Dementia in Scotland: **Everyone's Story**

Ministerial Foreword

Ministerial Foreword

Foreword from the Minister for Social Care, Mental Wellbeing and Sport and the Health and Social Care Spokesperson, Convention of Scottish Local Authorities (COSLA)

This strategy sets out a positive, shared vision for dementia in Scotland over the next 10 years. It makes clear the importance of a shared vision that is owned by all of us working together to deliver a better experience for people living with dementia, their families and carers. It builds on several years of globally-recognised public policy on dementia in Scotland and commits to ongoing reflection and learning, greater inclusion and delivery from the start.

It's called "Everyone's Story" because it belongs to all of us. How we understand, support and see dementia impacts everyone, regardless of gender, ethnicity, additional disability or age. Across all settings, at all stages we must embed and enable empowerment, inclusivity and citizenship. That will require us to listen and respond more to the needs of people from different communities and backgrounds across Scotland.

We know that people with dementia still face many challenges, which are often rooted in poor understanding, inequality or stigma. This strategy recognises the need to develop our collective understanding of dementia and build an understanding of brain health over time. That may challenge some attitudes on what dementia is and raise questions about the best ways to enable or deliver support, but it also creates opportunities for doing some things differently and making new connections. That has to include ways to address long waits experienced by some people needing a diagnosis, as well as ensuring more consistent access to good quality post diagnostic support, co-ordinated care that supports people to live the best life possible and access to palliative care. But over time it will also require a focus on ways to ensure dementia services and supports feel more integrated into systems and communities.

The best way to deliver better experiences for people is to include them in policy design and delivery. Scotland has a strong record of working closely with people with lived experience of dementia to inform policy and delivery. This strategy – its approach, design and focus takes this work further. Last year, Scottish Government established a National Dementia Lived Experience Panel, drawing membership from different backgrounds, experiences, and places. This Panel has worked alongside local and national government, and with wider partners, to develop this strategy. We are hugely grateful for the time, commitment and expertise shared to date and look forward to continuing to work with the panel as we move into delivery. This document is enriched by their experience and contribution.

Our sincere thanks also extend to the Strategy Advisory Group. Meetings brought together a wide range of people and organisations who helped to inform and agree this vision, alongside the Lived Experience Panel. The group included a range of different voices and expertise, some with differing perspectives but a commitment to collaborate, learn and innovate as we move forward, keeping people and their experiences to the fore. Again, we look forward to continuing to work with this wide range of partners as we embark on delivery.

That commitment to ensuring delivery is our most important priority. Our rolling 2-year delivery plans, which will be developed with national and local oversight, will increase accountability and keep us focused on impact. The first delivery plan will be developed and agreed this year for implementation in 2024-25.

There is no doubt that agreeing and resourcing the first set of priorities for delivery will be challenging given the pressures being experienced across all parts of the system. Whilst the increased national and local investment in dementia in recent years demonstrates our shared commitment to improving people's experience, we know we must work with others to maximise the impact of existing spend. We must ensure investment is focussed in the right areas and delivering greatest impact on our priorities. We will make the most of opportunities to align and test improvement as part of wider health and social care reform where that's appropriate.

We have hard work ahead to deliver on the level of ambition set out in this document. We want to thank every individual and organisation across Scotland who participated in the engagement and development process that has led us to this point. We know that people gave their time and experiences with expectations that change will happen, and it will. We are confident that this 10-year strategy sets the right course for dementia policy in Scotland. The next step is agreeing our plans for delivery. The strategy is everyone's story, but it only changes things if we each take a role in its delivery.

Maree Todd

Maree Todd MSP
Minister for Social Care,
Mental Wellbeing and Sport

Paul Kelly

Councillor Paul Kelly
COSLA Spokesperson for
Health and Social Care

Acknowledgments

Acknowledgments

Thank you to everyone who has contributed to the development of this strategy. We often talk about 'standing on the shoulders of giants' when publishing work that has been informed and shaped by people who have brought years of knowledge and experience and share a vision for a better future.

This has been such an experience.

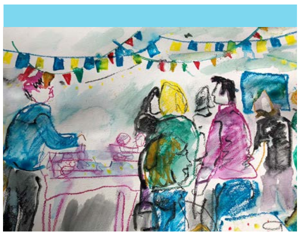
A special thank you to the newly established National Dementia Lived Experience Panel that came together over a series of busy meetings to share their experiences and steer the work that led to this strategy.

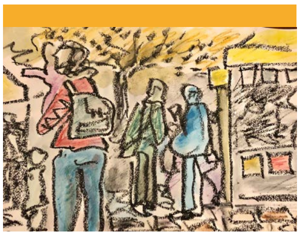
Thank you also to the Strategy Advisory Group that has added wide-ranging professional knowledge and expertise to the Conversation.

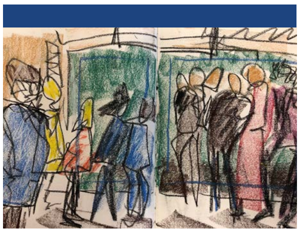
While we want this strategy to be everyone's story, you'll see a that a small number of unique experiences are highlighted throughout. Use a smartphone to click onto the QR codes to engage with their stories.

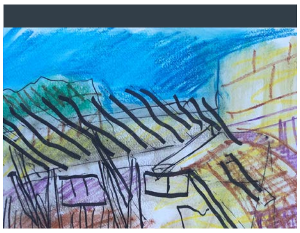
This strategy has been illustrated by Willy Gilder, a sketch artist and member of the National Dementia Lived Experience Panel. Particular thanks for your inspired contribution, Willy.

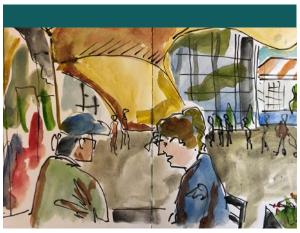
Contents











Why a Dementia Strategy?

Why a Dementia Strategy?

> **“Dementia is all around us, in our families and in our genes; perhaps in our own futures. If it’s not you or me, it’s someone we love.”**
>
> Nicci Gerrard, Author

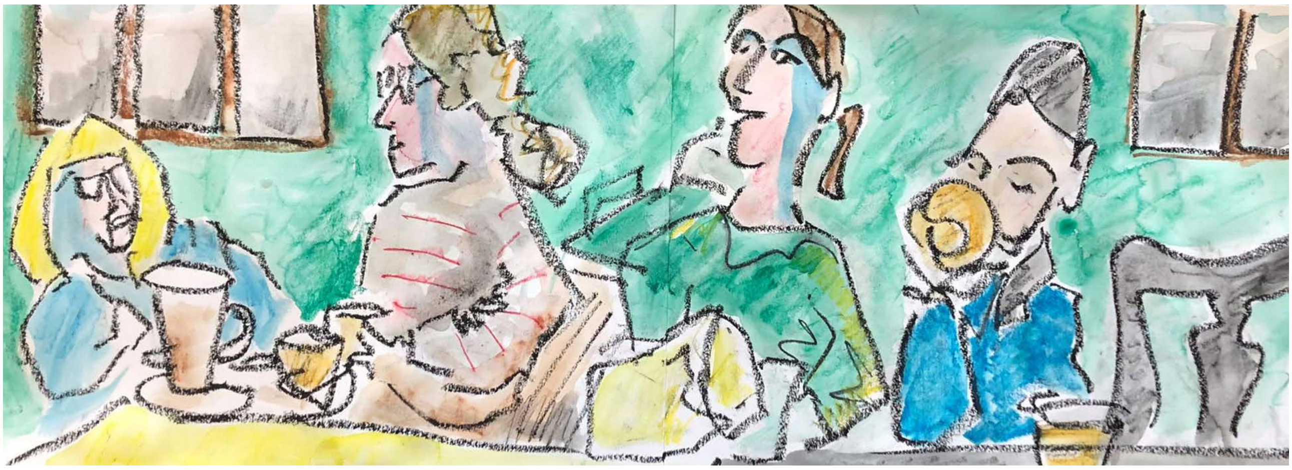
Some estimates suggest that **1 in 3 people** born today will go on to develop dementia.

This dementia strategy for Scotland is important for us all. While clinical research continues in Scotland and globally to produce medicines to slow or modify symptoms of dementia, projected estimates show a 50% increase in the number of people with dementia over 65 over the next 20 years[1]. Some estimates suggest 1 in 3 people born today will go on to develop dementia[2].

This is a 10-year strategy. It sets out a vision for how life with dementia might be experienced and the policy, service and societal changes that are needed to support this. It describes what people living with dementia and their families have told us they want and expect and ‘what good looks like’ as people progress through dementia. We believe this step change will be cumulative and incremental and may take up to ten years to realise so, whilst measurable improvement will be evident in a shorter timeframe, we are realistic about the time societal change will take.

---

[1] Alzheimer’s Disease International Dementia Statistics
[2] Alzheimer’s Research UK Dementia Statistics



We know that Scotland and the wider world will change dramatically during that time and that what the Scottish Government, Convention Of Scottish Local Authorities (COSLA) and delivery partners set out to do now will need to adapt and change as the strategy progresses.

This means that how the strategy is delivered needs to be clear and focussed, making the best use of resources at a time when we know money for individuals is tight, budgets are stretched and pressures on services and systems are intense.

Delivery plans will have a **two-year lifespan**, subject to review at 18 months.

Delivery Plans

To ensure we learn from what works, stimulate innovation and maintain relevance through the ten years, we will work collaboratively with our partners to produce a series of delivery plans that detail how key themes within the strategy will be delivered and when. Delivery plans will have a two-year lifespan, subject to review at 18 months. We believe that this will hold us to account on the long-term transformation we want to see and that people living with dementia and their care partners are entitled to expect.

This rolling programme of delivery plans will be informed, shaped and reviewed through the governance structures and wider stakeholder engagement, continuing the approach of our National Conversation to make sure this remains everyone's strategy from now until 2033.

The first delivery plan will be agreed by end 2023 for delivery at the start of financial year 2024/25.

The Challenge

The Challenge

Dementia affects an estimated **90,000 people** in Scotland.

Dementia is not an inevitable part of ageing. It is an umbrella term that can be caused by a number of diseases which, over time, damage the brain, typically leading to deterioration in both brain and bodily health. Dementia is life-shortening and, though there are limited pharmacological interventions, there is no cure.

Whilst memory loss is often a symptom of dementia, changes in mood and behaviour sometimes happen even before memory problems occur. Symptoms worsen over time. Eventually, people with dementia will need others to help with daily activities.

Dementia has physical, psychological, social and economic impacts, not only for people living with dementia, but also for their care partners, families and society at large. There is often a lack of awareness and understanding of dementia, resulting in stigmatisation and barriers to diagnosis and care.

Dementia affects an estimated 90,000 people in Scotland, an estimated 3,000 of whom are under 65[3]. However, every person with dementia is unique. Dementia affects people in many different ways, depending on the type of dementia they have as well as personal factors such as their social situation.

---

[3] Scottish Government - National dementia strategy - 2017, based on European Prevalence Rates

Irrespective of the type of dementia, the impact on a person's life extends beyond their brain health to affect their whole life. Maintaining employment; financial security; independence and autonomy about how and where to live as the illness progresses and relationships with family, friends and community are all affected to varying degrees.

In 2012 the World Health Organisation declared dementia a global public health priority[4], so Scotland's new dementia strategy is everyone's story.

We are committed to upholding rights, civic participation, social inclusion, support and care for people living with dementia in Scotland now and in future. We need to consider how the support we provide, the places we design, the homes we build and the communities we create allow us all to live happy, meaningful and connected lives, regardless of age or stage of dementia.

---

[4] World Health Organization information on Dementia

We want this 10-year strategy to **go further** than before.

In Scotland, there is a proud history of dementia support. In 2010, we were one of the first countries to publish a dementia strategy and input from people with lived experience is long-established. We acknowledge the positive contribution of partners and we want this 10-year strategy to go further than before. Our engagement highlighted the wide, expanding and active dementia community here and the variation in the support people access. Some approaches are longstanding, whilst others have developed more recently. For people to live as well as possible with a dementia diagnosis, we need to harness and coordinate all of this. Indeed, enabling a more inclusive conversation on dementia that reflects everyone's story is something that this strategy has sought to embed from the outset.

Good progress has been made but there is more to do. By working together, we can make better connections, find new opportunities and increase the impact of our work to ensure anyone in Scotland can live as well as possible with dementia.

A note on language about unpaid care: Throughout this strategy we have used the term 'care partner' concurrently with unpaid carer to describe people who have an unpaid caring role (unpaid carer/ care partner). Members of our National Dementia Lived Experience Panel expressed a preference for the term care partner over the term 'unpaid carer'. Those living with a diagnosis of dementia identified with the term care partner as one that values them as equal citizens, progressing through dementia with a spouse, partner, family member or friend who supports them without pay. Panel members who have a caring role agreed the term as being reflective of a more equal relationship with the person they support, something they value and want to maintain, despite the significant challenges dementia can present. Recognising this as a partnership is important in upholding and maintaining choice and dignity for those with a diagnosis and those who support and care.

However, we know that the term [unpaid] 'carer' has a specific role in legislation and policy, that it covers all different types of caring circumstances and that it can be very difficult for people to recognise themselves as carers (or be recognised). We also know that there is much more work needed to ensure that people providing care to someone, unpaid, are truly recognised as partners in care. But we want to respond to the views of those with lived experience and build on this discussion, and therefore would like to use this strategy to kickstart a longer national conversation on what is the right term for unpaid caring moving beyond 2023 – to uphold the rights and equality for all and respond to the lack of recognition and inequality that caring can cause.

Vision

Vision

Our vision is of a Scotland where people living with dementia have their strengths recognised, their rights upheld, and where they, their families and care partners/unpaid carers are supported to live an independent life, free from stigma and with person-centred treatment and care, when and where they need it.

The difference we want to make:

1. Dementia is recognised in public health and in practice as disease of the brain that affects a person's whole life and those close to them. Diagnosis can bring significant mental health and wellbeing challenges that need to be acknowledged and addressed to ensure a person's rights are upheld.
2. Policy makers, support and service providers, communities and society all have an understanding of dementia, including the importance of prevention and early detection, and are inclusive of people living with dementia, able to engage and respond confidently and appropriately, creating environments that enable people to live well with dementia.
3. People living with dementia and their care partners/unpaid carers have equity of access to high quality, information and advice, evidence-based treatment, care and support when and where they need it, including dementia-specific palliative care, and have access to practitioners with appropriate dementia care knowledge and skills.
4. The human rights of people living with dementia and their care partners are upheld throughout their dementia journey.
5. People are supported by a skilled and knowledgeable workforce that accesses the highest quality dementia specialist education and training and implements evidence-based, including trauma-informed, practice.

Scan Here for Gerry's Story

Gerry's story

Gerry talks about his perceptions about dementia, his dementia diagnosis, how he felt afterwards and how it affects him and his experiences connecting with other people living with young onset dementia.

My name is Gerald King but everybody calls me Gerry. I am 59 years old and live in Glenrothes, Fife.

As a result of the diagnosis, I was retired from work, I had to surrender my driving licence and lost many of my friends and liberties that many of us take for granted. After the initial difficulties of accepting and learning how to best cope with the diagnosis, with help, I picked myself up and I worked hand in hand with Fife Councils Dementia Friendly team to making Fife Dementia Friendly by taking Dementia Awareness presentations to all corners of Fife. Most recently we have been doing a lot of intergenerational work by taking our Dementia Awareness presentations into a number of Fife schools.

I am a founding member of a peer-to-peer support group in Fife called STAND. We are a peer lead charity that provides peer-to-peer support to people newly diagnosed and living with mild to moderate stage dementia and their wives, husbands, and families. Our ethos is to empower people living with early and mid-stage dementia to be the best they can be and to support them to live well with dementia.

Principles

Principles

In developing the strategy, and as we implement it, we will:

Promote and monitor **inclusion,** building working relationships with those who have previously felt excluded from the dementia community including people with a comorbidity such as Parkinson's disease, people with Down's Syndrome or a learning disability, minority ethnic communities, those for whom English is not their first language, people with hearing or sight loss, lesbian, gay, bisexual and transgender/transsexual (LGBT)+ communities and marginalised communities throughout Scotland.

- Monitor the impact of the strategy on groups that face **additional barriers**
- Continue to be informed by **evidence** and research about dementia
- Collate, analyse and publish **data** on the impact of the strategy
- Continuously **listen, learn and adapt to the changing environment** the strategy seeks to deliver within
- **Strive to promote and uphold Human Rights Principles** through everything we do alongside our partners, including how we influence the education, training and professional development of the workforce
- Take a human **rights-based approach** through the dementia journey and for all types of dementia.

These guiding principles are set out in the internationally recognised PANEL approach[5]:

Participation

Everyone has the right to participate in decisions which affect them. Participation must be active, free, and meaningful and give attention to issues of accessibility, including access to information in a form and a language which can be understood.

Accountability

Accountability requires effective monitoring of human rights standards. For accountability to be effective there must be appropriate laws, policies, administrative procedures and mechanisms of redress in order to secure human rights.

Non-discrimination and equality

A human rights-based approach means that all forms of discrimination must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most vulnerable situations who face the biggest barriers to realising their rights.

Empowerment

People should understand their rights, and be fully supported to participate in the development of policy and practices which affect their lives. People should be able to claim their rights where necessary.

Legality

The full range of legally protected human rights must be respected, protected and fulfilled. A human rights-based approach requires the recognition of rights as legally enforceable entitlements, and is linked in to national and international human rights law.

---

[5] Scottish Human Rights Commission - Human Rights Based Approach

The UN Convention on the Rights of Persons with Disabilities (UNCRPD)[6] builds on and expands the European Convention on Human Rights (ECHR)[7] with regard to disabled people. This strategy seeks to uphold the Convention on the Rights of Persons with Disabilities (CRPD) Articles with particular detail relating to:

- The same access to quality health services as other people
- Community services and facilities are available on an equal basis
- Supported decision-making, as opposed to substituted decision-making
- Choice and control about where people live and an equal choice to both an inclusive life and access to support services where they live
- The right to independent advocacy including in relation to future care planning.

---

[6] United Nations Convention on the Rights of Persons with Disabilities (CRPD) - 2008

[7] European Court of Human Rights - European Convention on Human Rights

Scan Here for Ron's Story

Ron's Story

Ron talks about his experience when he was first diagnosed and how meeting other people with dementia made a difference and Karen talks about all the creative work Ron has been doing since.

My name is Ron and I live on the Isle of Lewis in the Outer Hebrides. I was diagnosed as having a cognitive impairment over four years ago. My last psychiatrist was in the process of deciding whether my dementia was vascular or Lewy bodies when he left and my new psychiatrist is starting from the beginning, my third start.

This has left me with a real interest in how the system addresses dementia in the Pre-Diagnostic phase, the one year post diagnostic support phase and more importantly what happens when the one year is over. I have written two plays about dementia and made a number of videos with my partner about living with dementia.

I am the chairperson and a founding member of Deepness Ltd, an organisation where 9 of our 12 board members are people living with dementia. Deepness set up Deepness Dementia Radio, an online radio station for people with dementia by people with dementia. We currently have 220,000 listeners per year and growing. I believe that by joining this panel I will be able to contribute both critically and positively to our dementia community.

Equalities

In developing this strategy we met with, talked to and heard from hundreds of people across Scotland who are affected by dementia. We heard the unique ways younger people are affected by a diagnosis; how addiction exacerbates dementia for those affected; the difficulties faced by people with sensory loss including from the deaf community and those with sight loss, and how people with a learning disability or Parkinson's disease can feel excluded from the dementia community that has developed and grown its voice in Scotland.

65% of people living with dementia are women. 60%-70% of those caring for someone with dementia are women and women are more likely to care for someone for more than five years than men are[8]. Women, particularly those who are caring for someone, told us about the assumptions made that they would adopt the main caring role resulting in the loss of their own identity, careers and financial security. Evidence, beyond age factors, about why women are more likely to develop dementia is growing and we will reflect this as the strategy is delivered.

However, we know there are voices we didn't hear enough from, especially those from minority ethnic communities, and we are committed to addressing this through improved connections with community organisations.

Through the life of this strategy, we will have an enhanced focus on equalities issues, working with others to help to minimise the structural barriers to participation, diagnosis, treatment, support and care, regardless of ethnicity, race, sex, gender reassignment, sexual orientation and additional disability or neurodivergence. We include a focus on economic disadvantage and the specific issues for remote island and rural communities.

---

[8] Alzheimer's Research UK - Dementia Statistics Hub

The Building Blocks

The Building Blocks

This strategy builds on more than two decades of progress in dementia policy, development and investment. The timeline below shows significant milestones.

2001

Scottish Dementia Working Group (SDWG) established. First dementia lived experience group in the world.

2007

Scottish Government makes Dementia a **national clinical priority.**

2009

Charter of Rights published from work of Parliamentary Cross Party Group on Dementia, Scottish Human Rights Commission and Alzheimer Scotland, informed by a series of national consultation events with people with lived experience.

2010

First National Dementia Strategy published 2010-2013 and first Alzheimer Scotland **Dementia Resource Centre** opens in Dundee.

2011

Standards for Care in Dementia in Scotland published and **Promoting Excellence** Learning and Skills Framework, to support the delivery of the Standards, published. The **National Dementia Carers** Action Network was established by Alzheimer Scotland.

2013

Second National Dementia Strategy, including the **first post diagnostic standard** in the world, published. 2013 also saw the establishment of the **Life Changes Trust**. Established with a £50 million, ten-year endowment from the National Lottery Community Fund, the Trust invested in 318 projects focussed on people living with dementia and their unpaid carers, to have a say in their own lives. The **National Dementia Consultants Programme** was also established in 2013 to support the implementation of rights-based dementia standards in hospitals across the country and the Scottish Dementia Research Consortium was established by Alzheimer Scotland; a network of dementia researchers, policy makers and people living with dementia.

2014

The Glasgow Declaration was signed at Alzheimer Europe's conference in Glasgow. The Glasgow Declaration called for the creation of a European Dementia Strategy and national strategies in every country in Europe. The signatories also called upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

2016

The Scottish Government was a key partner in the **European Union second Joint Action on** Dementia. The action was led by the Scottish Government on behalf of the United Kingdom, with participation from Bulgaria, France, Greece, Italy, Netherlands, Norway, Poland, Romania, Spain and the United Kingdom.

2017

Third National Dementia Strategy published, launching the **Connecting People: Connecting Support**, the first ever National Allied Health Professionals Dementia Workforce Framework, based on rights-based, person-centred principles and integrating the contribution of AHPs to dementia care. 2017 also saw the launch of the Care Inspectorate's **My Life, My Care Home,** establishing rights based dementia standards for inspection and publication of **Dementia Pathways** guidance to the housing sector on supporting people living with dementia.

2018

Proposals to modernise **Community and Specialist Dementia Inpatient Care in line with rights based principles established**. 2018 also saw the post diagnostic support (PDS) **Quality Improvement Framework**, a benchmark for best practice in post diagnostic support (PDS), created by Healthcare Improvement Scotland's Focus on Dementia Team.

2019

Age Scotland establishes **About Dementia Project**, engaging people living with dementia and their carers to have a meaningful impact on policy and practice. **Kirrie Connections**, Scotland's first **Meeting Centre**, opens in Kirriemuir. **Housing and Dementia Framework**, toolkit for housing organisations to better support people living with dementia, created by Chartered Institute of Housing Scotland (CIH), Healthcare Improvement Scotland (HIS) iHub and Alzheimer Scotland, launched.

2020

The Scottish Government's **Dementia COVID-19 Action Plan** was published in recognition of the disproportionate impact the pandemic was having on people living with dementia and their families.

2021

Sponsored by the Scottish Government, Scotland's first **Brain Health and Dementia Research Strategy** launched.

2022

The Scottish Government's first **Dementia Lived Experience Panel** established as part of the governance structure for the development and delivery of a new national dementia strategy. **The Life Changes Trust** concludes leaving a legacy of **11 funded projects** led by Age Scotland's **About Dementia**. The Scottish Government report on excess Deaths from Dementia and Covid-19 published.

2023

New National Dementia Strategy launched.

Connecting to a Wider Policy Landscape

Connecting to a Wider Policy Landscape

Dementia affects a whole person and the people around them, so this strategy has to connect and align with other policies and frameworks together with relevant legislation. This includes but is not limited to:

- "20 minute" Neighbourhoods
- Age, Home and Community
- Care and Wellbeing Portfolio
- National Carers Strategy , Carers (Scotland) Act 2016 and other carer legislation and policy
- Creating Hope Together: suicide prevention action plan 2022 to 2025
- Health and Social Care: Data Strategy
- Development of the National Care Service (NCS)
- Digital Health and Care Strategy
- Getting it Right for Everyone (GIRFE)
- Housing to 2040
- Learning/intellectual disability and autism: transformation plan
- Mental Health and Wellbeing Strategy
- My Health, My Care, My Home, the new Framework for Care Homes
- National Planning Framework (NPF) 4

- Neurological Care & Support: Framework for Action 2020-2025
- Palliative and End of Life Care Strategy
- A Scotland for the Future: opportunities and challenges of Scotland's changing population strategy
- Public Health policy
- Rehabilitation Strategy
- Review of Housing for Varying Needs
- Scott Review - Scottish Mental Health Law Review
- See Hear Strategy
- Self-Directed Support (SDS)
- The Scottish Intercollegiate Guidelines Network (SIGN) Guidelines (To be published in later in 2023.)
- The national Social Isolation and Loneliness Strategy: Recovering our Connections 2023 to 2026
- The Older People's Framework: A Fairer Scotland for Older People: framework for action
- The values and outcomes of Scotland's National Performance Framework
- National Transport Strategy
- Women's Health Plan

Willy’s Story

> **“We are people who still have a zest for life, we still laugh, we still take joy in things.”**

Since being diagnosed a year ago I have become involved with peer-to-peer support groups, and believe that people living with brain disease have an important role to play in supporting others in the same situation. Whilst carers and professionals can be well informed and well meaning, they cannot know what it is like to be diagnosed with a disease around which there is still much misunderstanding and stigma.

I have tried through making a series of YouTube videos, through starting a podcast and using social media to shine a light on some of these issues, through the prism of my own experience. I feel something of an obligation to use the professional skills I accrued whilst working as a journalist to help further people’s knowledge about dementia, and to challenge some of the commonly held misconceptions. Luckily I am at an early stage of illness, so am able to do this – but others at a later stage need to have their voices heard too. I’m interested in ways that could be developed to help them.

Scan Here for Willy’s Story

A More Connected Experience

A More Connected Experience

The isolation many experience **suggests there is more to do** to make society more dementia inclusive.

Scotland is recognised as among global leaders in dementia policy, from our commitment to post diagnostic support (PDS) to the establishment of the Scottish Dementia Working Group (SDWG), the first lived experience campaigning group which has inspired people living with dementia across the globe.

Great strides have been made in brain imaging and accuracy of diagnosis, resulting in the ability to deliver accurate and timely diagnosis and ingoing research has taken us to the cusp of a new generation of treatments.

However, these successes are not yet the experience of everyone living with dementia and their care partners. Lived experience can be lonely, isolated, affected by stigma; with loss, trauma and financial hardship experienced by many. Significant waiting times for assessment and the absence of a seamless diagnostic pathway acts as a barrier to early diagnosis and treatments and inconsistent approaches to commissioning and delivery of post-diagnostic support (PDS) means that people may not receive the support they need, when they need it.

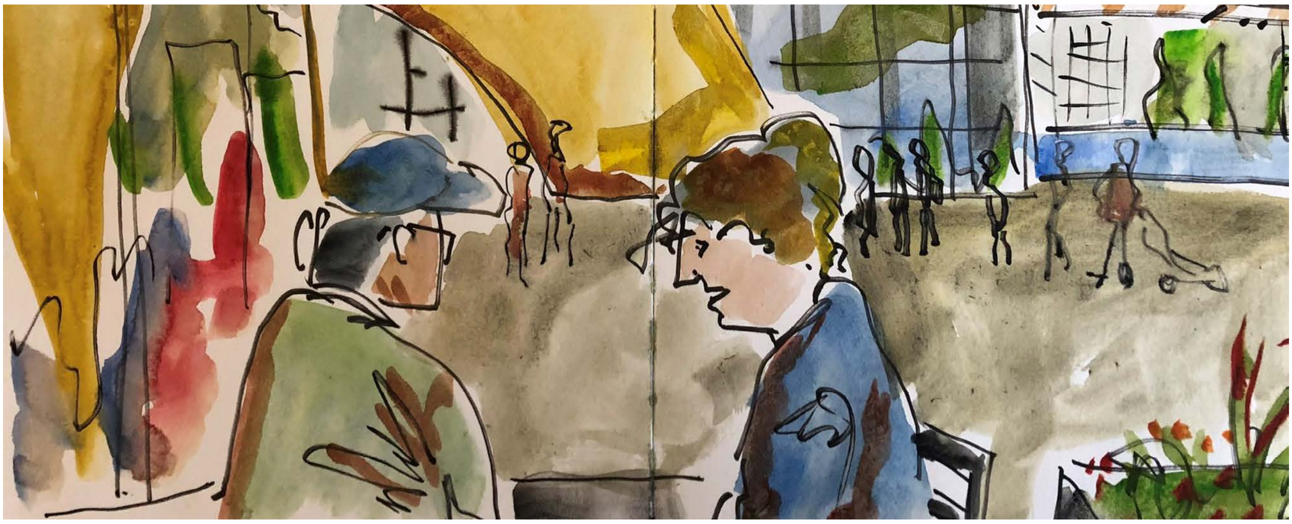
The mental health of those diagnosed with dementia is not always fully recognised. This includes an increased risk of suicide, particularly for those diagnosed when under 65. The isolation many experience suggests there is more to do to make society more dementia-inclusive. Scottish Intercollegiate Guidelines Network SIGN guidelines offer both clinical and human interventions to support mental wellbeing.

For many people, achieving clarity of information, guidance and support about all aspects of life, from health to housing; social care to community participation; arts and cultural opportunities and support for those who are in work when they are diagnosed, is experienced as a confusing and inconsistent maze to be navigated.

For younger people receiving a diagnosis, defined as those under 65, the disruption to work, family life and financial independence adds additional complexity and pressure.

We recognise that people living with dementia and their care partners/unpaid carers are experts by experience; best placed to know what they need and when they need it. Support to develop this expertise can help avoid stress, struggle and the growing sense of loss that a dementia diagnosis can bring.

Acknowledging the expertise of lived experience reflects both human rights principles and person-centred support which places the person at the centre, as an expert in their own experience.



Person-Centred

With an emphasis on doing with rather than doing to, high quality person-centred treatment, support and care is evident in both individual and group settings, with people not only active in their own support and care but also in the design and delivery of services, ensuring it meets their needs and ambitions.

From diagnosis to end of life, our ambition is that all dementia diagnosis, treatment, support and care in Scotland is high quality, person-centred and trauma-informed in all settings, which includes:

- Ensuring people have access to information and advice on prevention and early detection of dementia
- Ensuring that culturally appropriate dementia information and services for people from marginalised communities, including those from ethnic minorities and LGBT+ communities, are available and accessible
- Recognising and respecting people's rights and values and putting people at the centre of care
- Making sure people have equity of access to appropriate quality treatment, support and care that they need, when and where they need it
- Maximising the reach and impact of post diagnostic support (PDS)
- Maximising equal access to Self-Directed Support (SDS) that increases choice of support and care

- Ensuring that targeted supports are developed and implemented to meet the specific needs of communities with additional needs including those with learning disabilities and sensory loss
- Ensuring people are physically comfortable and safe, recognising that housing security and sustainability and the ability to meet rising living costs are not assumed
- Emotional, practical and financial support for care partners and families including bereavement support
- Ensuring people get all the information they need, in a way that is accessible for them, to make informed decisions about their treatment, care, support and housing options
- Ensuring that people have access to dementia-specific palliation.

From here we describe what a more connected approach to dementia can be and what we will work with our partners to achieve.

Scan Here for Irene & Allan's Story

Irene & Allan's Story

Hopes and Dreams for the new dementia strategy for Scotland.

Irene: No one should feel so desperately and utterly without purpose or value as I was made to feel. No one should feel so isolated and unconnected to the world around them as me and my family did. No one should rely on good luck to find the right support. If I can do something to prevent this, I will. Everyone on the other hand should know the support and joy of the professionals and organisations and volunteers who gave me back my life. A different life but in so many ways a better one. I'm really looking forward to doing what I can when and where I can to realise this.

Allan: I am classed an unpaid carer for my partner who was diagnosed with Young Onset Dementia 7 years ago when she was 53. I do not see myself as her carer but her support when she needs it.

Since the diagnosis we have learned how I can help her to live as full a life with meaning and purpose. After the initial diagnosis it was really hard to come to terms with what this would mean; being one of the founder members of STAND has led us to meet a number of individuals and organisations that can assist us to fulfil our aim and to ensure that my partner can live a life filled with meaning and purpose and in fact help spread the message that there is life after diagnosis, albeit a different life. I am an active member of STAND and following the registration of the group as a charity I have taken the role of a Trustee.

Challenging stigma

Stigma affects our perceptions and understanding of dementia through:

- The origins of dementia and the language used until recently; words such as 'senile' which are disempowering and negatively impact on all aspects of people's wellbeing, including presenting for diagnosis and support
- Continued lack of understanding of dementia as a progressive neurological condition rather than an inevitable consequence of ageing
- The lack of effective drug treatments which, at its worst, may affect clinicians' motivation to diagnose
- Assumptions about the value and rights of people living with dementia, experienced through loss of employment; withdrawal of driver's licence at diagnosis and the continued assumption of reduced ability and capability.

The difference we need to make

We know that people living with dementia can live full and meaningful lives; active, creative, purposeful and connected to community. Through the life of this strategy, we want to lead a sea change in how dementia is understood and experienced, one where:

- Public awareness and understanding about brain health and dementia is raised and perceptions are changed
- Fear about presenting for and receiving a dementia diagnosis is reduced

- The workforce across health, social care and housing increases its understanding of dementia and is better connected
- A diagnosis of dementia is followed with clear, consistent quality information and support options including post diagnostic support (PDS), rehabilitation and other supportive treatments
- Employers have greater awareness of dementia and its impact on employees receiving a diagnosis and those with caring responsibilities, demonstrated by their sign up to programmes such as Carer Positive and Dementia Friends.

Martin's Story

> **"What I'd like to see in Scotland is everyone in society to see dementia is just another illness and for there to be no stigma."**

I am loud and proud about having dementia, not affiliated to any national dementia organisation. I do a lot of true Co-Research from helping with funding applications onwards. I am also a trustee of two national charities, outside the dementia world as I believe people with dementia should be fully inclusive members of society, not placed in dementia-only buildings.

Scan Here for Martin's Story

Brain Health

In 2019 The Scottish Government commissioned Brain Health Scotland, led by Alzheimer Scotland, to empower everyone in Scotland to protect their brain health and reduce their risk from diseases that lead to dementia. This reflected the increasing evidence that up to 40% of dementias are affected by risk factors that can be modified, similar to the risk reduction messages now widely understood about some heart disease and cancers[9].

Public and professional interest in brain health has accelerated significantly, as has the scientific and medical understanding of disease processes over the life course. Brain Health Scotland is responding to this by leading development of preventative health services which aim to provide early disease detection and personalised risk reduction plans. The initiative also delivers a health literacy approach that engages the people of Scotland with brain health principles, from primary education programmes to broader public awareness campaigns.

Scotland's first Brain Health and Dementia Research Strategy was published in July 2021, led by the Scottish Dementia Research Consortium and supported by the Scottish Government. The main focus of the strategy is to test innovative services and facilitate relevant high quality research that translates rapidly into health and social care practice as effectively as possible.

---

[9] The Lancet Commission - Dementia Prevention, Intervention, and Care Report - 2020

The difference we need to make

By supporting the work of Brain Health Scotland and the key messages of the Brain Health and Dementia Research Strategy, we will contribute to a better understanding of the complex impact of dementia on our brains and promote key messages about how to protect brain health throughout life.

Public awareness that some forms of dementia can be delayed or prevented by modifying life circumstances and lifestyle is increased.

People living with dementia and care partners have opportunities to participate in research, including informing and designing research.

Options for developing robust, multi-disciplinary and multi-agency care pathways, learning from research and practice, are explored.

Specific populations known to be at increased risk are supported to engage with brain health services.

Connections with, and support to, Scotland's research and academic communities will continue to inform the delivery of this strategy.

We need to support people with the fear about going for diagnosis.

Diagnosis

An inclusive, rights-based, accessible and timely diagnosis, with the option to have someone close present, is an important start to someone's dementia experience. This is particularly relevant for people with sensory loss, including hearing loss where use of British Sign Language (BSL) is required. We need to support people with the fear about going for diagnosis. To help do this the process needs to be accessible, should consider regional differences and best practice, and be person-centred. The experience should be supportive and sensitive, and people should be encouraged to seek diagnosis as soon as possible to maximise their opportunities to live as well as possible with dementia.

Our ambition is that the diagnosis is both person-centred and human rights based including:

- Ensuring that a person-centred diagnosis, one that is timely, communicated sensitively and recognises the person's goals and preferences, is available for every person with dementia including alternative pathways for diagnosis for people where a regular diagnosis is not appropriate, such as people with learning disabilities
- Individuals and their care partners/unpaid carers and family are supported up to, and throughout the process, recognising the mental health and wellbeing implications of receiving a dementia diagnosis
- Ensuring diagnosis is available and accessible irrespective of age, stage, sensory loss or where people live

- Ensuring stigma and fear around diagnosis are reduced and more people are diagnosed at an earlier stage
- The most effective models for diagnosis are understood and adopted
- Individuals will be respected, their concerns taken seriously and will be assumed to have capacity to ask for and understand a dementia diagnosis.

The difference we need to make

Access to timely, person-centred diagnosis that is consistent and equitable throughout Scotland but allows for flexibility to suit the locality. This includes diagnosis delivered by a broader range of those professionally qualified than current arrangements and delivery of diagnosis in a wider range of settings such as community hubs and care homes.

At the point of diagnosis people will be referred, or directly connected to, post diagnostic support (PDS), in whatever form each person chooses and is relevant to the stage of their disease.

People will be offered a treatment plan with arrangements for regular monitoring and review detailed.

People undergoing diagnosis and their care partners/unpaid carers or family have access to emotional support, acknowledging that there is often heightened anxiety or confusion in the lead up to the prospect of a formal diagnosis, as well as mental health consequences and trauma as a result.

A 'biopsychosocial' approach to diagnosis and treatment, recognising that, whilst dementia is a progressive brain disease, it affects the whole person.

Health checks for people with a learning disability include early screening for cognitive changes.

Audrey's Story

"It's OK Gran, we ken your brain's broken"

My name is Audrey Ross. I was diagnosed with young-onset frontotemporal dementia at the age of 54. My hobbies include walking my dog Bouncer, art, crosswords, jigsaws, quizzes and nature. Being invited to join the Scottish Government Lived Experience Panel was an absolute honour and pleasure for me. Involving people with lived experience of dementia also gives that person a sense of purpose.

Scan Here for Audrey's Story

Awareness of the service is also variable and so extending the awareness and reach of this valuable right is a priority.

Post Diagnostic Support

Post diagnostic support (PDS) has been Scotland's flagship policy in dementia for 10 years. However, we know that less than half of those who are entitled to post diagnostic support receive it. Awareness of the service is also variable and so extending the awareness and reach of this valuable right is a priority. The growth of peer support networks, of Meeting Centres, Dementia Friendly Communities and other community supports can all contribute to our ambition to ensure everyone who receives a diagnosis of dementia can access person-centred post diagnostic support. This is replicated in professional networks such as Healthcare Improvement Scotland (HIS) led post diagnostic support network of service managers across Scotland.

The evaluation of the Primary Care Dementia Innovation Sites demonstrated the importance and benefits of connecting post diagnostic support with primary care, from streamlining support for people to seek and receive a diagnosis, to receiving post diagnostic support, to being able to liaise with the general practitioner (GP) to update Key Information Summaries with personal planning and anticipatory care planning information.

The difference we need to make

Post diagnostic support is available and accessible to people for a minimum of 12 months, irrespective of where they live or how old they are.

Post diagnostic support is person-centred and trauma-informed, based on what people want and need at the time they access it.

People can choose how and when to take up their post diagnostic support once they have been informed of the options that are available in their locality. This may include the 5 Pillar Model of Post Diagnostic Support (PDS) delivered by an Alzheimer Scotland Link Worker, participation in a Meeting Centre, peer-led support as part of a Dementia Friendly Community or post diagnostic support delivered by an Allied Health Professional (AHP), Community Psychiatric Nurse (CPN) or other health or care professional. This recognises the central role community networks, health and social care professionals and organisations can play in developing and delivering person-centred post diagnostic support.

Understanding of the purpose, availability and acceptance of post diagnostic support is included in workforce development programmes.

There is equitable access to post diagnostic support irrespective of factors such as the person's age, disability, ethnicity, residence and ability to use technology to engage with support.

Post diagnostic support (PDS) services are better connected to primary care.

Post diagnostic support should be relevant to the person's stage of their dementia, for example people may have more moderate or advanced dementia at the time of their diagnosis and so may benefit more from a care co-ordination model of support including Alzheimer Scotland 8 Pillars Model or Advanced Model.

Post diagnostic support services are better connected to primary care.

Post diagnostic support includes self-management support that empowers people to manage their health and wellbeing, day by day, as effectively as possible, including via peer support.

Post diagnostic support data gathering is extended to include the method of post diagnostic support offered and chosen as well as qualitative outcomes delivered via post diagnostic support.

Healthcare Improvement Scotland's (HIS) iHub's Quality Improvement Framework, which includes detail about key elements of quality post diagnostic support such as guidance about Power of Attorney, is universally adopted as the quality measure for post diagnostic support.

Living the Best Life Possible

The end of post diagnostic support (PDS) should represent a transition to connections and support that enable people to live the best life possible, including being able to remain in their own home for as long as they want to. Whilst this may already be in place where Meeting Centres and Alzheimer Scotland Link Workers have connections to local services, this should be the norm at the end of post diagnostic support (PDS).

We know that homes that are designed or adapted to support daily living along with families and communities, supplemented by well co-ordinated person centred health and care support, are core to achieving this.

The Hospital Experience

Currently, one in four people at any one time in hospital will have dementia. People living with dementia often experience longer hospital stays, delays in leaving hospital and reduced independent living[10]. The pandemic has had a disproportionate effect on people with dementia in hospital.

Though delirium is increasingly recognised as a risk factor for developing dementia, it is also recognised as a risk for worsening dementia. It is common in hospital patients and for people living in care homes and much more common for people when they become ill. It can be mistaken as worsening dementia and as such, is a source of distress for family members. There are evidence-based non-pharmacological measures around which partners have built an evidence base.

A small number of people will also be admitted to specialist dementia wards. Research[11] tells us that the lack of integration, including communication and support to enable a person's preferences to be upheld, between these specialist hospital environments and wider social care, health and housing systems can result in people becoming 'stuck' in hospital, missing a safe return to home or transition to a more appropriate community setting.

---

[10] NICE- Hospital Care - dementia

[11] Scottish Government - Transforming specialist dementia hospital care: independent report - 2018

Evidence shows that effective care co-ordination can lead to better outcomes for people living with dementia and their care partners, such as fewer attendances at Accident and Emergency and fewer hospital admissions. The 2022 independent evaluation of Healthcare Improvement Scotland's (HIS) whole system care co-ordination programme stated the Programme should serve as a good practice example for Dementia Care Co-ordination nationally in Scotland.

Healthcare Improvement Scotland (HIS), Mental Welfare Commission (MWC), Scottish Patient Safety Programme (SPSP) in Acute Care and national frailty programmes continue to highlight the need for support to improve person-centred planning in hospital settings and the engagement of care partners. This approach to care planning supports the de-escalation of stress and distress, to avoid re-admission, or admission to specialist dementia units, enabling timely discharge and effective transitions of care.

The difference we need to make

People living with dementia have equity with other diagnoses in accessibility to high quality treatment and support to live the best possible life with dementia.

People living with dementia and their care partners are able/supported to stay as connected and active in and with their community as they choose.

People with dementia and their care partners have the support of multidisciplinary and multiagency teams to co-ordinate their care and support and ensure their general health and mental health is supported. This includes regular follow-ups with their general practitioner (GP) practice as well as clarity of communication between services.

Community networks and organisations, such as Meeting Centres and Resource Centres, are accessible, inclusive and sustainable, recognised for their role in supporting people and their families, particularly in the early stages of dementia.

People are supported to make informed choices about their home, including how to plan a timely move or stay in their own home for as long as possible, with guidance about how to make suitable home adaptations.

Arrangements to access home adaptations are clear and accessible, regardless of tenure.

Reflecting Getting It Right For Everyone (GIRFE) principles and Dementia Scottish Intercollegiate Guidelines Network (SIGN) guidelines, people are supported to navigate through treatment, support and care that will uphold their quality of life and what's important to them, which might include: employment; legal procedures to express preferences; their home and future housing options including adaptations; peer support and community networks, arts and culture; staying well, both physically and mentally; care at home and care when they can no longer live at home.

People are informed about Self-Directed Support (SDS) options when their need for care is identified, recognising the role of care partners in supporting a direct payment and including the purpose of Option 2 to maintain choice and control when capacity is reduced.

The developing Integrated Health and Care Record is used to better co-ordinate support and communication about and between services.

Support and care is a partnership between the person living with dementia, their care partner and the identified professional, throughout the dementia experience.

Standards of Care for Dementia in Scotland, Scottish Intercollegiate Guidelines Network (SIGN) Guidance, Getting it Right for Everyone (GIRFE) and the need for anti-discriminatory practice and cultural sensitivity are familiar to practitioners, service planners and providers and used as the benchmark for commissioning and good practice across housing, care, health and community services. Sector-based workforces access and understand evidenced based biopsychosocial interventions as part of dementia education and training.

Scotland's 10 Dementia Care Actions are adopted as a benchmark for good practice in dementia treatment and care in hospitals.

Across health, social care and housing we maximise the use of new and emerging health and technology innovations, including citizen tech such as Alexa, to help enhance people's lives, complementing the crucial importance of skilled and compassionate human interventions.

Advanced dementia

Advanced dementia is associated with the later stages of the illness when the complexity and severity of dementia-related changes in the brain lead to recognisable symptoms associated with dependency and an increase in health and social care needs and risks. Scotland's national dementia Scottish Intercollegiate Guidelines Network (SIGN) guidelines detail that people at this stage need expert health care, more intensive social work assessment and support, nursing and palliative care assessments together with insights from carers and others, particularly when the person has difficulty communicating their own needs and emotions. Advanced dementia involves living, sometimes for years, with advanced illness and multiple health conditions and the advanced dementia continuum includes the terminal stages of death and dying.

The transition to, and the experience of, advanced dementia is both complex and challenging. In the later stages of advanced illness, healthcare needs are increasingly complex and palliative.

The prevalence of advanced dementia among the dementia care home population based on evidence reviews is around 40%

The number of options that support family caring begin to narrow. For example, people with advanced dementia are often discharged from standard day care which is not designed for their complex needs. For families who have relied on this there may be no suitable alternative. Advanced dementia day care is possible and there have been successful pilots in Scotland, such as Alzheimer Scotland's Enhanced Sensory day care in Dumfries.

For someone with advanced dementia, communicating with and understanding others becomes extremely challenging. They may feel very isolated and even scared but may not be able to make others aware of how they are feeling.

We know that approximately a third of people with dementia in Scotland are in residential care; and those residents make up about 65% at least of the overall care home population[12].

The prevalence of advanced dementia among the dementia care home population based on evidence reviews is around 40%[12]. The application process and cost of a care home are a source of confusion and concern to families and one that, whilst not unique to dementia, disproportionately affects people living with dementia and their families.

While we have good information on the high percentage of people with advanced dementia in care homes, we need more information on issues like how many people at this stage of the condition live at home, alone and/or without close family support, which could mean that symptoms are advancing without being identified.

---

[12] Care services - Dementia Statistics Hub

The difference we need to make

Specialist dementia training, benchmarked against the Promoting Excellence Framework, for staff working in housing, care at home services, care homes and hospital settings is developed and delivered from induction to Continuing Professional Development, appropriate to role.

Training in dementia-specific palliative care and access to palliative care guidelines are available to all health and care staff caring for people with dementia.

Care pathways for advanced dementia are informed by, and connected to, Getting it Right for Everyone (GIRFE) and the wider Scottish Government Care and Wellbeing Portfolio programme.

Enhanced level knowledge and skills are evidenced in Advanced Care Planning processes and plans.

The role of Multi-Disciplinary Teams (MDTs) including dieticians and speech and language therapists in managing common conditions such as weight loss and swallowing difficulties, is embedded in care planning and carer support.

Non-pharmacological interventions may improve cognition, social engagement and quality of life and decrease stress and distress. Reminiscence Therapy, Validation Therapy, Cognitive Stimulation Therapy and, Playlist for Life, form part of education, training and improvement practice in residential settings.

Housing providers and arrangements for housing adaptations become more proactive and preventative to both prevent unnecessary hospital admissions and support people to return home following hospitals stays.

The value of the developing Integrated Health and Care records to improve co-ordination is maximised.

People living with advanced dementia in care homes have equitable access to multi-disciplinary co-ordinated support, including rehabilitation and other Allied Health Professionals (AHP) specialisms, as those living in their own homes.

People living with dementia and their care partners have equity of access to future care planning, palliative care, care around death and bereavement support.

My Health, my Care, my Home based on the Getting it Right for Everyone (GIRFE) is adopted by care home providers as a benchmarking framework for good practice.

Recommendations for the reform of mental health and incapacity law are maximised to empower people living with advanced dementia to express and have their preferences respected in hospital and care settings.

A greater number of long term care options for people living with dementia are explored and costed with partners, increasing choice and control about how long term care needs are met.

Quality, accessible information and advice on the cost of residential care for self-funders is freely available to all people who require it.

Caring

The growth of dementia awareness, dementia-friendly communities and specialist dementia support in Scotland is to be celebrated. Despite these positive developments, unpaid care remains essential to how care is provided in Scotland and we recognise the significant contribution, value and expertise that care partners make on a regular basis.

20% of female carers have gone from full-time to part-time employment.

Scotland's Carers Strategy (2022) indicates that 700,000-800,000 people cared for someone in the years before the pandemic, contributing the equivalent of £13.1 billion of care per year. We already know that 60%-70% of those who care for someone living with dementia are women. This strategy recognises the contribution care partners/unpaid carers make to dementia care, and the impact this has on them personally, as a result.

Caring can be a positive experience, especially for those with good support and connections in place. However, caring for someone can often lead unpaid carers/care partners to experience negative impacts on their health, wellbeing and financial security. 20% of female carers have gone from full-time to part-time employment; others leave work or retire early as a result of their caring responsibilities[13].

Care partners/Unpaid carers have told us that, following a diagnosis of dementia, there can be trauma both for the person living with dementia and their care partner/unpaid carer, including loss of identity, financial freedom and changes to employment. Life can often feel less spontaneous and more isolating for care partners/unpaid carers. 'Living grief' or 'anticipatory grief' are terms used to describe the sense of daily and growing loss experienced when caring for someone living with dementia. This is acknowledged in the new Dementia Scottish Intercollegiate Guidelines Network (SIGN) guidance.

---

[13] Scottish Government - National carers strategy - 2022

The Review of Adult Social Care that informed the early development of the National Care Service acknowledged that ‘unpaid carers are integral to good care, so it is important that we recognise the value they bring and ensure they are included as equal partners in the team of people who together plan and provide support and care. The phrase “nothing about me without me” should apply equally to people who use services and their unpaid carers’. Amongst other recommendations specific to unpaid carers, the report recommends an improved complaints process.

Caring also does not stop just because someone goes into a care home. Attachment, understanding the uniquely personal triggers for stress and distress, knowledge about likes and dislikes and how best to uphold choice are all part of unpaid care that remains wherever the person lives. The proposed Anne’s Law is recognised as upholding the right to a family life for those living in, as well as those caring for, someone living in a care home.

Continued caring also applies to hospitals. It is critical that care partners/ unpaid carers’ rights to be involved in discussions about the ability to provide care at the hospital discharge planning stage are communicated to families and upheld.

The Carers (Scotland) Act 2016 aims to ensure that unpaid carers have choice and control about what care they can provide and can access support, including preventative support, to help ensure the caring role is manageable. The Act extends and enhances the rights of carers to help improve their health and wellbeing, so that they can continue to care, if they so wish, and have a life alongside caring.

Our National Dementia Care Standards mean people who have recently been diagnosed and their carers must be provided with educational resources. However, written information on its own is only a starting point. Care partners/unpaid carers and families need dementia education and practical skills training, delivered at the right time for them with sensitivity. Sensitivity is needed to support complex emotions associated with grief experiences and other psychological impacts. Trauma-informed approaches to education; signposting to navigate care systems; legal and financial mechanisms to support increasingly vulnerable relatives are all core to dementia-specific carer education.

Innovations such as the Carer's Academy in both NHS Ayrshire and Arran and Lanarkshire, developed in partnership with Alzheimer Scotland Centre for Policy and Practice team at University of the West of Scotland offer an example of a co-designed programme of skills training, delivered by a multi-disciplinary and multi-agency team, integrated with local services, that is being adopted more widely across Scotland.

The difference we need to make

Post diagnostic support (PDS) for care partners/unpaid carers as well as people living with dementia covers both practical issues such as housing options and adaptations that support people to stay in their own home, as well as emotional support in recognition of the 'living grief' and bereavement that care partners and families experience.

Following a Self-Directed Support (SDS) assessment, flexible care and support is available to all unpaid carers/ care partners, including ‘day services’ and respite.

Advice and guidance on health and technology innovations and solutions are embedded in post diagnostic support and reviewed with people and their care partners through their progress through dementia.

The knowledge and skills to upskill care partners in therapeutic support held within the Allied Health Professional (AHP) community is widely shared through Meeting Centres, Dementia Resource Centres, Carers’ Centres and Dementia Friendly Community Networks.

People living with dementia and their care partners/ unpaid carers are informed of and supported to access all Self-Directed Support (SDS) options where this is appropriate and identified through the support plan.

Local assessment of care partners’/unpaid carers’ needs must, in common with assessment of the needs of people using social care support services and supports, better involve the person themselves in planning support, including when their caring role ends.

Carer education is recognised as an investment in care partners/families which will support people living with dementia to live the best life possible.

Access to independent advocacy is widely available and publicised across dementia services and community networks.

The right to Scottish Carer’s Assistance is realised by unpaid carers/care partners.

Scan Here for Kenny's Story

Kenny's Story

A care Partner experience with his late father, some of the hidden family issues caused by dementia and the importance of the input from those with lived experience of caring for someone living with dementia.

My father suffered from dementia caused by alcohol (ARBD or Korsakoff's) and over a period of around 10 years.

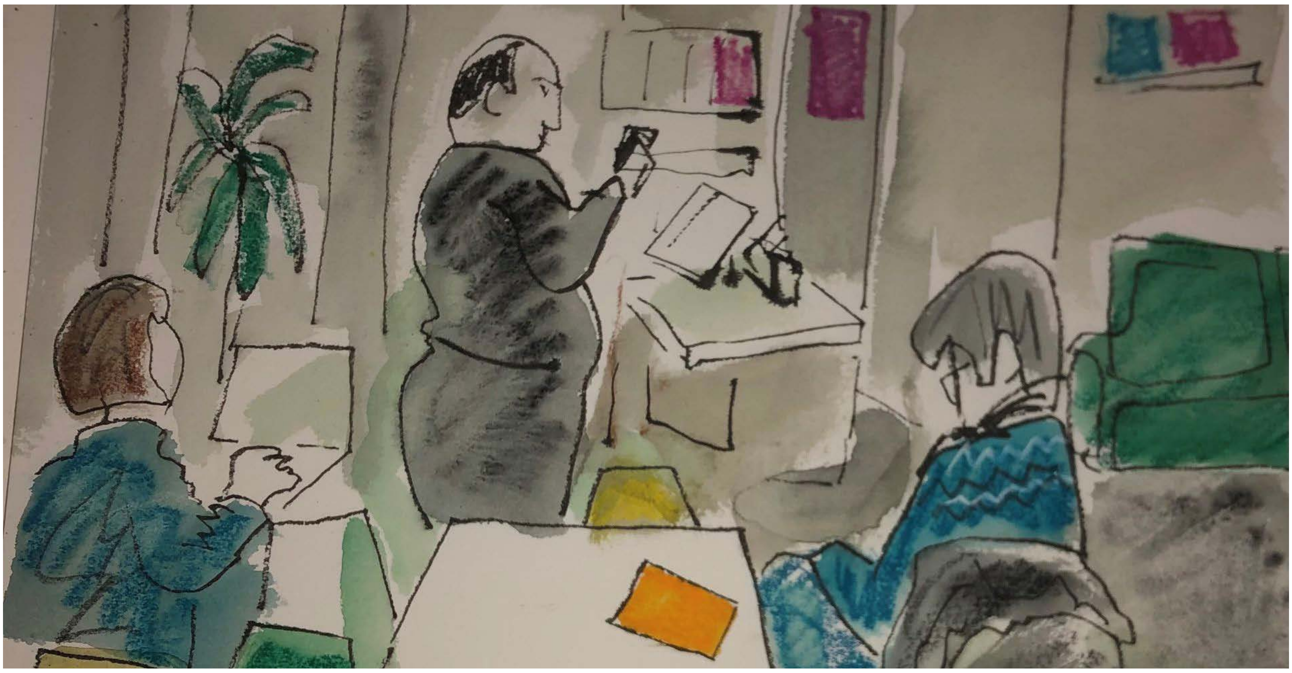
After my father passed away, I also dealt with and supported my sister-in-law who also became ill with dementia. I discovered that her weight loss and other issues were due to not eating well.

The move to get some lived-in experience of dementia is so vitally important, the effects and impacts that it has on the people who are looking after a family member suffering dementia are in my experience quite devastating and can end up in severe mental health challenges and physical wellbeing.

I regret to add that it also affects how that person is then regarded by family members; my father was a great dad to us all when we were growing up in West Pilton. A hard working man who had seven kids who were raised well.

Childhood dementia

There is a growing interest in understanding more about the rare genetic conditions, such as Sanfillippo Syndrome, that affect children and cause symptoms of dementia including memory loss, confusion, trouble concentrating and communicating. Personality and behavioural changes and emotional issues, such as fear and anxiety, also impact children who are affected. Through our engagement with the research community and affected families, we will consider with colleagues and partners how best to engage with and respond to emerging findings.



Enabling Delivery

Enabling Delivery

Governance

For any strategy to be delivered, it requires commitment and shared responsibility from all relevant partners. This is our ‘call to arms’ along with effective and transparent structures for decision making with clear lines of accountability that develop trust and enable ongoing improvement.

The governance structures that have been created to support the development of this strategy have been instrumental in:

- Informing the strategy from a broad base ranging from lived experience to service planners; professional perspectives to policy makers and academia
- Shaping the strategy through a series of detailed round table and follow up 1:1 discussions where knowledge and experience was shared and commitments made to ensure both were reflected in the strategy
- Reviewing, commenting on and contributing to an iterative strategy development process.

In addition, the Scottish Government commissioned an independent research review of evidence delivered by University of Stirling’s Dementia Services Development Centre (DSDC). This independent evidence has both informed this strategy and will continue to inform delivery plans throughout its implementation.

This inclusive approach to governance and governance structures should continue to meet to agree and oversee its delivery. The strategy will also need to call on a broad base of knowledge and expertise as it is delivered. A series of focussed, multi-disciplinary groups will help identify what priorities are included in delivery plans and support their implementation.

All priorities and associated areas of work should be agreed by the governance groups within the following structures, including plans for monitoring and reporting.

Minister for Social Care, Mental Wellbeing and Sport

COSLA Health and Social Care board

Lived Experience Panel

Strategy Delivery Group

Practitioner Advisory Forum

Academic Advisory Forum

Short-term Delivery Groups

supported by short life multi-disciplinary delivery groups focussed on specific action areas and reporting back to above.

Evidence, data collection and analysis

To design and deliver the right support for people living with dementia and their care partners/unpaid carers, we need access to the latest available data and evidence. Access to updated data and evidence, from government, public bodies and academia, focussed in the right areas, will develop our shared understanding of dementia in Scotland. This will allow us to more effectively assess the extent to which our support is targeted in the right areas and is responding to the additional barriers being faced by particular groups and drive forward improvements in support.

For data, this will include quantitative and qualitative evidence covering areas such as:

- How many people are living with dementia in Scotland now, including the type/types of dementia
- How many people have a formal diagnosis
- Number of people under 65 years receiving a diagnosis
- How many people are accessing high quality post diagnostic support, the length of time they receive support and how long they wait from referral to receiving support
- The outcomes it delivers for people and their care partners/unpaid carers, captured by embedding the Healthcare Improvement Scotland (HIS) led Single Quality Question for post diagnostic support (PDS) into service evaluation methods

- The number of people with a learning disability and neurodivergent people diagnosed and receiving dementia-specific support
- Number of unpaid care partners of people living with dementia, the support they receive and the outcome support delivers
- Protected characteristics breakdown
- Housing circumstances such as number of people living with dementia in supported, extra care or sheltered housing; adaptations accessed.

For evidence, we will develop better connections to the lessons from the latest academic literature on dementia and agree ways to proactively identify and share innovation in practice that can support delivery.

It will be for the dementia governance groups to inform, commission and receive reporting on data collection and evidence, actively connecting to the Data Strategy for Health and Social Care, that can be used to assess performance and impact.

Education and Training

Education and Training

Supporting Policy into Practice through Education, Training and Implementation Support

Education can tackle stigma, promote inclusion, enable greater participation and uphold the rights of people living with dementia and their care partners/unpaid carers. It contributes to changes in attitudes and behaviours that are critical to our vision of a strengths-based approach to dementia.

Those providing information, treatment, care and support need access to specialised dementia education and training that helps them better understand the symptoms and experience of dementia to ensure care responds to need and supports overall wellbeing.

We know that someone living with dementia and their care partners/unpaid carers will interact with the health and care system at different points, for a wide variety of reasons. Some people may already have a dementia diagnosis whilst others would not. Our dementia training and education offer needs to reflect that people living with dementia and those closest to them will know their experience best and preferences on options, from diagnosis to long term care, should be supported where that's possible. This includes people with a learning disability and those with sensory loss whose sources of information and choice of support have been more limited to date.

The difference we need to make

Education and training reflects the needs of the whole dementia community in Scotland. We share ownership of priorities, recognise the contribution of different types of support and look for ways to actively coordinate effort to improve impact.

Senior leaders across the health, care and housing systems support and prioritise the need to provide staff access to dementia training and support improvements in practice, understanding its importance and impact and allowing staff the time and support they need to understand the issues and tools to build this into practice.

Future education and workforce development aligned to this strategy should include a focus on:

- Enabling the workforce to understand their role in respect of post diagnostic support (PDS) and care co-ordination
- Human rights and rights-based practice
- Wellbeing and psychological safety for the workforce
- Mental health and wellbeing including assessment of suicidality, distress and risk
- Understanding that dementia sits within public health and preventative contexts
- Identification and management of the symptoms of stress and distress across care settings
- Improving capacity and capability to support practice improvement and integrate the evidence base in practice.

We develop and reinforce a culture of support that looks for ways to share innovation and success, but which allows people to be open and honest on what has not worked so we can also learn from that and change or tailor approach where necessary.

Staff can evidence they have used learning in practice through continuing professional development, supervision and service-specific measures to show impact of education and training.

We prioritise the need to ensure people with dementia have a voice, and look for ways to skill up staff on legal protections and safeguards to ensure people have the opportunity to participate in decisions around their care to the greatest possible extent. This includes greater awareness and understanding of Guardianship, Power of Attorney, independent advocacy and Anticipatory Care Planning.

We find ways to profile, educate the workforce and unpaid carers and make better use of the wide variety of tools available to drive impact such as:

- Standards of Care for Dementia in Scotland
- Scottish Intercollegiate Guidelines Network (SIGN) guidelines
- Promoting Excellence Framework
- A Quality Improvement Framework for Dementia Post Diagnostic Support in Scotland
- Health and Social Care Standards
- Connecting People: Connecting Support framework

- Chartered Institute for Housing (CIH): Scottish Housing & Dementia Framework
- British Deaf Association (BDA): Dementia Toolkit
- HIS iHub's: 12 Critical Success Factors for Care Co-ordination
- HIS iHub: Dementia in Hospitals Improvement Toolkit
- HIS iHub: Change Packages to support improvements in PDS, Care Co-ordination and Hospital Care
- Proud to Care: LGBT and Dementia: LGBT+ Dementia Toolkit
- My Health, My Care, My Home: healthcare framework for adults living in care homes
- Getting it Right for Everyone (GIRFE) Framework

Training and education providers are supported to work together with communities to agree programmes of work that complement and reinforce impact on our agreed priorities, responding to what is needed with clear and understood monitoring and reporting arrangements in place to measure success.

As well as responding to need now, we will plan for the education, training and implementation support that will be required in future by understanding and preparing for predicted changes in demographics. This includes work to recognise, promote and celebrate the positive contributions of a wide variety of people and professions working in dementia to incentivise and encourage more people to pursue a career in dementia.

How this Strategy was Developed

How this Strategy was Developed

The strategy recognises we start from a strong base. It has been designed to reflect and recognise the wide range of dementia experience and activity already in delivery across Scotland. It has looked for ways to learn from and embed what has had a positive impact as well as identify where the need for change and improvement remains.

We know that the experience of those living with dementia is varied and through our National Conversation, we intended to capture this and amplify seldom heard voices. We also want people living with dementia in Scotland to recognise their own stories in this strategy as a story of collaboration, empowerment, where strengths are recognised and rights are upheld.

Fostering an inclusive approach, where people living with dementia are supported and empowered to influence the strategy, has been integral in capturing this national story that is essential to transparent policy development. Our engagement with dementia communities from across Scotland has been invaluable in recognising unique and complex challenges that dementia brings to those who are diagnosed, care partners, families and service providers.

Lived Experience

The establishment of a National Lived Experience Panel, appointed by an independent group on behalf of the Scottish Government, has formed part of the formal governance which oversees the development (and subsequent delivery) of this strategy. The Panel comprises 22 people: 11 with a diagnosis; 11 as care partners/unpaid carers. Current Panel members have agreed to support the development and delivery of the strategy for two years when membership will evolve.

As well as working with the National Dementia Lived Experience Panel, we have and will continue to engage with pre-existing lived experience groups as reflected during the National Conversation.

Strategy Advisory Group

A new National Dementia Strategy Advisory Group has been established to inform and oversee the development of this strategy, chaired by the Scottish Government's Chief Social Work Advisor. The group is multi-agency, engaging a wide range of backgrounds and interests including clinicians, the Third Sector, local government, providers of residential care, academia, Convention Of Scottish Local Authorities (COSLA) and Scottish Government colleagues covering areas such as planning and the National Care Service (NCS).

National Conversation

With our Lived Experience Panel and Strategy Advisory Group providing oversight, a National Conversation on dementia ran from September to December 2022. It was our invitation to everyone in Scotland with an interest in dementia to make a contribution on what is needed now and where we should go from here. The questions posed to stimulate conversation were:

1. What does dementia mean to you and those around you?
2. What supports work well for you?
3. What challenges need to be addressed?
4. How would addressing these change lives?
5. What do we need to build on/learn from what has been done before?
6. What else would you like to tell us?

139 responses were received via CitizenSpace, with an additional 22 from organisations and 6 from individuals submitted directly, giving us **167** in total. Of these, 64 were from organisations (38% of responses).

Roundtable Discussions

Four roundtable discussions with two groups, practitioners and academics, were brought together focussed on understanding and reflecting the latest practice and research. The practice round tables included a wide range of practitioners from community support to old age psychiatry. The academic roundtables brought together respected dementia specialist academics from Scottish universities to discuss how we connect with, understand and use the latest research on dementia. All four discussions formed part of the analysis of responses.

Community engagement

Taking a ‘go to people where they are’ approach, we held or joined with partners to deliver in person engagement sessions on the strategy in communities across Scotland; Orkney, Dunoon, Aberdeen, Dundee, Whitburn, Kirriemuir and Peebles to name a few. Events were designed to ensure that people were able to offer their views in places and environments that were comfortable for them. Alongside a limited number of online engagements for those who prefer that, this totalled 110 strategy events with a wide range of organisations and groups, reflecting our commitment to hearing a wider and more diverse range of voices.

We also held online meetings and sessions with a wide range of organisations including Alzheimer Scotland, Age Scotland: About Dementia, British Deaf Association (BDA), Minority Ethnic Carers of People Project (MECOPP), Social Work Scotland, Scottish Care, Allied Health Professional (AHP) Directors, Allied Health Professions Federation (AHPF) Scotland, Mental Welfare Commission, Scottish Social Services Council (SSSC), Post Diagnostic Support (PDS) Leads Network across Scotland and the Care Inspectorate (CI). Our open online engagement sessions drew mixed attendance from people living with dementia, care partners, and professionals.

All of the engagements were written up and used to supplement the formal written responses as part of our analysis process.

The Investment

The Investment

We will begin to implement this strategy in a very challenging fiscal context. While spend on dementia across Scotland has increased steadily over recent years by approximately 13% since 2014, with additional, ring-fenced national investment in frontline dementia services from 2021, we know that more people with dementia (and with other health conditions) want to continue to live safely and well in their own communities for as long as possible.

This means not only maximising the impact of ‘upstream’ investment in areas like community and post-diagnostic support (PDS) so that more people with dementia and their families are able to plan earlier and have more options. It also means continuing to minimise as far as possible unnecessary acute hospital admissions and re-admissions, which will also ensure that people who are fit to be discharged do not stay in hospital longer than needed, minimising risk of further deterioration. This supports the identification of stress and distress, Adults with Incapacity and future care planning to move upstream.

Local and national action is required to assess the effectiveness of current spend on dementia across the whole system, identifying options for redirecting investment to support delivery of this strategy’s vision and priorities.

Dedication

Dedication

I am still me – a poem by a father and a son (carer)

It's my wish and desire for my son to share our experience. I see with my own eyes that he has my best interest at heart, a kind heart, I tell him; the father becomes the son, the son becomes the father.

All you need is love… I still like this song. I need love and compassion from my family, friends, carers and neighbours; our memories are what makes us, they bind us together, even when they begin to fade… especially when they begin to fade…

My confusion and forgetfulness is something I'm unable to control; my son takes the time to see and understand this and that's why his care for me is tender, precious and loving. This is new to us, we didn't expect this, we weren't ready; that's why I need you to hear my voice, through his voice – our voice, we are one voice.

Some days I will forget what day it is, many days, most days… but not every day; it happened again… yesterday… or was it today… I'm sorry I'm unable to say… have I had my breakfast or medicine yet? The kind nurse who visits me at home every morning will know. A stranger became a friend; facial expression making language less of a barrier.

Time is a healer, is what they say. So why can't I draw a clock face or the two hands to show the time? I don't know why… despite the clock being my trusty lifelong friend, from India to Scotland… 86 years.

I am Indian; I am Scottish. I am a husband, a brother, a father, a grandfather. Some relations seem so distant now. Another life? I recall the streets of my youth; I do not know my address. But I am still me.

Light from the moon comforts me; I am a child again. The stars are magical. My son reads to me, stories, songs and poems; I used to sing once upon a time, and he helps me with ‘reliving’ lyrics. We walk. We talk. We comfort and console each other. My mind is weak; our bond is strong. My mind is weak… yes, my mind is weak… weak; but I know, he knows what I see, what I hear, what I feel… what I need. He will be happy to tell you, if you may be so kind as to ask. Please, do ask.

Love, love, love… all you need is love…
love, love… love is all you need… love is
all you need… love is all you need…

My voice may have quietened, my thoughts may have slowed; but I am happy to hear my voice and thoughts about what matters to me, to us, spoken and shared with you by my son; when need be, he is me, I am him.

Even though my thoughts are not always clear to me, my loved ones or to others, I thank God for a lifetime of happy memories… I know in my heart of hearts; they are there somewhere. Let it be… let it be…

Arvind Salwan

A poem by Arvind Salwan who is a member of the National Dementia Lived Experience panel, dedicated to his late father Sudershan Kumar Salwan (1936-2023)

Governance Groups

Governance Groups

National Dementia Lived Experience Panel

- Allan Gall
- Angela Worthington
- Arvind Salwan
- Audrey Ross
- Collette Riley
- Daniel Murphy
- Denise Finlay
- Elaine Symington
- Emily McGill
- Geoff Orry
- Gerry King
- Ian Symington
- Irene Donaldson
- James M Milne
- Kenny Moffat
- Kenny Wright
- Martin Robertson
- Paula Ferguson
- Ron Coleman
- Tony Worthington
- Willy Gilder

National Dementia Strategy-Advisory Group

Iona Colvin (Chair)	Scottish Government
Alistair Cook	Principal Medical Officer to Mental Health Directorate
Claire Lamza	Mental Welfare Commission for Scotland
Diane Fraser	Social Work Scotland
Fiona Collie	Carers Scotland
Graham Galloway	Kirrie Connections
Jane Douglas	Scottish Care
Jim Pearson	Alzheimer Scotland
Kainde Manji	Age Scotland
Karen Reid	NHS Education for Scotland (NES)
Lesley Palmer	University of Stirling
Lorna Gibbs	Scottish Government
Lynne Douglas	Coalition of Care and Support Providers in Scotland
Margaret Chiwanza	Minority Ethnic Carers of People Project (MECOPP)
Rebecca Hoffman	LGBT Health and Wellbeing
Richmond Davies	Public Health Scotland
Ruth Griffith	Convention of Scottish Local Authorities (COSLA)
Sandy Robinson	Scottish Government
Susan Ferguson	Scottish Government
Vivek Pattan	NHS, Forth Valley

Scottish Government
Riaghaltas na h-Alba

This publication is available at **www.gov.scot**

Any enquiries regarding this publication should be sent to us at

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-80525-426-3

Published by The Scottish Government, May 2023

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS1221542 (05/23)