wheatley Group, and are grateful for the ongoing support from our existing partners such as William Hill, Gillespie Macandrew, Clyde Munro Dental, Wilko, McKesson, Thomas and Adamson, Willis Towers Watson.

Our partnership with Brodies LLP has been transformative. In the past year they have funded the first phase of our schools Brain Health programme – 'My Amazing Brain'. In addition to providing funding for the project, including creating an animation to be used in class, they have been a key stakeholder in the development of the project. Brodies also kindly provided in kind support when we relaunched our new online shop in October, and they have continued to provide valuable advice to our supporters and staff through webinars on subjects such as Power of Attorney and visitation rights.

Our partnership with Braehead shopping centre continues to build momentum. We have been working together with the aim of creating the first dementia friendly shopping centre, with staff being given Dementia Friends training, and the centre making adaptations to make it more accessible and welcoming for people living with dementia to shop there. Several public engagement and fundraising events have also been held in the centre.

## Special thanks to our trusts and giving supporters

Andrew Paton's Charitable Trust  
Brownlie Charitable Trust  
Callendar Charitable Trust  
Cruden Foundation  
D.C. Leggat's Charitable Trust  
Foundation Scotland  
Gibson Graham Charitable Trust  
Gunter Charitable Trust  
Hugh and Mary Miller Bequest  
Hugh Fraser Foundation  
Mary G Burnett Trust  
Mary Janet King Trust  
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The Kells Trust  
The Landsberg Trust  
The Lizandy Charitable Trust  
The MacRobert Trust  
The Meikle Foundation  
The Morton Charitable Trust  
The Netherdale Trust  
The Netherton Charitable Trust  
The Paristamen Charity  
The Pettigrew Charitable Trust  
The Pump House Trust  
The Ronald Miller Foundation  
The Sir Iain Stewart Foundation  
The Stornoway Trust  
The Tanlaw Foundation  
TK Maxx and Homesense Foundation  
The Underwood Trust  
Westwood Charitable Trust

**And to all our other generous Trusts & Foundations that support our work.**

# Our people

## Our Board of Trustees

### Office Bearers



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Vice-Convener



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**Anna Borthwick**

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Executive Lead Stakeholder Engagement

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**Maureen Taggart**

Executive Lead for National Post Diagnostic Support

**Kenny Nicholson**

Executive Lead People, Wellbeing & Facilities

**Marri Welsh**

Executive Lead Communications & Campaigns

## Our staff and volunteers

We have nearly 400 part time and full time staff at Alzheimer Scotland. Our staff and volunteer's hard work, dedication, and commitment is vital.



# Our finances

## Income and Expenditure 2021-22

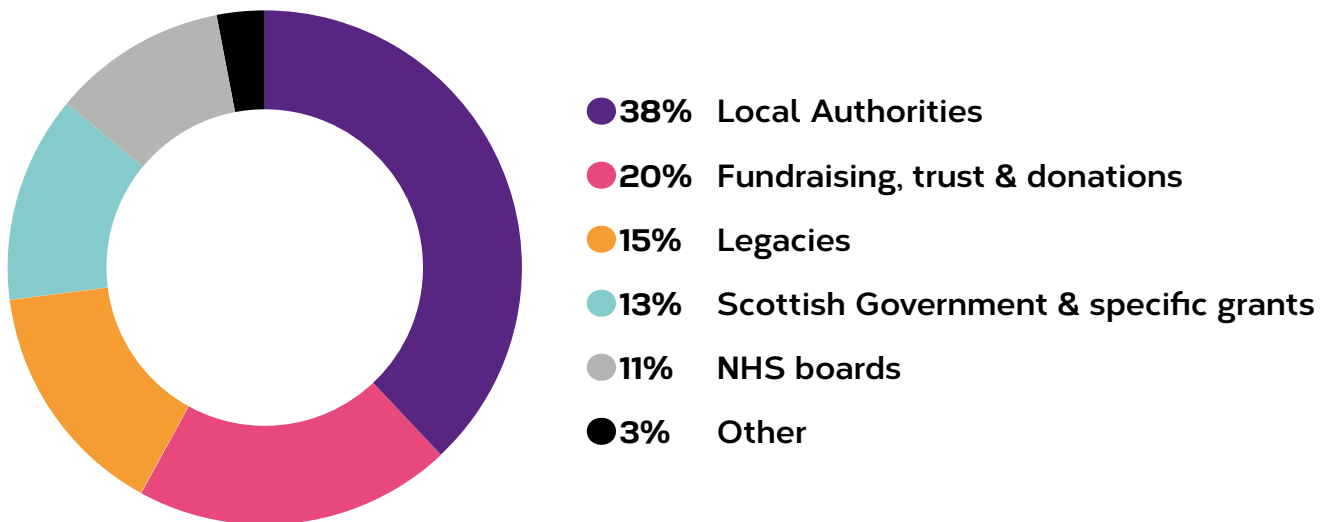
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### Consolidated Income and Expenditure account for the year ended March 2022

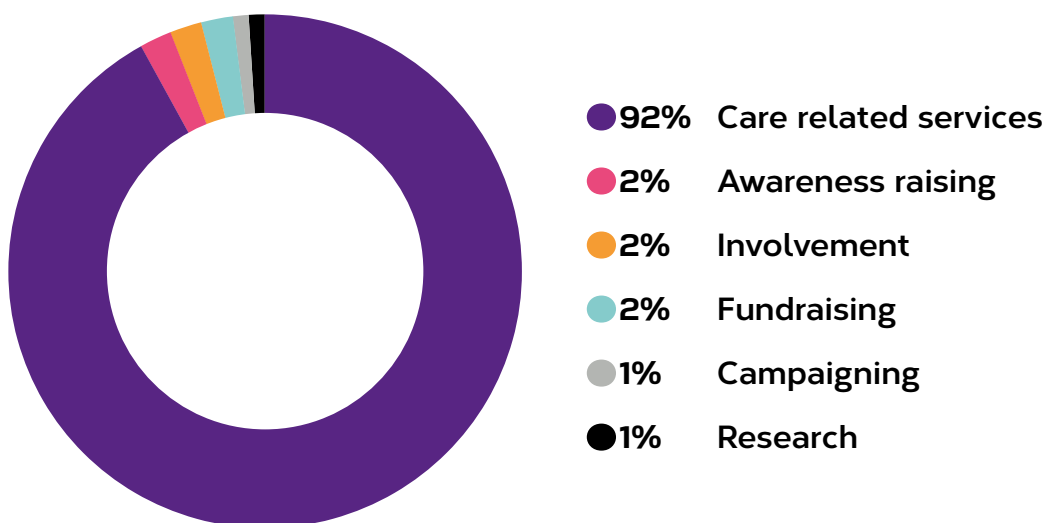
	2022 £	2021 £
<b>Income and endowments from</b>		
Donations and legacies	5,153,956	5,044,491
Other trading activities	87,769	86,886
Income from charitable activities	8,982,461	9,508,807
Income from investments	74,976	77,029
Share of surplus of associate	-	10,162
Other (gain on disposal of tangible assets)	74,060	1,214
<b>Total income</b>	<b>14,373,222</b>	<b>14,728,589</b>
<hr/>		
<b>Expenditure on</b>		
Raising funds	222,430	200,672
Charitable activities	12,662,250	13,634,442
<b>Total expenditure</b>	<b>12,884,680</b>	<b>13,835,114</b>
Net gains on investments	46,796	401,098
<b>Net income</b>	<b>1,535,338</b>	<b>1,294,573</b>



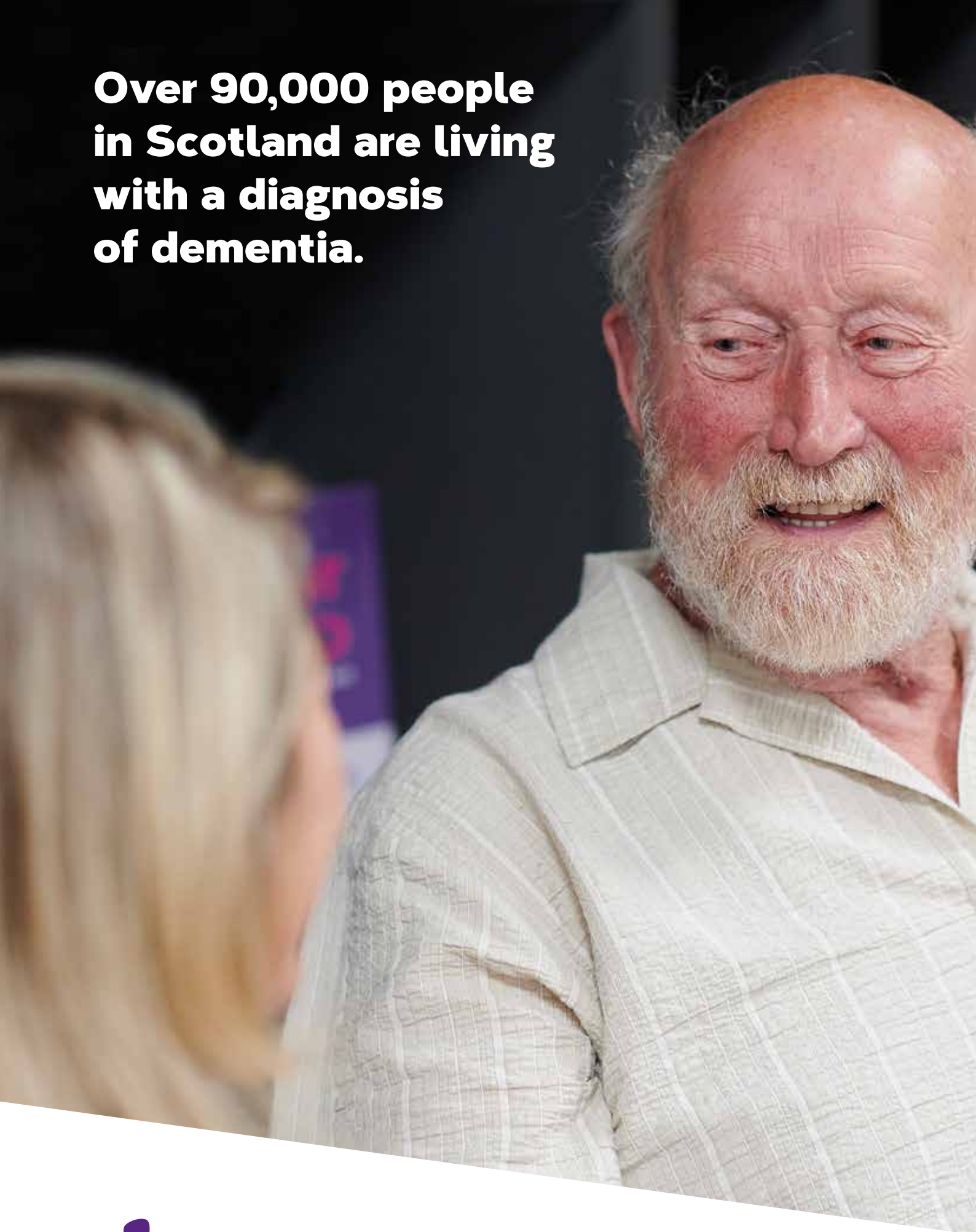
## Income



## Expenditure



**Over 90,000 people  
in Scotland are living  
with a diagnosis  
of dementia.**



**Alzheimer  
Scotland**  
Action on Dementia

Prevent.  
Care.  
Cure.

# How we help

## Dedicated 24 hour Freephone Dementia Helpline



Our confidential Freephone Dementia Helpline offers information and emotional support 24 hours a day, 365 days a year.

## Local Dementia Resource Centres



Our growing number of Dementia Resource Centres provide personalised support, designed around the abilities and interests of the person.

## Expert Dementia Advisors



Our Dementia Advisors provide a local point of contact for individuals and their families through all stages of dementia. They offer individual support and work with communities to help them become dementia friendly.

## Experienced Link Workers



In Scotland, people diagnosed with dementia can benefit from a minimum of one year's support from a Post Diagnostic Support Link Worker after their diagnosis. They help people understand the illness, manage their symptoms, maintain community connections and make new ones.

## Prevention and cure



Dementia research is crucial to making a difference for people living with dementia now, and in the future. We support a wide range of dementia research to improve care standards, to better understand the causes of dementia, and ultimately, to find a cure.

[www.alzscot.org/support-us](http://www.alzscot.org/support-us)



# Thank you



**Alzheimer  
Scotland**  
Action on Dementia

**For more information on any of the work or projects featured  
in our Annual Review 2021-22, please visit our website  
[www.alzscot.org](http://www.alzscot.org) or email us at [info@alzscot.org](mailto:info@alzscot.org)**

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