

THE SCOTTISH DEMENTIA ALUMNI

Dementia & End of Life Choices

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



The Scottish Dementia Alumni

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This booklet is dedicated, with love and gratitude, to
Dr Julie Christie and Alan Houston, both sadly missed.



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 not only to inspire and support people with a new diagnosis of dementia but also to campaign for human rights.

Each member has contributed to and/or written publications, papers and policies, 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, 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, created and appeared in videos and have been referenced in many publications.

We set out with to produce this booklet with funding from About Dementia's Peer to Peer support funding grant.



There are at least two certainties in life - that we have been born and that one day we will pass away, die, reach the end of our life, or however we wish to describe it, our life will end.

We set out to discover what we would like from the end of our lives, as people living with dementia. Which choices do we have? How can we continue to uphold our human rights? Who can help us and where is the information that we need?

Whether you'd like to address these issues now or later, here is a handy guide, which we hope will be helpful.

Why We are Making this Booklet

'There's so much I didn't know. I think it would help others.'

'I had a DNR put on my file without my consent.'

'I like to plan ahead. It helps me to feel in control.'

'I have just found out that a dementia diagnosis puts us on an end of life planning pathway.'

'I didn't know that a doula can help with dementia too.'

'I want to know about what actually happens to the body at the end of life.'

'I don't want to talk about it now but I need the book for later.'

'My brother said he would deal with his Power of Attorney when the time comes. Well, the time came and it was too late - others had to decide for him.'

You can see from all of these experiences, that there is a need for clarifying issues with end of life support, planning and experiences, which can empower us to take charge of aspects of our life and to uphold our human rights.

We want to share our collective experiences, so that anyone concerned about their end of life experience can understand their choices, and so that we can all benefit from our shared experiences and our research.

What this Booklet is For

This booklet is to gather together resources and experiences with end of life and dementia and the solutions that people have discovered to work for themselves and others. We have also researched how to access help with positive planning for a good end of life.

We hope that this booklet supports your personal journey to a good end of life and that you feel empowered with the knowledge that you need in order to make your choices.

This booklet is NOT offering any medical or legal advice. It is a general research - based guide to getting a good quality end of life experience and accessing assistance where needed.

We researched this information in 2023 & 2024 alongside carers, professionals and people living with dementia. Change is inevitable. Please check with your GP, local services & Health Board for updates.

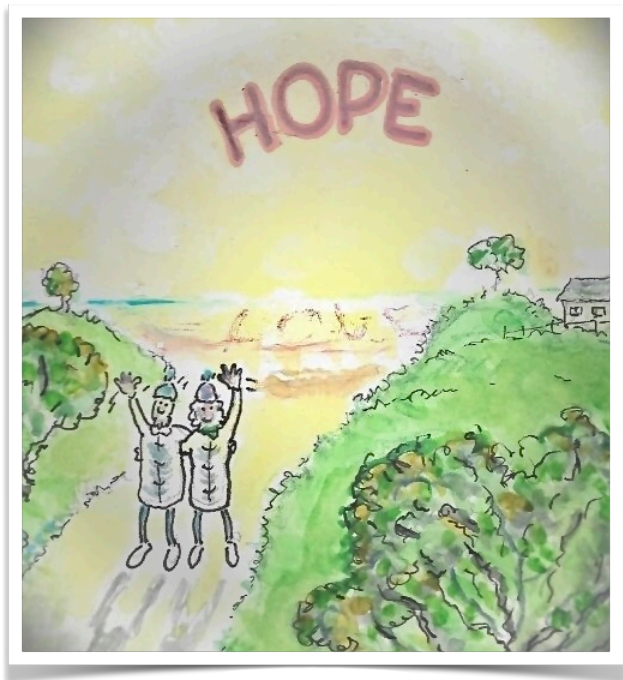


Who this Booklet is For

This booklet is for anybody who has dementia and would like to find out how to plan for a good end of life.

It is researched in Scotland and some services might only be relevant to Scotland.

It might be helpful to everybody, not just people living with dementia. We hope so. There is an often repeated phrase 'If you make things better for people living with dementia, you make things better for everyone.' This is our aim.



What Is Happening?

Our questions to people living with dementia:

- 1: Are you comfortable talking about the end of life?
- 2: What would a good end of life look like?
- 3: Have you made your Lasting Powers of Attorney?
- 4: Have you decided on your DNR status?
- 5: Have you discussed end of life with family/friends or professionals?
- 6: Do you realise that not making decisions is deciding that professionals can decide for you?
- 7: Can you tell us about good or bad end of life experiences with others?
- 8: What will support your well-being and mental health towards the end of life?
- 9: What about your spiritual needs?
- 10: Anything else?

Not in any particular order, here is a list of some responses:

Plain language. The word death is okay.

I don't like to hear about death - it has mental health impact.

Music. Having family close. Quiet. To be free from pain and comfortable. Comfort. Haircut. Flowers. Cold water to drink. Good sheets. A wee dram! Appropriate care in an appropriate place. To be at home. To have everything sorted out - loose ends tied up. Medication managed well. Stress free. All my ducks in a row. All the important things said. My church is very supportive. I do not want to be in hospital - it's too noisy and bright and confusing. An organised home. To be outside. Prayers around my bed. My Future Care has planning tools and a buddy system.

Responses from People with Dementia

I want to die as I lived my life, living fully to the end. Reading, listening to music, staying connected to my friends and family. Staying connected to the world through my iPad. Knitting. Take-aways in bed!

I want to gently step back from life, from responsibilities. I'm tired now.

I have cancer and I'm hoping for a hospice place at the end, at the right time. It feels appropriate.

I'm planning to move in with my family soon, so that we can make decisions together. I've enjoyed living on my own but now it's the right time to share the load.

Mum's medical needs are higher now and we have struggled to get an ambulance, a doctor, carers to help with lifting at home. We are all tired and think that Mum can have more of a life from a care home.

Never agree but I do, you know. You know. (Nodding). My daughter (holds her hand). need else.. words slippery (smiles). I hear you, Mum, I think we all need 'else'.

The MacMillan nurses are wonderful, without them, I just don't know.. they nursed us all through a comfortable and peaceful end for my wife at home. It has made me want to carry on living here with warm memories. They are angels.

It was all a bit chaotic. We were just backwards and forwards to A&E. I didn't really know about being able to stay at home or whatever. Now we have a hospice place and it's such a load off. A relief in all ways. I feel so cared for and so does my husband.

Questions to Professionals

Our questions to professionals

- 1: What are the criteria for being admitted to a hospice?
- 2: What are the criteria for 'actively dying'?
- 3: Is the Liverpool Pathway still used? Under any name?
- 4: What about language for/around the person/family?
- 5: Do you modify surroundings for people with dementia?
- 6: Does your team have dementia training?
- 7: Do you offer end of life care at home?
- 8: How do you support end of life well-being?
- 9: What kind of options do we have at the end of life?
- 10: How do you support spiritual well-being?
- 11: Anything else?

We used to quietly take deceased people out of the back door but now we have a guard of honour for those who want to pay respects. People tell us that it helps them to honour lives and to feel that their end of life is more of a celebration of life. We support families.

For people on their own, we leave the door open and encourage everyone passing to sit and chat quietly.

We train in Dementia, yes. We use a Respect Candle.

We often read from a favourite book or news articles we know the person will like. Hearing is one of the last senses to go. Out in nature. Visits from pets are important, if they aren't already here. Hand massage, watching films, coloured lights, manicures, haircuts, growing seeds. 24/7 family visits. Food preferences, seamless medication. We discuss hospice admission, individually when a person is ready and when there is a space. The Liverpool Pathway is a complex discussion - designed to be a helpful and positive addition to care planning but it was not always implemented well.

Responses from Professionals

We aim for everything to support wellbeing at all stages of a resident's life. This is their home and we aim to be their professional family.

A respect candle that is lit as a person is approaching the end of their life. It requests quiet respect and we leave it lit for some time afterwards, as a mark of respect for the person and their loved ones.

I like to work outside with a person. There's something about being able to see the natural life cycle of trees and leaves, seasons and weather that gently mirrors the seasons of life and death, moods of weather, we are born, we flourish, we fade and we die. There's an unspoken understanding of this when we look at nature. We don't always have the words but we can look at a tree and understand that it's okay. It's a part of life. I'm comforted by nature and I know that the people I work with, as an end of life doula, are comforted too.

If we can't go outside, I might sit on a balcony with a person I'm working with, or open a big window, so that we can sing loudly or wave to the neighbours. Community and connection remain important. Joy can live within us to the very end.

Because we work in a care home, in a small community, we usually know the person and their family and we are able to plan well in advance and adjust that plan continually, as we have more spontaneous discussions.

As a hospice, we have prompts for comforting conversations which can be shared with families, friends, neighbours. It can be hard to know what to say but our experience shows that 'I love you' 'I'm sorry for...' 'I forgive you' 'you have been a wonderful father/mother/friend/neighbour' is appreciated.

What Helps Us? Our Responses

Responses from our call for experiences:

- **Organise your DNR status in advance.**
- **Plan and activate your Lasting Powers of Attorney.**
- **Look at the Buddy service in My Future Care.**
- **Talk over your plans with family.**
- **Talk over your plans with professionals / your GP.**
- **You can book extra time with your GP to discuss.**
- **Make a Playlist for your music.**
- **Prepare your home.**
- **Ask visitors for help - they are often glad to help.**
- **Say yes to all the opportunities that you can.**
- **Say no to opportunities without guilt.**
- **Organise your prescriptions - blister packs etc.**
- **Try seated yoga or online classes in bed.**
- **Breathing exercises. Mindfulness.**
- **Talking books.**
- **A small craft bag.**
- **A hospital bag packed for unexpected admissions.**
- **A little cash for small purchases.**
- **Earplugs.**
- **Headphones for music or films or to reduce noise.**
- **iPad or phone with charger and battery pack.**
- **Religious books, beads, items of spiritual comfort.**
- **Chaplain or spiritual leader visits.**
- **Somebody to organise hospital visits and calls.**
- **Stay flexible - things can change quickly.**
- **Watch the film about the process of a life ending.**
- **End of Life Doula support.**

How We Manage Our Planning

What about us, who have dementia, visiting family at the end of their life?

Aromatherapy to relax.

I like quiet so I keep headphones with me and earplugs.

There was nowhere to find this information so we researched it ourselves.

I visited my GP to talk it over with a double appointment.

I downloaded a talking books app.

Music - a playlist.

I go to yoga online - I will keep it up even from my bed.

My community nurse is a treasure trove of information.

I made a plan to stay at home because hospital is not my choice.

My family plan with me.

I have done everything I can to plan and I feel lighter now

Our Tips

Earplugs help to dull the noise of hospital or busy waiting areas - look for the screening earplugs if you need the worst of the noise filtering out but still need to hear conversations. A sleep mask can help with lighting.

Water by the bedside and a sponge stick help with a dry mouth, or some refreshing ice chips. A lip balm.

My Future Care planning and buddy system is popular.

End of Life Doulas are often highly skilled and trained with the issues around dementia. You could try asking your GP for Social Prescribing to cover this.

The film *Dying for Beginners* by Dr Katherine Mannix is a gentle resource to help understand the process of dying.

You can make arrangements to have 'hospital at home' care in many situations.

Talk to your care providers about visiting arrangements because they can be surprisingly flexible, where needed.

Activate Lasting Power of Attorney at the bank and GP and make a will, being sure to have it witnessed.

Warm (not tight) socks can help with comfort - poor circulation can leave us with chilly feet.

Spiritual care is available through Chaplaincy Services for those without a religion. Support without prayer.

Conclusion

People living with dementia often need to work hard to find information, to make choices and to uphold their human rights. We, as people living with dementia, are incredibly resourceful and we are keen to share our resources.

People living with dementia from all over the UK got in touch with us about their end of life planning and shared their choices and discoveries so that others can see what is possible. We also researched different aspects of future planning widely, in order to share that knowledge.

While we have, unfortunately, heard about chaotic and challenging situations relating to trying to organise finances and struggles with last minute bank arrangements, challenging multiple visits to hospitals and miscommunications, we have also heard about some gentle, joined up working and some peaceful last days at home, or hospice, by choice.

We have heard about beautiful end of life doula work, incorporating communities, family, professionals, nature and personhood. We have read and watched some beautiful resources and have researched policymaking around end of life care and support.

We have heard about the planning of medication and good support for care partners, community nursing teams and fantastic paramedics.

Some people prefer not to talk about or to make choices about the end of their lives and this is okay, as long as everybody realises that this means that professionals will make those choices for them. This works for some people.

Our Campaign

What we will campaign for as a result of our research:
We would like to see:

- Further research into the specific challenges that happen alongside dementia at the end of our lives.
- Support specifically for our end of life choices.
- A named nurse for dementia at all GP surgeries.
- To have end of life choices included in our annual dementia review, if we wish.
- To have equity of services available across Scotland
- To raise awareness of potentially helpful services, for example End of Life Doulas and non-denominational services and support.

Human Rights Approach

Scottish Human Rights link

In Scotland, civil and political rights are protected by the [Human Rights Act 1998](#) and provisions in the Scotland Act 1998. These rights come from the [European Convention on Human Rights \(ECHR\)](#).

We have the right to life. Article 2.

We have the right to liberty and security. Article 5.

We have the right to a private and family life. Article 8.

We have the right to live free from discrimination. Article 14.

We have the right to reasonable adjustments to services.

Equality Act 2010.

One Last Thing - Review

I haven't read Wendy's previous two books, so I don't know her style. I certainly enjoyed reading this book, and kept nodding in agreement at various places, where it struck a chord with me. She and/or the co-author certainly did a lot of background research, and tiring travel.

Various options were discussed in depth, and I'm sure I picked up on the nuances. It gives people information, they might not have considered seriously before. And might reinforce what plans they have, or will make. The word "choice" kept cropping up, and I firmly believe, we should make an informed choice, whatever that is, and trust people will respect your individual wishes, where practicable. But those wishes, must be made clear to all, who will be involved later on.

Wendy, while I have heard her mentioned, I never got to meet her. As she is a keen photographer, I wonder why, there were no photographs taken by her, in the book? More power to your elbow Wendy.

I found the footnotes too small to read, even with my glasses. Martin too may have problems.

James McKillop

Our Own Research

Views of Care at End of Life: A Secondary Analysis of Online Feedback Using Care Opinion

<https://journals.sagepub.com/doi/full/10.1177/23743735221103029>

Dr Kathryn Mannix won at the Demystifying Death Awards 2023

<https://www.goodlifedeathgrief.org.uk/blogs/dd-awards-2023/407-5d81c9d8d8a2b1b641e519d080701a18/redirect/>

Death Doulas (End of Life Doulas)

<https://www.gla.ac.uk/research/az/endoflifestudies/projects/deathdoulas/>

<https://www.hospiceuk.org/> Marie Curie on Anticipatory Grief

<https://www.resus.org.uk/respect/respect-healthcare-professionals>

Humanism in Scotland <https://www.humanism.scot>

Bank experiences

<https://www.bankofscotland.co.uk/assets/pdf/HelpCentre/pdf/bos-power-of-attorney-guide.pdf>

I visited this bank, they were helpful. They explained that a POA is obtained from a solicitor then registered (Edinburgh). You then take it to your relevant bank to get it activated.

On your death it is automatically stopped.

The banks both said it's best to have a will as this allows your named executor to deal with your finances.

At Halifax and Bank of Scotland they said that they have in house bereavement advisors who will talk you through finalising your deceased's account. And they both wished us luck with our project.

All banks have the relevant information on their website.

Helpful Resources (digital version has clickable links)

Social Prescribing

<https://www.bhf.org.uk/information-support/heart-matters-magazine/wellbeing/social-prescribing>

A day to night (orientation) clock link

SIGN 168 dementia clinical guidelines

CRUSE

Dying For Beginners gentle film from Dr Kathryn Mannix

<https://www.youtube.com/watch?v=ayMhA1pRLeY>

Planning for Pets - SSPCA Forever Care is one example

<https://www.scottishspca.org/forevercare>

End of Life Doulas

<https://eol-doula.uk>

Playlist For Life

<https://www.playlistforlife.org.uk>

Dignity in Dying Scotland

Scottish information

Compassion in Dying

Living Will information

My Future Care

<https://myfuturecare.org>

Palliative / End of Life Care

NHS resource

Flare Earplugs (also search for sensory earplugs)

<https://www.flareaudio.com/products/calmer>

Dr Shibley Rahman shared Dying Well Chapter on X

<https://drshibleyrahman.files.wordpress.com/2023/12/shibley-rahman-grief.pdf>

Our Method

- We asked a set of questions of people living with dementia and of professionals across Scotland. We advertised this questionnaire widely through the DEEP network and other UK networks.
- People responded by video, voice, email, letter, telephone, completed forms and via discussion within their peer support group.
- When responses came in, we looked through them and looked for patterns, similarities and common themes.
- We noted that people's choices remain very personal. We listed the kinds of challenges that they told us about. We also listed the helpful support and self help that people told us about. We noted that people expect more choice than was commonly expected in the past.
- We purchased a copy each of Wendy Mitchell's book 'One Last Thing' and read this as part of our research.
- All of this information is shared here in this booklet.

Further Reading

You will find more of the Scottish Dementia Alumni's resources on our website:

scottishdementiaalumni.uk

Acknowledgements

We are very grateful for support and information from:
About Dementia Peer to Peer Grant
The DEEP Network Innovations in Dementia

Everyone who contributed - professionals, families,
people living with dementia.

Our friends at End of Life Doulas UK

<https://eol-doula.uk>

Our friend and Artist Paul Thomas

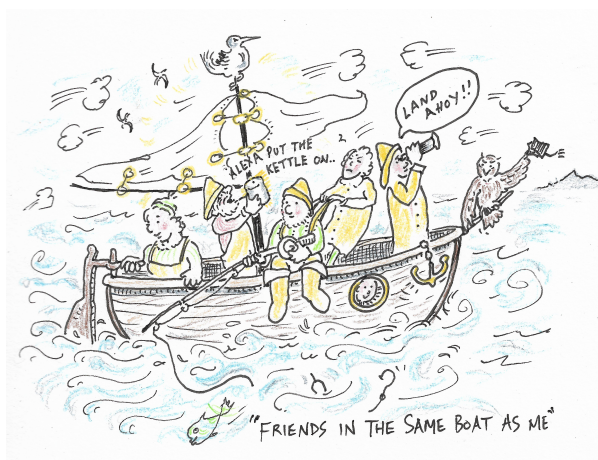
Our Facilitator Paula Brown

Dr Wendy Mitchell's blog:

<https://whichmeamitoday.wordpress.com/blog/>

Dr Shibley Rahman's blog :

<https://drshibleyrahman.wordpress.com>



Handy List For Calls



Your GP
Surgery:.....



Your phone number:.....



Your mobile phone number:.....

Your date of birth:.....

Your email address:.....

Do you have any allergies?.....

What 3 Words home:.....

Medications:

Glossary and Common Acronyms

MBE - Member of the British Empire

BEM - British Empire Medal

BSc - Bachelor of Science (degree)

BA - Bachelor of Arts (degree)

DEEP - UK Network of Dementia Voices

GP - General Practitioner

NHS - National Health Service

LPOA - Lasting Power of Attorney

POA - Power of Attorney

SIGN Guidelines - Scottish Intercollegiate Guidelines Network. SIGN produce evidence based, collaboratively developed clinical guidelines.

CRUSE - Bereavement Support
<https://www.cruse.org.uk>

DNR - Do Not Resuscitate

DNAR - Do not attempt resuscitation

**DNACPR - do not attempt cardiopulmonary
resuscitation**

deep

The UK Network
of Dementia Voices

