

THE SCOTTISH DEMENTIA ALUMNI

Dementia & Preparing for the Unexpected

A peer to peer resource
researched and written by people living with dementia



The Scottish Dementia Alumni

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The Scottish Dementia Alumni is a group of people living in Scotland with collective lived experience of a diagnosis of a dementia of almost sixty years.

The group was created to inspire and support people with a new diagnosis of dementia but also campaigns for human rights.

Each member has contributed to and/or written publications, made videos and has been cited in many publications.

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Introduction

This booklet was researched and written by the Scottish Dementia Alumni, a group of people who have lived with diagnoses of different dementias for several years. We are experienced campaigners who actively fight for the rights of people living with dementia.

Over the past decade, between us we have gained a Churchill Fellowship Award, two MBEs, a BEM, an Honorary Doctorate from Strathclyde University, a BA and a BSc, written books and booklets including the Self Management and GP Services booklets, created and appeared in videos and have been referenced in many publications.

We used a peer to peer grant from Life Changes Trust, which enabled us to produce this booklet and the accompanying video.



We have all experienced unexpected events over the past year or two. We set out to research and discover which urgent support a local authority or health care service should be providing and where you will be able to access this so that you can be prepared. We asked people living with dementia in Scotland about what concerns them and how they prepare. We will share our research widely in order to support others living with dementia to access quality services and to improve communication between people living with dementia and the teams which provide services in emergencies.

Why We are Making this Booklet

'I wasn't expecting to become a carer, myself!'

'A nurse told me what do after a fall - I had no idea!'

'I live alone. There was a flood in the night.' **'I got lost.'**

'I woke up on the floor' **'I have self directed support'**

'My wood shed fell down.' **'There's nobody to walk with.'**

'You can't take a pill for loneliness' **'I miss my iPad class!'**

'I was scammed.' **'I have a community alarm wristband.'**

'My mobility is unexpected. Some days I can barely walk - other days I can walk outside. I don't know who to call if I fall. Family? There is no physiotherapy or anything.'

You can see from all of these real experiences, that there is a need for clear communication around preparedness, sharing of knowledge, and that services in different areas vary.

We want to provide clear and well researched information to support people with dementia to confidently cope when things unexpectedly change and to build and maintain resilience. We want to highlight the kinds of issues people living with dementia in Scotland are having so that we can help each other and so that we can build our resilience to cope better with unexpected events.

What this Booklet is For

This booklet is to present clear information from our extensive research about what Urgent Care services in Scotland should provide you with, as a person living with a dementia. We also want to support each other's resilience.

We hope that this booklet will help GP practices, NHS Trusts, Emergency Services and Social Work teams to better support people living with dementia. By taking this information and providing clear communication to people living with dementia and care partners about available services, options for preferences in communication and how to access services, we hope that services will learn with us.

This booklet is NOT offering any medical or legal advice. It is a general research - based guide to getting good access to your Urgent Care services and building your personal and support network resilience.

This booklet will show you how we have navigated change. Change is inevitable - although we researched this information to be correct for November 2021, it will change. Please check with your GP, Local Authority, Fire, Police, Ambulance services & Health Board for updates.



Who this Booklet is For

This booklet is for people in Scotland living with dementia and for care partners to understand what is available for Urgent Care and supporting resilience in Scotland.

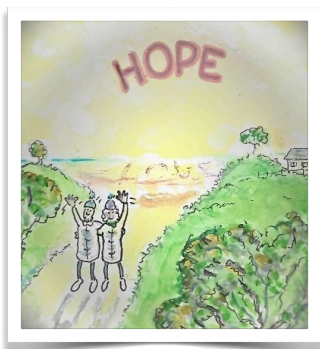
It is for sharing information gathered by people living with dementia to strengthen and build resilience.

It is also for Urgent Care teams to support them to understand more fully what people living with dementia need support with.

Our aims are :

- To offer clear and well researched information, gathered together in one handy booklet to support everyone impacted by dementia in Scotland to have more confident access to Urgent Care and other services.
- To support Urgent Care and community teams to communicate with and serve people living with dementia in Scotland more confidently.

The reason that this booklet is only for Scotland is because other regions are organised and funded in different ways.



What Are We Concerned About?

'If we plan ahead, we can get on with living life, not worrying about the future.' Agnes Houston MBE

'Expect the unexpected. Your life can change in a minute, here is some advice you can trust.' Martin Robertson. BA(Hons), BSc(Open).

Not in any particular order, here is a list of some concerns of our survey respondents:

Pets - who will care for them? **Loneliness** - community.

Panic attacks - finding safe spaces. **Dying** - preparedness.

Concern for **public judgement**, being unable to wear a mask.

Scams - some people had experienced this.

Keys - some people had lost or forgotten keys.

Becoming a carer - how do we mix both carer/cared for?

Falls - prevention, keeping mobile, what to do after falling.

Being able to **call an ambulance**. 'Do I still call 999?'

Medication - keeping doses regular while going to hospital.

People, **strangers** coming to the door, cold calling.

What Have We Experienced?

A note of gratitude to the **Police Community Safety Team**, who supported a person well, who had experienced a crime.

I wasn't ready to be asked about DNAR status and Lasting Power of Attorney, I only went to hospital for a routine appointment. I wish I had been able to think about it at home with a cup of tea.

I experienced a scam. I lost some money and I felt so stupid. It's not stupid though, it is a crime and I'm glad there's a website now, to make people aware. I wish I'd seen it sooner.

Somebody came to my door (angry), I was able to use my community alarm to ask for help.

My husband needs to keep practising with the community alarm so it's familiar to him. They don't mind. They are very good.

A nurse told me about what to do if I fell, I had no idea.

A diagnosis of dementia was unexpected! But connecting with others in the same boat helped.

I use a grabber stick

I have a sunflower lanyard

I go to yoga online

We use Safe Spaces on our outings - look for stickers in retail areas.

Alexa can't call 999

Paths for All is great for walking

What Have We Learned?

We have researched issues raised by our survey respondents, to guide you to finding what you need to build your resilience and preparedness. **Bold texts are links to click.**

ICE (In Case of Emergency) can be noted next to your emergency contact on mobile phones for easy access. Smart phones have emergency information settings.

Care package with your local authority - include an **emergency plan** and ask about Self Directed Support payments.

Ask for a Falls Risk Screen, make a falls plan - see **NHS Inform**.

You can select or update an Emergency Contact in the Alexa app by **visiting Communicate > Contacts > [Selected contact] > Add as Emergency Contact**.

Over 50s Home Fire Safety Visit from the **Scottish Fire Service** .

Here is a list of benefits available in Scotland, from **Mygov.scot**.

Support and training for carers is listed on **Mygov.scot**.

Telecare has a self check online tool on **NHSInform**.

Cinnamon Trust is a charity, which can help with pet care.

What 3 Words is an app and service that can help locate you.

You can call **999** for fire, police, ambulance and coastguard help in an emergency, but there are now numbers for less urgent situations, or if you aren't sure. You can call **111** for health problems that aren't life threatening and **101** for police support when it isn't an emergency.

Herbert Protocol forms can be downloaded from **Police Scotland**.

Talking About Our Experiences

'I asked my GP about Social Prescribing for gym sessions.'

'I helped my local police station with the Herbert Protocol. I needed to use it for my relative.'

I unexpectedly became a carer, myself, while I live with dementia. How do I live on both sides of the fence, dementia and carer?

'I learned to pause and take time to see if I was hurt and then gradually roll on to my knees before getting on to one knee and up on to a chair. Knowing what to do made it less frightening.'

'There is a falls service in my area. I call them instead of an ambulance.'

'I worked with the Police community Safety team to keep me safe (after an incident).'

'I went to knock on (member of DEEP group)'s door. I knew they would help.'

How to Access Immediate Assistance

(Bold texts are links to click)

Falls - Have a look at this **UPWARDS AND ONWARDS** film.

If you are unable to get up, call 999 from your phone if you need an ambulance or call 111 if you aren't sure. If you can't reach either a phone or alarm, you can shout loud for help or bang on a wall or floor with your hand or something you have close by. Follow your Falls Plan if you can.

Use your Community Alarm or mobile phone to summon assistance.

To contact **Police Scotland** in an emergency, call **999**. In a non-emergency, call **101**.

In a fire GET OUT, STAY OUT, CALL 999. (Fire Scotland)

If you smell gas in your home, switch off your gas, do not use electrical equipment/lights, open your windows and doors and call **National Grid 0800 111 999**.

NOTE HERE WHERE YOU CAN SWITCH OFF YOUR GAS:

.....

Knowledge Across Scotland

Here are some resources that we found during our research. **Bold texts are links to click.**

NHS Highland Falls Prevention & Management

The **Herbert Protocol** has been in place across Scotland since 21st September 2021, to assist with tracing missing people who have dementia. You can download the form via Police Scotland.

The Scottish Fire & Rescue Service has information on the **new regulations for home fire alarms** from February 2022 on their website.

Social Prescribing is something GP services can sometimes offer instead of medications, for example gym sessions, dance or swimming for reducing pain and improving mood. Ask your GP.

Self Directed Support Scotland has forums and information about Self Directed Support (SDS).

Your local authority website might have dementia pages. Here's **DementiaAberdeenshire**, Martin Robertson has contributed.

How We Prepare

Stay strong and mobile - if you can't get out, there are online movement, dance and exercise groups and classes. Ask your GP about Social Prescribing and local support to keep active.

Stay mentally well - try new things. Stay connected to your friends, family, neighbours and local networks, especially your 'dementia family' peer support groups.

Keep some keys with a trusted neighbour or in a key safe.

Community alarms can be used for many situations and you can test the service. Try the Telecare self check tool [here](#).

A charged mobile phone is like keeping family and friends in your pocket.

Create a message in a bottle.

Create a falls plan, a flood plan and an Emergency Plan.

Create a This is Me document with care plans, to include faith.

Get yourself a sunflower lanyard if it helps you. Get hold of any help cards or 'just can't wait' toilet cards if needed.

Familiarise yourself with local 'safe spaces'.

Set Alexa up to call an emergency contact for you.

Create a plan for your pets.

Prepare will, power of attorney, DNAR paperwork in advance.

Conclusion

UNEXPECTED! Our conversations with people living with dementia gave us some unexpected responses!

CONNECTION It was highlighted clearly that one of our greatest concerns is loneliness and becoming disconnected. The overwhelming feeling from the responses is that of staying connected to each other and finding ways to keep in touch.

PEER SUPPORT This highlights the importance and value of developing a network of friends, neighbours and family support and the value of peer support.

PLANNING WITH SERVICES Some well-prepared people told us about booking a Fire Safety Check with the Scottish Fire Service and making a Flood Plan if you live in a flood risk area.

RESILIENCE Many people talked about keeping themselves going with learning new skills, trying new things, particularly in groups and sharing experiences together. Art isn't just for professional artists and schools, it's for all of us and our feedback highlighted the value of art for communication and for being part of something bigger together.

PREPAREDNESS On a practical level, local knowledge and services, an alarm system, a completed This is Me document, lists, a packed bag, a couple of weeks worth of canned or frozen food, emergency phone numbers, a message in a bottle in the fridge and a charged mobile phone or list of family/neighbour/friend contacts are practical steps to take towards easing any unexpected situations. Advance planning of DNAR status, wills and future care planning all help to avoid pressured decisions.

Our Campaign

What we will campaign for as a result of our research

We would like to see:

- Suitable Oversight and **Involvement** - Nothing about us without us.
- Tailored **support for Carers** who are living with dementia.
- Carers to access **priority emergency care** to safeguard caring role.
- All areas offering similar, **fair services**, no postcode lottery.
- People living with dementia included on **priority lists** for communication from services in the event of supply interruption/noisy works etc.

Human Rights Approach

It is our right to receive quality services for our dementia. These rights need to be upheld, not as a 'should' or 'could', but as a quality standard that we can expect.

We have the right to life.

We have the right to liberty.

We have the right to a family life.

We have the right to live free from discrimination.

We have the right to reasonable adjustments to services.

Checklist

This is Me Document and **Emergency Plan** completed.

Falls Plan completed. **Flood Plan** completed.

Charged and switched on **mobile phone** in your pocket, filled with your important numbers and names. **ICE** In Case of Emergency number selected and **emergency medical/contact** information set up on smartphones.

Community Alarm.

A weeks worth of canned **emergency food** in the cupboard.

Message in a Bottle completed and stored in the fridge.

A packed basic **hospital bag** with some cash, hairbrush or comb, toiletries, a change of clothing and nightwear. Mobile phone charger. Spectacles. Pen and notepad or a book, whatever might help you to pass the time.

A list of important **telephone numbers** ready by the phone.

A plan for your **pets**.

A **key safe** or a spare key given to a trusted neighbour/relative.

Scam prevention preparation and knowledge.

Know your local **Safe Spaces**.

Keep your friends and family close and join dementia **peer support** groups to create a network of friendship.

Learn about your local area's resources.

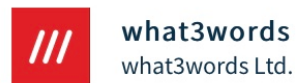
Our Own Research

Make sure that an ambulance can find you! There are practical things like making sure your house number is clearly marked and that your driveway is clear. You can also use a service like **What 3 Words** to locate your exact position if you live in a remote place or you are outside and don't know where you are. This is an app that you can download or you can find out the three words that locate your home.

The **Herbert Protocol** can assist with locating a person.

Carer support - if you become a carer while living with dementia, you have the same rights to access a Carer's Assessment from your Local Authority. Contact Carers' organisations and local support.

'I think we are looking at two things, here.
Resilience and Preparedness.
You need both.
You need to be strong and resilient to cope with unexpected things.
You need people around you. And you need a plan, that you can follow, when something goes awry.'
(Telephone response)



Helpful Resources - Click Links

BOLD TEXT ARE LINKS TO CLICK

Zoom Guide from Innovations in Dementia

**NHS Near Me Leaflet from NHS Highland
NHS Near Me Scotland Website**

Citizens Advice Bureau Guide to Human Rights in Healthcare

NHS Inform Falls information

Scotland's Service Directory

Scottish Ambulance Service - Message in a Bottle

Anticipatory Care Planning

Power of Attorney Information

How to Access Urgent Care

Dementia & GP Services - Scottish Dementia Alumni

Knowledge is Power (Scotland)

Dementia and Self-Management - Scottish Dementia Alumni

What to do when Someone Dies in Scotland

Human Rights - health/care

Resource Links - Continued

Police Scotland

This Is Me

Gas Leak Information

Cinnamon Trust

Friends Against Scams

Join a DEEP Group

What 3 Words

Flood Planning

Sunflower Lanyard

Changes to Fire Alarms

Up and About Leaflet

Just Can't Wait Toilet Card

Scottish Fire Service

References

Our Dementia Our Rights

The Dementia Policy Think Tank & Innovations in Dementia

Joint statement on Advance Care Planning

Social Prescribing in Scotland

**National Falls and Fracture Prevention Strategy
NHS Inform - Falls**

Acknowledgements

We are very grateful for support and information from:

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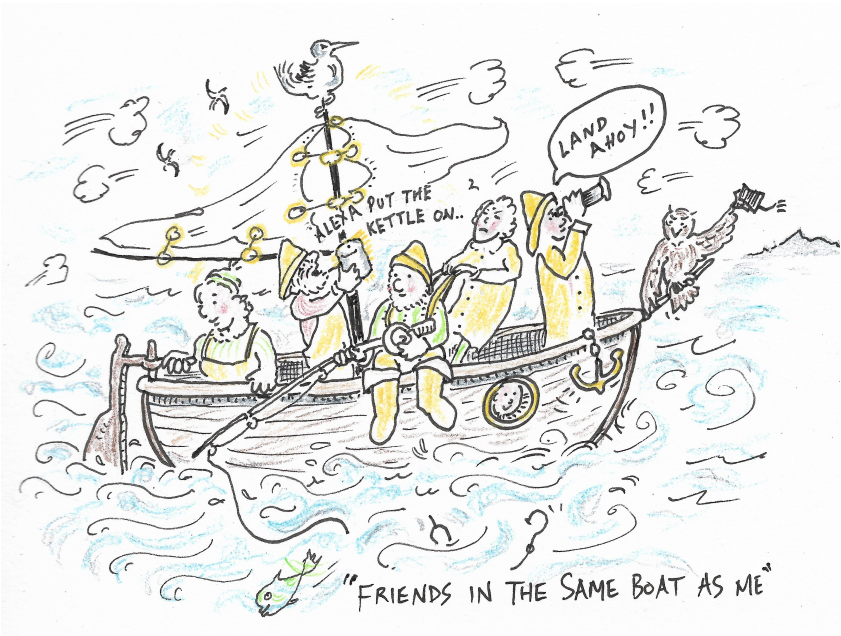
The STAND group.

Everyone who contributed.

Police & Fire Scotland.

Our friend and Artist Paul Thomas.

Our Facilitator Paula Brown.



Handy List for Emergency Calls



Your GP Surgery:.....



Your phone number:.....



Your mobile phone number:.....

Your date of birth:.....

Your email address:.....

Police Scotland 999 or
101 non-emergency or you aren't sure.

Ambulance 999 or
111 non-emergency or you aren't sure.

Fire 999.

National Grid (smell gas) 0800 111 999.

Glossary and Common Acronyms

BA - Bachelor of Arts (degree)

BEM - British Empire Medal

BSc - Bachelor of Science (degree)

DEEP - UK Network of Dementia Voices

GP - General Practitioner

ICE - In Case of Emergency

MBE - Member of the British Empire

NHS - National Health Service

PDS - Post Diagnostic Support

SDS - Self Directed Support

DNR - Do Not Resuscitate

DNAR - Do not attempt resuscitation

DNACPR - do not attempt cardiopulmonary resuscitation

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