



# Human Rights and Dementia

A resource for  
creating better lives

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# Foreword

The Life Changes Trust was established by the National Lottery Community Fund in 2013 with a spend-out endowment of £50 million. Its purpose is to accelerate the pace of positive change in Scotland for its beneficiaries over a period of ten years. The Trust is independent of the National Lottery Community Fund.

£25 million was allocated to the Trust's Dementia Programme work and we agreed our Dementia Strategy to 2023 (see [www.lifechangestrust.org.uk](http://www.lifechangestrust.org.uk)). In collaboration with people with dementia and unpaid carers, the Trust identified five key areas for investment:

- ▶ ***Enable people with dementia and unpaid carers to live in a place that suits them and their needs***
- ▶ ***Protect and promote the independence of people with dementia and unpaid carers***
- ▶ ***Support work that will guarantee that people with dementia and unpaid carers get the help they need when they need it***
- ▶ ***Create a culture in Scotland where people with dementia and unpaid carers feel safe, listened to, valued and respected***
- ▶ ***Empower people with dementia and unpaid carers so that they can do the things that are important to them***

The Trust has invested across these five areas and as the funded work is independently evaluated a clearer understanding is emerging of what can improve and support the life of people with dementia and unpaid carers. This boxset outlines much of the work that has been funded and draws together the first tranche of learning from 2015 until 2019.

Over the next four years we will produce further evidence-based resources online. After the closure of the Trust in 2023, this learning will be hosted online by another organisation so that it can be built upon.

We hope that you find this boxset useful and would appreciate any feedback you might have.

*Shona Hill, Chair*

*Life Changes Trust Dementia Programme Committee*





# Introduction

The purpose of this boxset is to share information and learning to date from work funded by the Life Changes Trust and other organisations in the field of dementia. We hope you find it useful and inspirational.



**‘Dementia: a whole life approach’** is one part of a wider programme of work that will continue for a number of years. We want to invite you to join us as this learning develops – we would value your contribution. The wider work includes:

- ▶ **‘About Dementia’ National Policy and Practice Forum**
- ▶ **Bold (Bringing Out Leaders in Dementia) School of Leadership**
- ▶ **Regional collaborative learning events**
- ▶ **Thematic learning events across Scotland**

Further details about the regional collaborative learning events, Bold and ‘About Dementia’ are available later in this volume. Our thematic learning events will cover topics such as:

- ▶ **The arts and dementia**
- ▶ **Befriending**
- ▶ **Black, Asian and Minority Ethnic communities and dementia**
- ▶ **Choirs, singing and dementia**
- ▶ **Dementia Friendly Communities**
- ▶ **LGBTi Communities and dementia**
- ▶ **Outdoors activities and dementia**
- ▶ **Peer support**
- ▶ **Rights Made Real in Care Homes**
- ▶ **Self-directed support and dementia**

All events are free and will take the form of conferences, seminars or webinars. We have bursaries available for accommodation and travel for people living with dementia and unpaid carers to attend.

If you have evidence-based learning of your own that you would like to tell us about, please email us:

[dementiaprogramme@lifechangestrust.org.uk](mailto:dementiaprogramme@lifechangestrust.org.uk)

*Arlene Crockett*

*Director of Evidence and Influencing  
Life Changes Trust Dementia Programme*





# Human rights and dementia

*Dr Donald Macaskill  
CEO, Scottish Care*



## What are human rights?

Some of you might be reading this and wondering *‘what have human rights got to do with dementia?’*. I believe they have a huge contribution to make in helping us all to ensure that people living with dementia and their families are able to have the best life that is possible.

On one level, human rights are a set of legal principles approved by world leaders in the United Nations Declaration of Human Rights in 1948. They describe the rights which give protection to everyone across the world including persons with dementia. These include key principles such as the right to life, the right not to be discriminated against and the right to have family life and privacy. There are also specific Conventions which have been developed more recently, like the Convention on Cultural, Social and Economic Rights and the Convention on the Rights of Persons with Disabilities.

However, human rights are not just a set of high legal statements and aspirations – although this should never be forgotten – they are also a description of the humanity that we should all be seeking to embody and the society that we should be striving to create.

But lest you think they are utopian and unachievable, at their best human rights are highly practical and useful. They hold up a mirror to who we are as individuals and what our society is like. Part of the reason that they do this, is that there is a deep moral core underpinning our legal rights which is reflective of a long heritage found across centuries of religious belief systems and philosophical traditions. Such traditions describe how it is possible for individuals to live in relationship with others who are different from them, they set a high mark for behaviour and relationships, and they describe what it means to offer dignity, act justly and to value others. Human rights paint a picture of the best of our humanity and encourage us to strive to create that image every day in our living and within our communities.





Over the last few years, Scotland has undertaken a considerable amount of work at policy and practice level to embed a human rights-based approach in the care and support of people who live with dementia. Virtually every piece of social care legislation that has been passed by the Scottish Parliament has had a core set of human rights principles at its heart. This is true of the Adults with Incapacity Act, the Mental Health Care and Treatment Act and the Social Care (Self-directed Support) Act – all of which have something to say about life lived with dementia.

Scotland has also been a pioneer in embedding a human rights-based approach in relation to dementia. Nearly a decade ago in 2009 the Scottish Parliament adopted the Charter of Rights for People with Dementia in Scotland which used the PANEL Principles as their basis. This is about making sure that the words of law have meaning in real life and that the rights of individuals are upheld.

Most recently, the establishment of the National Health and Care Standards and the development of a new service inspection framework for care services have helped to put human rights at the heart of the care and support of people with dementia.

## **What difference can they make?**

Human rights are the rights which every human individual has. They cannot be removed or taken away. They are intrinsic to our humanity. Sometimes, however, there are instances when individuals have had their rights limited or when someone seeks to diminish or abuse those rights. The history of persons with dementia has often been one which has seen others try to limit or restrict these basic rights. There have been times when people have not been heard and their voice has been ignored, there have been instances when psychoactive drugs have been used to control behaviour, there have been occasions when people have been denied choice, and when they have not been treated with dignity and respect.

The core principles which lie at the heart of our human rights legislation are essential for the support and care of people with dementia, but also to enable their exercise of full citizenship and their ability to participate, have voice and gain control – all of which the rest of us demand and expect and often take for granted.

When things go wrong, when society or an organisation limits or restricts human rights it is important that we are able to recognise this, understand what is happening and if necessary to seek redress. It is also important that, as a society, and as individuals, we are able to hold our institutions and Government to account for the duties and obligations they have to protect and advance the rights of people living with dementia.

One way of doing that is through the PANEL model. PANEL stands for Participation, Accountability, Non-discrimination, Empowerment and Legality.

An approach like this is about going beyond the minimum legal requirements and instead mainstreaming human rights in dementia services, policies and practice to make them run better for everyone.

## Participation

People should be involved in decisions that affect their rights.

## Accountability

There should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.

## Non-Discrimination and Equality

All forms of discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.

## Empowerment

Everyone should understand their rights, and be fully supported to take part in developing policy and practices which affect their lives.

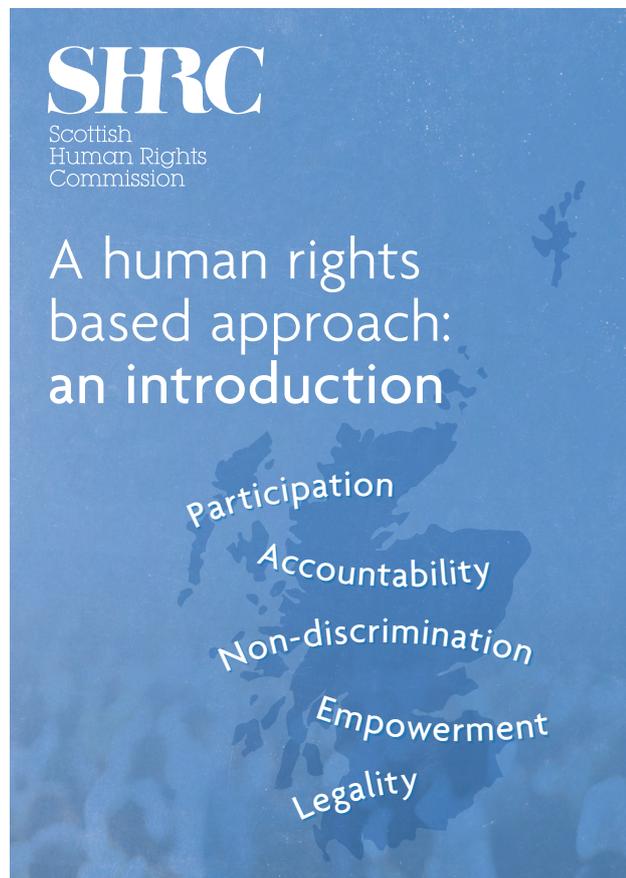
## Legality

Approaches should be grounded in the legal rights that are set out in domestic and international laws.



The person living with dementia and their families have the right to participate in decisions which are being made about their lives, as well as having the right to influence the development of policy and strategies which might impact upon them. Participation isn't just about being in the same room, it isn't just about being told what is happening, or about being 'consulted'. Human rights participation means being involved in a way that includes you, that meets your communication needs, and that enables you to take part in decision-making right from the start of any planning or decision-making process.

But participation goes even wider – it is the right of people with dementia to be enabled and supported to play their full part as citizens in their local community and in national bodies. Human rights are very clear about all people receiving equal treatment and access to services, opportunities and influence. In this sense, access isn't only about appropriate signage, though design is important. It means public authorities and others and others thinking about how they can better include and more effectively engage with people who have dementia. Participation is a right for full involvement, not partial contact on issues someone else decides might interest you.



Accountability means that those who have duties and obligations to protect and fulfil human rights have to be held responsible in the carrying out of those duties. People with dementia expect that those who are responsible for ensuring they receive the highest level of care and support are held to account for their respect and protection of human rights. In instances where they fall short there should be a clear process for someone with dementia and their carers to have the ability to be heard and have redress.

People living with dementia have the right to be free from discrimination and to be treated with equality. This means that who they are as an individual, the characteristics of age, gender, sexual orientation, disability, race, ethnicity, religion and belief – all of the things that make us into unique individuals – these characteristics have not only to be simply acknowledged, but valued, respected and upheld in all the care and support we receive and in every way we seek to live our lives as members of our communities.

Sadly this is not always the case and there is still, even today, too much stigma around dementia which means that people are treated less favourably than if they had other diseases. Equal treatment means giving equal and appropriate value to a person who has dementia as to any other citizen.

To empower anyone is to enable them to have the freedom and ability to have a self-worth which allows them to be free, should they want, to express who they are in whatever form they may wish. Empowerment means that people with dementia need to know their rights and how to claim them. Empowerment means that the human rights which belong to anyone living with dementia should be freely exercised and used. Critically, this involves challenging the inappropriate use of any measures such as legal capacity which might serve to restrict or limit the autonomy of any person with dementia.



Lastly, there is a clear legal framework of rights. The legality dimension of PANEL requires all the laws, policies and practices around dementia within any country to be held up to the light of clear human rights principles. So, for instance, we have to continually ask ourselves: is our health and social care system and legislation based on the highest standards of attaining human rights or not?

Therefore, PANEL is a useful framework because it reminds us of the reality that it is sometimes easy to talk the language of human rights but much harder to put those rights into practice. For people living with dementia, there is a profound requirement that the whole of civic and political society is continually reminded of the basic human rights and needs of an often stigmatised and marginalised group of people.

## **Working towards a human rights future for dementia**

One of the recent human rights conventions which speaks directly to the life experience of people living with dementia and their families is the UN Convention on the Rights of Persons with Disabilities (CRPD), which was adopted in 2006. People with dementia are included in the definition of CRPD in Article 1:

***“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.”***

It is worth reflecting on what each of the Articles in the Convention might mean when they are looked at through the lens of dementia. Some of the particular human rights challenges at the present time in Scotland might include:

**▶ Living independently and participation in the community**

In a time of restricted public finances, are we enabling individuals to properly exercise the choice of staying in their own home with appropriate assistance, including technology, or are we limiting their human rights by deciding that it is cheaper to have someone stay in a care home?

**▶ Respect for home and family**

Are we, in our social care and clinical practice, paying due regard to the importance of someone's sense of belonging to a place and community and are we supporting the maintenance of family life in its totality, including rights around sexual expression and identity?

**▶ Employment**

Do we see individuals living with dementia as continuing to contribute to and be an asset for society by changing employment support to enable the thousands who want to continue to work and be employed to do so?

**▶ Adequate standard of living and social protection**

Is our benefits system and social care support one which is based on equal treatment and non-discrimination or do we treat people with dementia less favourably? Do we ensure that people with dementia have sufficient protection from poverty, loneliness and mental health challenges?

The above is simply an illustration of the powerful questions that a human rights-based approach asks of practice and social policy.



Human rights experts and lawyers often speak about the realisation of human rights. This is a term which presupposes that we are working towards a time when, through deliberate action and intervention, the human rights of all citizens will be upheld and respected and adhered to within a society. That time has not arrived.

Scotland has come a long way along that road but it has some way to travel. It is fundamentally important that those who live with dementia are part of that journey and are enabled to walk the path of struggle to the point where we are able to acknowledge the fulfilment of human rights in the way in which Scotland acts as a nation, the way in which our communities include, and the way in which citizens live in dignity and respect with one another.

# Developing local dementia policy

*Anna Buchanan,  
CEO Life Changes Trust*



Scotland has had a National Dementia Strategy since 2010 and several local areas have a local dementia strategy. Since 2018, the Life Changes Trust has hosted regional collaborative learning events in the Highlands, Grampian, Orkney, the Western Isles, Ayrshire and Arran. See the next section for information about these and future events in the other health board areas.

One of the aims of these collaborative events is to help local Integration Joint Boards (IJBs) and communities think afresh about their local dementia strategies and delivery plans. In 2017 the Life Changes Trust commissioned an analysis of local strategies and delivery plans. Where an area had a strategy or plan, we found that:

- ▶ no strategies demonstrated a human rights-based approach
- ▶ a medical model of disability was predominant
- ▶ almost no consideration was given to the social model of disability and wider social inclusion of people with dementia
- ▶ there was no cross-portfolio consideration, such as how wider services could contribute to supporting people with dementia
- ▶ little was said about unpaid carers and their valuable contribution
- ▶ the needs of unpaid carers in their own right were mentioned infrequently
- ▶ there was very little about the role of housing services
- ▶ almost nothing was said about self-directed support and dementia



It was not an encouraging picture, particularly since Scotland's first National Dementia Strategy was clear that the Scottish Government's dementia strategy, carers strategy and strategy on self-directed support are *“three pillars of a larger reform agenda that recognises carers as equal partners in care placed at the heart of the health and social care system, and which will see more control given to individuals to choose the care and support that is best for them”*.

However, in the past few years we have seen a number of IJBs looking more closely at their local dementia strategies and delivery plans. If your IJB is doing this, we would like to offer some pointers based on our learning through our regional collaborative events and our work more broadly.

## **A human rights-based approach**

A human rights-based strategy will be very clear about the specific rights it aims to secure and retain for people living with dementia and unpaid carers. It will describe how people will know about and claim those rights. A good strategy will explain the ways in which individuals and institutions are responsible for respecting, protecting and fulfilling rights and how they will be held accountable.

A rights-based strategy will also give those people who are most affected by it early opportunities to shape it and will consider how it will impact on their human rights. This does not mean asking people with dementia and unpaid carers to make comments on a near-complete strategy in response to carefully crafted questions. It means early and carefully facilitated, open-ended discussion around the things that matter most to those affected by the strategy. This will lead to a far richer strategy. Discussion may highlight issues that were in nobody's mind when they first put pen to paper. It may also provide solutions that had not been thought of before.

You may need to consider how you are going to explain human rights in a way that people can really understand what is meant. The PANEL principles described in the previous section can be helpful, as can the FAIR approach and the ‘Charter of Rights for People with Dementia and their Carers in Scotland’. See the Scottish Human Rights Commission website for more details: <https://bit.ly/2T1hKg9>.

There are a number of creative ways to involve people in discussions, for example, the storytelling sessions described below in the section on the Life Changes Trust’s regional collaborative events. Remember that not everyone leads a 9 to 5 life and people affected by the strategy may not be able to take part during office hours. Plan some evening or weekend sessions and provide a variety of ways in which people can share their thoughts.

This process should be carried out at key stages throughout the development of a strategy or delivery plan. This type of approach, focused on human rights, will lead to a stronger strategy that is focused on outcomes for those it seeks to empower.

## Equality Impact Assessment

The Equality Act 2010 harmonises and replaces previous equalities legislation. The Act includes a public sector equality duty which replaced the separate duties relating to race, disability and gender equality. The public sector equality duty came into force on 5 April 2011.

Under the Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012 (as amended), listed authorities have a duty to assess and review policies and practices. The duty to assess impact applies to new or revised policies as well as to existing policies and would apply to local dementia strategies. The protected characteristics of age and disability are particularly relevant to any dementia strategy, though the other seven are also relevant and should be assessed for impact. See: <https://bit.ly/2V4E9M8> (Equality and Human Rights Commission – protected characteristics).



Assessing impact enables practical action:

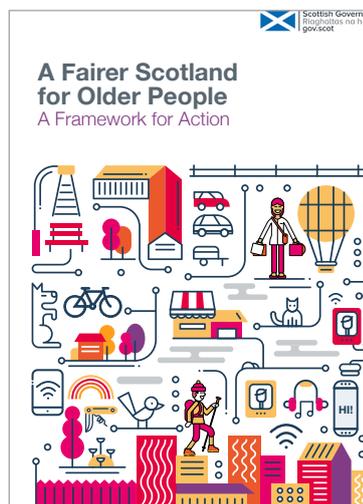
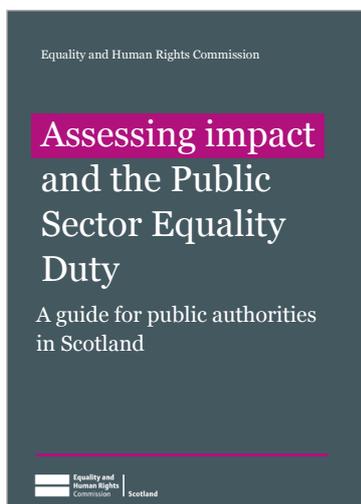
- ▶ more effective action on equality
- ▶ developing a better strategy and delivery plan, based on evidence
- ▶ greater transparency and accountability

The EHRC is clear that assessing impact is not an end in itself and should be an integral part of policy development and decision-making. The impact of applying a proposed new or revised policy is what must be assessed, and the assessment process must happen before a policy is decided. The assessment should not be retrospective, or undertaken near the end of the process, but should instead be integral to the earliest stages of the development of proposed policies or practices, and in the revision of existing policies or practices. Effective assessment will involve people with protected characteristics.

Assessing impact does not finish once the new strategy is published. It is important to monitor the actual impact of the strategy as it is implemented, and revisit the assessment as part of any review. It should be an ongoing, end-to-end process, from early discussions right through to the final decision about whether to go ahead with a strategy or service change and beyond.

For more guidance on equality impact assessment and legal duties in Scotland, read 'Assessing impact and the Public Sector Equality Duty: a guide for public authorities in Scotland' (EHRC).

See <https://bit.ly/37BJAEJ>



## Policy context and evidence

As well as outlining key policy relevant to a dementia strategy, such as Scotland's National Dementia Strategy, consider other wider policy areas and legislation, e.g.

- ▶ A Connected Scotland (social isolation and loneliness strategy)
- ▶ A Fairer Scotland for Older People (older people's strategy)
- ▶ Adults with Incapacity (Scotland) Act 2000 – under review for reform
- ▶ Age, Home and Community strategy
- ▶ Carers (Scotland) Act 2016
- ▶ Health and Social Care Delivery Plan
- ▶ Health and Social Care Standards
- ▶ Homes Fit for the 21st Century: the Scottish Government's strategy and action plan for housing in the next decade 2011-2020
- ▶ 'Housing to 2040' is currently out for consultation
- ▶ Implementation Plan for Self-Directed Support 2019-2021
- ▶ Neurological Care and Support: framework for action 2020-2025
- ▶ Quality Strategy
- ▶ The Patient Rights (Scotland) Act 2011
- ▶ Scottish Government's Inclusive Transport Strategy
- ▶ Scottish Sensory Impairment Strategy
- ▶ Social Care (Self-directed Support) (Scotland) Act 2013
- ▶ Strategic Framework for Action on Palliative and End of Life Care (2015)

There is also a strong evidence base growing in relation to community and therapeutic interventions. The Life Changes Trust is releasing new evidence on a regular basis and the '*About Dementia*' policy and practice forum is reviewing existing evidence bases as part of its work. This boxset contains details of reports that have been and will be published. Also see [www.lifechangestrust.org.uk](http://www.lifechangestrust.org.uk), where you can sign up to the Life Changes Trust's regular ebulletin.



## Dementia friendly information

It is important that a local dementia strategy can be clearly understood by those whose rights it seeks to secure. It should outline what the Integration Joint Board hopes to achieve in a manner that speaks directly to the person with dementia and the unpaid carer. This does not mean it needs to be simplistic but it does need to be jargon-free and dementia friendly. This also applies to any other information that accompanies the strategy.

The DEEP network has produced some excellent guides on writing information for people with dementia. See <https://bit.ly/2T2hFZk>.

People with dementia and unpaid carers appreciate practical information and guidance that explains what help will be available to them when, and who to contact to access it.

## Monitoring and evaluation

### Monitoring

A good dementia strategy will say how the strategy will be regularly reviewed and how progress will be measured. There are two aspects to monitoring that are important. First is monitoring of progress against agreed actions and, secondly, monitoring of the human rights elements of the human rights-based strategy. This could be done by one monitoring group, but you may wish to have two parts to the group that can meet separately as well as together during the year: the actions monitoring group (implementation) and the human rights monitoring group (strategic human rights outcomes).

The group should produce an annual progress report which is published for anyone to read.

## Evaluation

It is good practice to commission an independent evaluation of your local dementia strategy. Although this may seem like a considerable expense, the right evaluators will help you set up your monitoring systems if you bring them in from the very start. Appointing them towards the end of the strategy's implementation does not provide value for money. If commissioned too late in the day the evaluators may be frustrated that you have not collected data in a systematic fashion and so valuable information may be lost. The evaluation can be carried out in a hurried manner and you will not have had the benefit of interim evaluation reports that could help you better monitor and shape the strategy as it progresses.

Creative evaluators, brought in at an early stage, will be able to capture a wide range of quantitative and qualitative data that can be turned into materials that show how the strategy is working in practice. Those materials can be the basis for further reflection and learning for staff, for the monitoring group(s) and for people with dementia and unpaid carers too. This will help inform the next strategy so that it is even better than the current one.

Make sure you involve people with dementia and unpaid carers in the recruitment of independent evaluators. They will have insightful questions and observations that you may never have thought of. Also, if the evaluators cannot convey their approach and methodology well to them, it is unlikely they are competent to work with those your strategy hopes to benefit.



# Regional collaborative learning events

## Human rights, community and dementia...let's keep the discussion going!

In 2018, the Life Changes Trust embarked on a series of collaborative learning events across Scotland called 'Community and Dementia: Creating Better Lives.'

These events will support local communities to uphold the human rights of people with dementia and unpaid carers.

Western Isles  
September 2019

Orkney  
May 2019

Inverness  
Nov 2018

Aberdeen  
March 2019

Perth  
May 2018

Edinburgh & the Lothians

Ayrshire & Arran  
November 2019

"The destiny of human rights is in the hands of all our citizens in all our communities"  
(E. Roosevelt)

2020:  
**Next Event:  
Edinburgh & the Lothians**

 **Contact**

Arlene Crockett:  
arlene.crockett@lifechangestrust.org.uk or  
phone 0141 212 9608.

On 1 May 2018 the Life Changes Trust held a conference in Perth to explore the subject of Human Rights, Citizenship and Dementia. This marked the beginning of a four-year tour to cover every health board area in Scotland, with the purpose of bringing together communities for shared learning, identifying the priorities of people living with dementia and unpaid carers in that area, and consideration of what could be done to better address those priorities.

The first event was held in Inverness in November 2018 and was for the Highland Health Board area. The three-day event was organised by a collaborative planning group from across the region. Given the complex geography of the Highlands, the conference on the third day was live streamed to three areas (Fort William, Portree and Wick). Since then there have been four more events (Grampian, Orkney, Western Isles, Ayrshire and Arran), with a further nine planned for 2020-2022, some of which may be delivered online. You can view the live stream videos on the Life Changes Trust Facebook page: <https://www.facebook.com/pg/LifeChangesTrust/videos/>

## Storytelling and priorities

In order to better understand the priorities of people living with dementia and unpaid carers, we have worked with the Village Storytelling Centre. Using their well-developed skills, the storytellers use innovative yet comfortable approaches that draw out the experiences, views and aspirations of people with dementia and unpaid carers. Often the people who meet each other during these sessions do not know each other at the beginning but feel they have developed a bond of friendship by the end of the session. Several sessions are run across the health board area over the course of two or three days.

The learning from the sessions is written into a report and distilled to common themes. These themes shape discussion at the conference on the final day, so that the priorities of people with dementia and unpaid carers drive conversations and considerations on the day.

To hear more about the storytelling method used, watch this video of Sam from the Village Storytelling Centre: <https://bit.ly/2Qm9h6x>



# Priorities of people with dementia and unpaid carers at the Ayrshire and Arran event in November 2019

## Priority 1:

**We want those that support people with dementia to be better connected.**

- ▶ We need a dedicated single point of contact, a hub
- ▶ Make a directory of what info and services are available pan-Ayrshire, with FAQs
- ▶ More partnership work: Councils and Health & Social Care Partnerships need to come together, share services and learning, and facilitate social connections
- ▶ 24h helpline (phone/email)
- ▶ Need to tackle social isolation: better transport options, upskill people on technology
- ▶ Better targeted advertising and signposting: from no info to info overload, it can be overwhelming

**“Power doesn’t lie in agencies and statutory services, it lies in communities. Statutory services need to facilitate social connections.”**

## Priority 2:

**We want decision makers to make decisions based on an understanding of what it is like to live our lives/do our jobs.**

- ▶ Carers empowered to get involved with decision making – for example an Advisory Group, or sharing carers diaries with policy-makers
- ▶ Policy-makers should shadow staff, see what it is like on the ground
- ▶ Better communication: decision-makers must ask, listen and act
- ▶ A space where staff can safely share with decision-makers; storytelling: lived experience is much more impactful
- ▶ More dementia awareness training – use of dementia suit
- ▶ More focus on the person and quality of care, less focus on time restrictions and money

**“Are there feedback loops? Is there a space to get together and have a voice? People need to feel like they are going to be valued at these sessions”**

### Priority 3:

**We need professionals to be better valued and supported to help address high staff turnover. This means that the support we receive would be of higher quality and consistency. This would help make our task a bit easier.**

- ▶ Better and suitable training for all staff and carers, and not in their own time
- ▶ Remove time-limited care: focus on the person, not the task
- ▶ Raise awareness in the community: Dementia Friendly Communities, local businesses
- ▶ Recognise and celebrate good work and improvements: positive case studies
- ▶ Salaries need to reflect the huge amount of work involved

**“Investment in staff training and development is necessary: training must be continual”**

### Priority 4:

**We need places and time where we can find mutual support and guidance. We want to talk to people who have walked in our shoes. We need proper training, proper understanding and proper relationships**

- ▶ Support for carers to attend training
- ▶ Carers conferences run by carers
- ▶ A hub in each locality, with various professionals available, workshops, training opportunities and information sharing
- ▶ 24h helpline (phone/email)
- ▶ Businesses could provide venues for free within their corporate social responsibilities
- ▶ Community cafes
- ▶ Informal networks on social media

**“There’s not enough staff to look after people with dementia, to enable carers to join groups to access info, speak to other carers (peer-to-peer), etc.”**



## Priority 5:

**We as unpaid carers have a bank of knowledge and experience that others simply do not have. Because of this, we should be involved in the development of policy that affects us and those we care for.**

- ▶ Involve unpaid carers in training, give them opportunities to share knowledge and lived experience
- ▶ A Carers Forum for the whole of Ayrshire
- ▶ A Carers Advisory Group involved in policy-making
- ▶ Use social media for informal invaluable intel
- ▶ Requirement for more local engagement to share information and allow all to be consulted and involved

**“Authoritative organisations (e.g. Care Inspectorate) MUST engage more with individuals and representatives: directly, through forums, surveys, any way to give people a voice”.**

## Priority 6:

**Kindness, respect, compassion and recognising the value of each person – these are not easily quantified, but should never be overlooked.**

- ▶ Face to face interactions
- ▶ Give paid carers time for training and time to get to know the people they care for
- ▶ More person-focused care, less task orientated
- ▶ Share good news stories instead of always focusing on the negative
- ▶ Recruitment based on these qualities: character is more fundamental than skillset

**“Train staff to be more empathetic. Dementia suit was very useful to give staff more empathy – best training tool I’ve ever had!”**

## Feedback from the 'Creating Better Lives' collaborative events

*Exceeded expectations, fabulous day! Inclusion of carers and people living with dementia really impacted the discussion at table/groups.*

*True opportunity to meet and connect with others working in dementia and care support services.*

*It's really given me a lot of food for thought about how we look to properly engage with people with dementia on our new strategy.*

*Take away from this morning's session: the amount of groups and work going on...re dementia services/support and how little knowledge I had on these, when working with dementia patients and relatives daily.*



*Collective atmosphere of hope and the broad audience that represented what is actually happening on the ground. So often conferences are style over substance, this wasn't.*

*There was a real buzz about the place and a sense of genuine and supportive community.*

*Real challenges were acknowledged, yet the enthusiasm and passion and vision of attendees was inspiring.*

*A really humbling experience to listen to presenters.*

## Carers' poem

At the collaborative event in Orkney, Ann Tait and Merle Walls presented a powerful poem about the role they have as unpaid carers:

A carer's life is very strange, life's dreams go all awry  
The things you planned to do together you can no longer try  
Dementia sneaks up quite unseen, not always recognised initially  
The hardest thing for any carer, is to get it diagnosed officially  
If only everyone reacted the same, we'd soon be told what it was  
But some people are angry while others forget  
– it's difficult to find the cause  
Where do I go, who do I see, what is the right procedure  
Who can assist this loved one of mine, there's help out there I'm sure  
We'd like to have a safe space where immediate assistance can be found  
If an urgent appointment comes out of the blue  
and there's no help around  
Or what if a carer can't manage short term  
– do their loved ones go into care?  
Making life so confusing as they'd not know why they are there  
Rather we could have someone come to our homes,  
a familiar face that they've learned  
To do a night and day home service,  
giving peace of mind to all concerned  
To quote a certain professional, let reality come from rhetoric  
Listen to what is being said and do your best to implement it  
There's no use having a conference if it's nothing but hot air  
Now is the time to put in place what is needed for those who care  
We've spelled it out quite clearly and we're willing to do our bit  
Prioritise what we need to happen, you have the power  
– USE IT!



## Upcoming 'Creating Better Lives' collaborative events\*

- ▶ Creating better lives in Edinburgh and the Lothians
- ▶ Creating better lives in the Borders
- ▶ Creating better lives in Fife
- ▶ Creating better lives in Tayside
- ▶ Creating better lives in Shetland
- ▶ Creating better lives in Lanarkshire
- ▶ Creating better lives in Forth Valley
- ▶ Creating better lives in Greater Glasgow and Clyde
- ▶ Creating better lives in Dumfries and Galloway
- ▶ Creating better lives in Scotland (national conference)

*\* Sign up for the Life Changes Trust ebulletin on our website and follow us on Twitter @lifechangestrst for up-to-date information.*

# ‘About Dementia’ National Policy and Practice Forum

Age Scotland is proud to host About Dementia: Shaping Our Worlds Together – Scotland’s forum for improving lives.



Launched in April 2019 thanks to funding from the [Life Changes Trust](#), we work with people affected by dementia to make changes to the things that are most important to them. We know that there is a lot of good work being done around Scotland both nationally and locally, but we also know that many people affected by dementia are still struggling to get the support they need when they need it. The About Dementia project believes that people with dementia and unpaid carers are in the best position to say what is and isn’t working and most importantly, how to do it better.

Over the next five years we will bring together people affected by dementia and organisations who are interested in working for change, to look at how we can improve policy and practice across many different areas of life.

## What we do

Working with a wide range of partner organisations, we hold regional forum meetings four times per year, rotating around different locations across Scotland. In addition, smaller groups look at particular issues in greater detail, also meeting four times per year.

It is up to you how involved you would like to be as a member of the forum. You can attend a regional forum meeting, share your knowledge and experience of a particular issue through a group, or just be kept informed of the work we do. By signing up to become a forum member, you will be sent news and information about the project and kept updated about upcoming meetings. On the ‘get involved’ page, (you can find it here: <https://bit.ly/398jESd>) you can specify which areas of the project you are interested in.



As a forum member, you will have a number of ways of being involved in the project, including attending meetings in person and giving contributions via email, over the phone, or by post. There will also be ways to be involved via video and online messaging, and we will keep you informed of the different options for involvement.

## What are the groups?

Over the course of five years, About Dementia will look in detail at 15 topics in relation to dementia policy and practice. Below is a list of the topics.

- ▶ Befriending
- ▶ Black and Minority Ethnic Communities
- ▶ Dementia Friendly Communities
- ▶ Dementia Prevention
- ▶ Faith and Belief
- ▶ Financial Inclusion
- ▶ Housing and Home
- ▶ Human Rights of People Living with Dementia
- ▶ Human Rights of Unpaid Carers
- ▶ Information, Advice, and Independent Advocacy
- ▶ LGBTQI+ Community
- ▶ Sport
- ▶ Technology
- ▶ The Arts
- ▶ Transport and Mobility

Work in each of these areas will be undertaken by groups within the larger forum. Each group will run for two years, with the exception of the group on Prevention, which will run for all five years of the project. We will start four new groups each year.

The four groups that started in 2019 are:

- ▶ Dementia Prevention
- ▶ Human Rights of Unpaid Carers
- ▶ Housing and Home
- ▶ Transport and Mobility

The work of each group will be underpinned by our project values: equality, human rights, relationship-centred care, peer support, early intervention, and prevention.

## Our aims

- ▶ To discuss and debate evidence and learning from existing practice, drawing out best practice and influencing policy makers so that it is embedded in policy and used in practice.
- ▶ To identify gaps in policy, practice and research and carry out work to address these gaps, seeking funding where necessary.
- ▶ To identify seemingly insurmountable challenges in policy and practice and discover solutions to these challenges, which could be implemented.
- ▶ To influence policy makers, key leaders, practitioners and others in Scotland to adjust or re-write policy so that the needs of people with dementia, their families and unpaid carers are met and their lives fundamentally transformed for the better.
- ▶ The forum will operate from the grassroots up, and influencing at a local level will be as important as influencing at a national level.



## Become a member

You can sign up to become a forum member and specify your areas of interest at the 'Get involved' page here: <https://bit.ly/398jESd>

### For more information

For further information about the project, please contact the About Dementia team. We are happy to help with any queries, and can be contacted by email at: [aboutdementia@agescotland.org.uk](mailto:aboutdementia@agescotland.org.uk)

If you are interested in staying up-to-date with the project via social media, you can follow us on Twitter. Our handle is [@AboutDementiaSc](https://twitter.com/AboutDementiaSc).

You can also contact us by phone via the Age Scotland switchboard on 0333 323 2400.

### Our postal address is:

About Dementia Team  
c/o Age Scotland  
Causewayside House  
160 Causewayside  
Edinburgh  
EH9 1PR

# Bold (Bringing Out Leaders in Dementia) School of Leadership

Everyone should be able to flourish throughout their life. This is the ethos of Bold, funded by the Life Changes Trust.

**bold** Bringing Out Leaders in Dementia

There are lots of misconceptions about persons living with dementia and we'd like to change that.

We imagine a Scotland where having dementia doesn't matter for 'who I am as a person' or 'how I live my life'. A lot of people feel the same and are already, in many different ways, taking a lead and doing something about it.

Bold is bringing diverse types of leader together on an equal footing, providing free leadership development opportunities and working to make a difference.

## Why Bold?

We've called the project 'Bold' for two reasons:

- 1. 'Bold' reflects our aspiration to be courageous, distinctive and imaginative in our approach.***
- 2. The full project title, Bringing Out Leaders in Dementia, recognises that a large number of new leaders of all ages and from all walks of life, including many persons living with dementia, are already finding their place in 'the dementia world'.***



Bold is bringing different types of leader together on an equal footing and providing free leadership development opportunities across Scotland.

Bold leaders can expect to try things out and learn from each other and by doing things. They can expect to form lasting, supportive relationships, make a difference and have fun.

Key features to support this include:

- ▶ taking time to know and look after yourself
- ▶ working in small groups across the whole of Scotland
- ▶ learning together using an established Social Learning approach
- ▶ working with creative partners, using stimulating spaces and creative arts-based approaches
- ▶ a Personal Assistant framework to assure persons living with dementia of the types of support they value
- ▶ an 'academy' model connecting leaders from all groups upon 'graduating' with established national and international leaders to achieve wider changes in society

## Inspiring leaders across Scotland

We hope to turn imagination into reality so that more people can flourish throughout their lives. We hope to grow a movement of inspiring leaders across Scotland. We'll be challenging the common view of dementia as a personal tragedy shared only by close family members. We aim to replace this view with the understanding that flourishing is achievable for everyone, that we are all living with dementia in different ways and can all do something positive. Through the actions of Bold leaders and the wider Bold community, we hope to become a more dementia inclusive Scotland where we can all live well together.

***‘Bold leaders’ are people who are already making a difference in ‘the dementia world’ and who would welcome the opportunity to develop further as leaders.***

## **You don’t have to be in a position of authority to be a ‘leader’**

Bold hopes to bring together people of all ages and from all walks of life, with different skills, personalities and life experiences – including persons living with dementia.

We are looking for people who are making a difference in lots of different ways – in their neighbourhoods, social groups, communities, organisations and in the world around them.

## **Social leadership**

Bold is encouraging a more social and responsible type of leadership, social leadership.

While we are keen to attract diverse types of leaders, there are six things that all social leaders will do:

- ▶ **Be Curious** – leaders who are willing to question, to challenge when necessary and to be challenged.
- ▶ **Try, Learn, Try** – leaders who are willing to experiment, to give things a go, make mistakes, to stretch and to support others as they stretch too.
- ▶ **Share** – leaders with a desire to share – when you try, succeed, fail and learn.
- ▶ **Be humble** – leaders who are willing to accept that you don’t have all the answers, to truly listen and to act with humility.



- ▶ Tell stories – leaders who are able to craft experiences into stories that resonate with others, short stories, stories told in the moment, longer, more reflective stories and stories written with others.
- ▶ Be fair and protect – leaders who are willing to fight and do what's right, not what a system or set of rules tells you to, who are prepared to rock the boat if necessary.

Bold is working in partnership with '*About Dementia: Shaping our worlds together*', Scotland's dementia policy and practice forum led by Age Scotland, also funded by the Life Changes Trust.

Several partner organisations and individuals, including persons living with dementia, are helping to plan, promote and deliver different parts of the Bold project.

### **How can I get in touch with Bold?**

You can contact us through the project website:  
[www.bold-scotland.org.uk](http://www.bold-scotland.org.uk)

Or email [info@bold-scotland.org.uk](mailto:info@bold-scotland.org.uk)

*We'd love to hear from you!*

## Getting in touch

If you have any queries or wish to share your views and ideas, you can contact the Life Changes Trust in a number of ways:

**Phone:** 0141 212 9600

**Email:** [enquiries@lifechangestrust.org.uk](mailto:enquiries@lifechangestrust.org.uk)

**Website:** [www.lifechangestrust.org.uk](http://www.lifechangestrust.org.uk)

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