

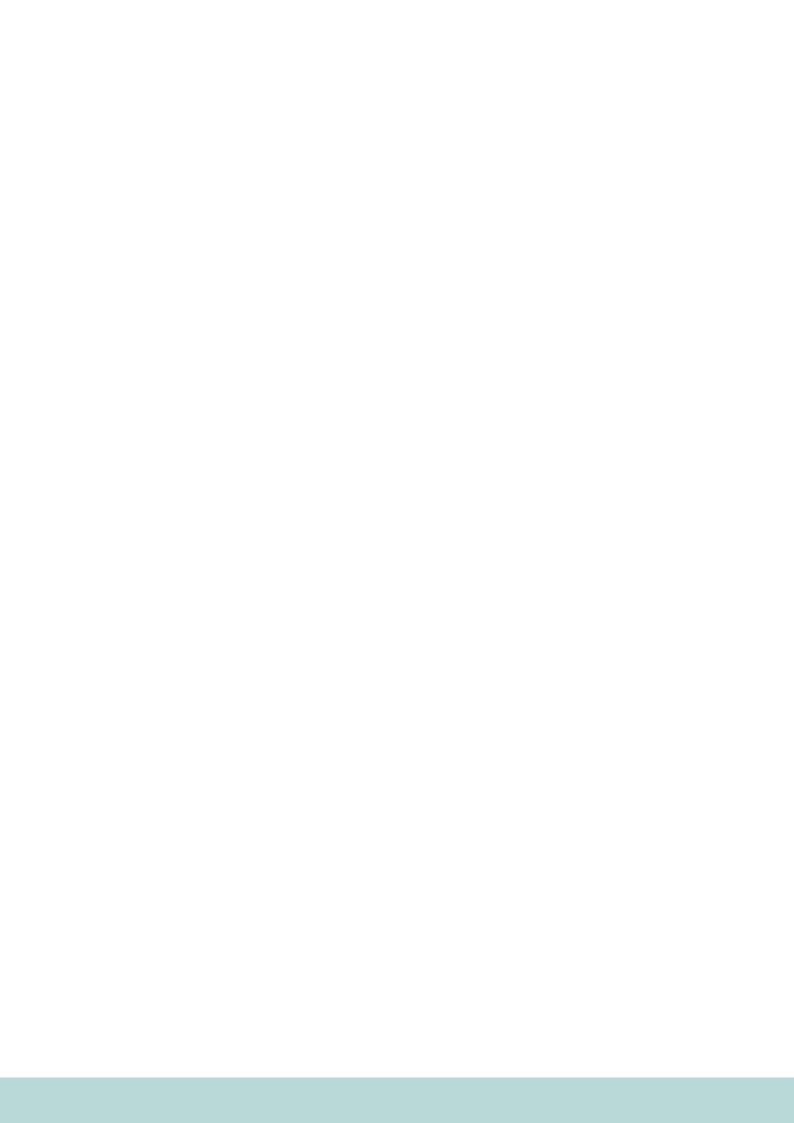
# Recognising, respecting and responding:

promoting human rights for residents of care homes in Scotland









#### **Contents**

Foreword by the CEO of the Life Changes Trust	4
Introduction	6
Engage me, enable me, empower me	8
Bankhall Court, Govanhill	8
Focusing on abilities, not disabilities	14
Jenny's Well, Paisley	14
Filled with song and laughter	21
Anderson's Care Home, Elgin	21
This is normal life	<b>27</b>
North East Angus Care Home Improvement Group	27
Changing habits	33
Fairfield Care	33
Thinking about the future	40
Laurel's Lodge, Aberdeen	40
A garden for the isles	47
Tigh a 'Rudha, Tiree	47
Comment by the Chief Executive of Scottish Care	54

## Foreword by the CEO of the Life Changes Trust

Human rights can sometimes seem a subject that is lofty, vague and academic. The purpose of Rights Made Real in Care Homes is to show how human rights are



made real in practice. It's about adding flesh to the bones of human rights legislation, policies and standards.

On 9 October 2019, the Scottish Parliament hosted a celebration of 10 years of Scotland's Charter of Rights for people with dementia and carers. It is good that Scotland has these documents, however, they mean very little to residents of care homes if they do not experience them in practice.

Human rights reside in the hands of those who actually deliver rights on a day-to-day basis. And that's why the Rights Made Real in Care Homes project is so important.

Human hands deliver a whole variety of rights to people hour by hour, minute by minute, in the jobs they do.

When hands are used to support someone to walk from one place to another because that's where the care home resident wants to go, those hands are delivering a human right (the right to liberty). When hands apply cream or turn someone to avoid pressure ulcers, when they open the door to welcome family and friends, when they hold the hand of someone who is dying and the voice perhaps sings a meaningful song, human rights are being delivered (right to protection from inhuman and degrading treatment; right to private and family life; right to freedom of thought, conscience or religion).

When a hand grasps the computer mouse and scrolls through an important training package so a staff member can learn more or is laid on the shoulder of a colleague who's struggling, those hands help nurture a culture that delivers human rights.

One key element of Rights Made Real in Care Homes is Scotland's Health and Social Care Standards, which seek to uphold basic human rights and offer a real opportunity to further develop our understanding of what human rights look like in practice (see <a href="https://bit.ly/3hucj3q">https://bit.ly/3hucj3q</a>.) The Life Changes Trust funded Rights Made Real because we want the care homes in this report to demonstrate what legal human rights and the Health and Social Care Standards look like in practice.

We hope that this project will enable other care homes to identify where human rights are being met in their own homes. We also hope that this project will develop a new and more accessible language around rights in care homes; a language that care staff, residents and families will feel confident using.

#### **Anna Buchanan**

Chief Executive Officer, Life Changes Trust



#### Introduction

## RIGHTS© Made Real in Care Homes

Rights Made Real in Care Homes is an exciting project, funded by the Life Changes Trust and delivered in partnership with Scottish Care and the University of the West of Scotland.

The overall aim is to improve the quality of life of those living in a care home and to help support staff to not only recognise, but embed, human rights in their everyday practice.

The initiative funded creative and innovative projects and ways of working that will benefit people living with dementia and show others how to make rights real in care homes. All partners in the project are committed to ensuring that older people, including those living with dementia, have a right to maintain strong connections with family and friends, with their communities and with the things that matter to them regardless of where they live.

The Life Changes Trust invested £135,000 to support seven projects across Scotland to promote the inclusion and participation of care home residents with dementia in a meaningful way. Scotland's new health and social care standards state that everyone in Scotland deserves to receive the care and support that is right for them. Each of the funded projects was designed to show how these standards can work in practice.

This collection of stories from the project sites showcases good practice in the care homes, particularly in relation to observing and promoting people's human rights. It shows that adopting a human-rights based approach is not something people working in care homes should view with anxiety, but instead recognise that it is about building on many of the attitudes they currently possess and activities they currently practise.

The overall aim of the project and the stories is to inform and encourage workers in care homes across Scotland in their efforts to meet the new health and social care standards and provide care that recognises human rights, promotes people's dignity and demands only the highest-quality level of service.

## Engage me, enable me, empower me

#### Bankhall Court, Govanhill

Bankhall Court, a dementia residential care home in the Govanhill area of Glasgow, is unusual in that it is arranged over five floors with a conservatory on top. But it also stands out for the ambition of its residents who are not inclined to be restricted by any cognitive impairment. Running a 5k, attending the opera, visiting a safari park, dropping into the pub – activities at Bankhall Court are designed to suit individuals' interests and to give their life real meaning.

Susan Glen, the home's project manager, says Bankhall Court has been on a journey. Before receiving a £20,000 grant through the Rights Made Real in Care Homes project, budget and resource constraints meant there were limited opportunities for residents to feel part of the community. Activities were geared more to groups than individuals and some residents rarely went out. 'It made me really quite sad,' Susan says.

A first step in embedding more of a human rights approach to care and support was the introduction of one-page profiles for everyone, staff included, with the aim of pairing key workers more closely with particular residents.

'The profiles helped us bring likeminded people together – staff and residents who had similar interests, were on the same wavelength, had the same sense of humour, the same interests.' says Susan.



Some colleagues were wary at first, she recalls. 'It didn't sit very well with them and they asked why they should share personal information.

'So I took my profile to a staff meeting, read it out and said, "I'm not telling you anything you don't know about me – but you can tune in to what makes me tick".

And then they got it, they understood.

'It's not as though we were asking for their bank details – it's more about knowing that family is important to them, or they always need a coffee in the morning, or they don't like to be woken before 8am on days they're not working.'

Bankhall Court team leader Kristine Douglas adds: 'The profiles are simply about getting to know the finer details about someone. My profile is about my husband, my three children and my dog, and how they make me happy – and how cake and tea is the way forward when I'm stressed!'

Another development was to involve residents in the recruitment of staff. 'We felt it was important,' says Susan. 'Although it wasn't something we'd done before, our residents have the right to voice an opinion about who would best support them, help them feel involved and included.

'And the residents participated really well in the process. They asked questions and gave feedback at the end, and that was really nice to see. We're going to keep doing it and will ask more of them to become involved.'

Creating Conversations, an approach pioneered by dementia specialists working with people with the condition and their carers, has also helped Bankhall Court shift towards a more rights-focused philosophy.

Part of the charity Artlink Central and now a social enterprise, Creating Conversations aims to enhance the lives of those with dementia and anyone connected to them through communication and activity kits that help overcome any barriers. Tested in care homes, NHS wards and mental health units, Creating Conversations products include a tablecloth designed with images that help access memories, stimulate engagement and strengthen relationships.

'Our tablecloth is outdoors-based so, for example, it has little flowers on it,' Susan explains. The cloth and the conversations it stimulated has led to other things. Bankhall Court now has its own roof garden up in that fifth-floor conservatory where residents can grow their own produce, an initiative that helped the home win a Food for Life Served Here bronze accreditation from the Soil Association.

Kristine says: 'We were trying to teach residents about where their food comes from and to help them grow their own. They were really involved in the roof garden, they felt included and they really like it.'

A subtle but equally important factor in Bankhall Court's success has been more careful consideration of communication and of the language used to encourage residents to express their wishes and desires.

#### 'The use of language, and how language can be perceived, is a big thing in our project,' Kristine says.

An example she cites is the word 'aspirations'.

'I was often talking about 'aspirations' and 'long-term goals' but it just didn't sit right. If I said to a resident, 'What's your aspiration?', they would just look at me and I thought, 'Right, they're getting the same feeling as I am'.

The home's lounge even featured a painting on a wall of a 'tree of aspirations', which Kristine asked to be painted over because she disliked it so much.

In conversations with residents, 'aspiration' became 'if I could, I would ...', a phrase they readily understood and which meant much more to them. It also gave insight into attainable objectives such as a visit to Glasgow's Royal Concert Hall, rather than outlining long-term, possibly unobtainable goals.

Some very practical changes brought immense reward for particular residents. One man, for example, wanted internet access so he could follow sport and feel more connected to his family.

But the building's unusual layout made a connection difficult. Potential solutions were tried but all proved unsuccessful. Undaunted, staff persevered and eventually technicians were able to *'run wires all over the building'*, as Kristine puts it, and an internet connection was established.

'I would have paid a million pounds to see his face when he was finally able to watch his sport channel on TV,' Susan says. 'He was just so delighted.'

Ensuring activity is tailored to an individual, rather than focused on a group, is central to the home's approach now.

Susan says: 'Some of our guys love doing 5ks.

Even though they all have dementia, there are different stages and different types of dementia. It doesn't mean they lose the ability to use their legs. I'm not saying we'll run a 10k next but if someone wants to do it as a project, we'll definitely try it.'

Of course, some activities are not without risk – running a 5k is one example, as is going to a swing park, which some residents tried, where they also descended a slide. Susan acknowledges that potential dangers must be assessed but adds: 'Sometimes, benefits outweigh the risks.' Photographs of laughing Bankhall Court residents on the swings and slide suggest she has a point.

Kristine concludes with a maxim that embodies the Rights Made Real in Care Homes philosophy:

### 'Engage me, enable me, empower me to live well with dementia.' - Kristine

Bankhall Court has taken that philosophy and, in partnership with residents and families, turned it into life-affirming action.

#### **Rights secured:**

✓ Right to liberty and security

Article 5, European Convention on Human Rights

"I can maintain and develop my interests, activities and what matters to me in the way that I like."

Health and social care standards, 2.22

✓ "I make informed choices and decisions about the risks I take in my daily life and am encouraged to take positive risks which enhance the quality of my life."

Health and Social Care Standards, 2.24

"I know who provides my care and support on a day to day basis and what they are expected to do. If possible, I can have a say on who provides my care and support."

Health and Social Care Standards, 3.11

√ "I... can choose to grow, cook and eat my own food where possible."

Health and Social Care Standards, 1.38

### Focusing on abilities, not disabilities

#### Jenny's Well, Paisley

Promoting someone's human rights in a care home setting requires more than just actions. It needs to build from a mindset that values people's rights to make choices, even if that may present risks.

'Talking about human rights usually means we are also talking about risk-taking,' says Nicola Dow, deputy manager of Jenny's Well, a 54-bed care home in Paisley for people who are blind or partially sighted.

'Many staff tend to be risk-averse. We're trying to change their mindset so they don't consider a resident wanting to use a hammer to put nails in a bit of wood as a risk to the person's safety, but rather an expression of his right to take a risk. The resident would be building stuff if he was at home – why should that stop just because he's in a care home? Residents are people. They have the right to make that decision and be confident to do it with appropriate support.'

- Nicola

Royal Blind, who run the home, used the opening of Jenny's Well to seize the opportunity to encourage staff to rethink care approaches, as head of care for Royal Blind, Morag Francis, explains:

'When we opened Jenny's Well in 2017, it was a completely new building and a completely new staff team. Staff came from lots of different places. Many had been working in task-oriented cultures that focus on routine. Our aim was to develop a person-centred, enabling approach that focuses on what people can do, rather than what they cannot do. The focus then is on ability, rather than disability.'



The home set up a project that aimed to promote human rights and encourage a person-centred approach by focusing on activities for residents.

'We wanted to work with residents who are vision impaired and have dementia to ensure that any activities they are involved in are chosen by them,' Morag explains. 'The aim was to offer a wide range of options based on the residents' preferences and which would enhance their lives in ways that are important to them.'

The project has enabled Morag and the team to take the care home forward in the positive way intended.

'Having the opportunity to take part in this project has been brilliant,' she says. 'It's helped support us to get the team going in the direction we want to go in. We have 90 staff and very few, if any, had experience of working with people with vision impairment before Jenny's Well. It was quite a steep learning curve, but the focus of the project has helped us get there.'

Ensuring older people have a voice in decisions about their care and support is a core principle of the work of Royal Blind. The project in Jenny's Well was taken forward by two meaningful-activities assistants, who designed activities programmes based on discussions and evaluations with residents. But progress was never going to be straightforward.

'All our residents are blind or partially-sighted, and around 70% also live with dementia,' Morag says. 'It can be a huge challenge to make sure people who have a vision impairment and dementia get involved as much as possible in activities, so our initial approach was to encourage them to understand that they can still do things.'

Questionnaires were passed among residents, staff and families and two focus groups were held with residents.

'What was really interesting from the questionnaire responses was that families and staff viewed activity as big-ticket items – concerts, outings, big events. But for the residents, activity meant someone to be with, to do things with and to pass the time of day with. That's what's important to them. So we had to start getting that message across to families and to the staff as well.'

- Morag

'Staff thought there wasn't a lot of activity going on in the home,'
Morag continues. 'But from the residents' perspective, there was. If
someone was in the resident's room, spending time with them and
helping to pick their clothes for the next day, that was seen as activity.
Trying to get that message across, though, has been quite challenging.'

Residents' ideas from the focus groups were taken up by the activity assistants and absorbed into the programmes. It became clear quite early, though, that 'exercise' was not top of the residents' list of potential activities.

'In the first focus group we did, nobody wanted to do any exercise at all,' Morag says. 'As soon as we mentioned exercise – absolutely not! But they wanted to go dancing, bowling, walking and gardening, so exercise was covered in a different way – we just didn't use the word exercise!'

A range of projects sprang from the focus group. Two of the main ones were developing a reminiscence room and setting up a bar.

'Reminiscence is quite important to the residents – they like to talk about the old days,' Morag says.

Football was a particularly big topic for reminiscence, and the home used contacts with St Mirren Football Club to secure some donations that have been placed in the reminiscence room.

And the bar is open.

'The bar serves a dual purpose,' Morag says. 'First, it's a hub where people can meet and chat over a drink. Some of the families work for a large drinks company and have been able to donate drinks for the residents.

'Second, we've turned it into a bit of a games room. The residents were involved in that part of the project, and we've listened and acted on the advice they gave us.'

A remarkable turnaround in attitudes to exercise was found at the second focus group, as Morag explains.

'We went from a group of people who didn't really want to exercise to a group of people who were very keen to get involved. So the activities were turned around to be more exercise-based. We've now got footsteps around a central area that the residents can follow – the number of yards walked is marked up, so some competition has emerged over who can walk the furthest.

'Some of the residents also did a 5k walk a couple of weeks ago. That helped to bring the community in – a big part of our project is to involve the community as much as possible.'

So where is the project at this time, and where is it heading?

'The residents have been listened to, they are seeing their thoughts turned into actual activities, and staff are getting a bit braver,' Morag says.

'We try not to have absolute set timetables.

It's about going with the flow a little and if the residents decide, "We don't actually want a quiz today, can we do something else?", we do something else. There's no rule book – we're constantly adapting and changing.

'One of our challenges for the future is trying to get families more involved,' Morag continues. 'There's a lot of things we would like to do, but we need families' support. And while many like the ideas, some are still quite hesitant about joining in. That's something we're going to start tackling over the next year.'

Nicola feels that while challenges do remain, the home, the staff and the residents have come a long way in a short space of time.

'It was a big step for the residents and the team to move forward, but they've done an absolutely brilliant job,' she says. 'One of our proudest achievements is that we've made a fully functioning well. It has been sanded, varnished and stained with the help of the residents and they are absolutely beaming with pride. It's one of the very big things in Jenny's Well that we're really happy to be part of.'

#### **Rights secured:**

✓ Right to liberty and security

Article 5, European Convention on Human Rights, with Article 14 – right secured without discrimination.

"I get the most out of life because the people and organisation who support and care for me have an enabling attitude and believe in my potential."

Health and Social Care Standards, 1.3

✓ "I can maintain and develop my interests, activities and what matters to me in the way that I like."

Health and social care standards, 2.22

✓ "I make informed choices and decisions about the risks I take in my daily life and am encouraged to take positive risks which enhance the quality of my life."

Health and Social Care Standards, 2.24

√ "I am recognised as an expert in my own experiences, needs and wishes."

Health and Social Care Standards, 1.9

#### Filled with song and laughter

#### Anderson's Care Home, Elgin



#### 'Music is massive in Anderson's'

says Yoni Lefevre.

Yoni is a researcher from the Innovation School at Glasgow School of Art and she's referring to a charitable trust care home in Elgin where she worked on a project called the 'Anderson's Experience'.

'Our goal was to bring communities and care together through music,' Yoni explains. 'So we really tried to explore what role music can play in the care home context.'

She describes how the project used a rights-based approach to redefine 'care home', both within Anderson's and more broadly. Working with residents, staff, families and the wider community, the project team first explored perspectives of care homes and collected stories about them from various public locations in Moray.

The next stage was to dig deeper into people's understanding of what it means to live in, work at and visit Anderson's. 'Based on that understanding, we then collectively explored the role of communities and care through music,' Yoni says.

Sarah Granitza is activities co-ordinator at Anderson's. She agrees that music plays an important role in the care home. There was already a wide range of music activities involving nursery-age children, for example, and schools, as well as entertainers coming in to play for residents. 'So we decided music was definitely the approach to take in this project, working with Yoni and her colleague, Dr Tara French.'

The year-long project began with observation – Yoni and Tara making themselves familiar with the home, its residents and staff. A 'pop-up' event was staged, where people – including an actor from the TV soap Emmerdale who happened to be visiting – were asked about their impressions of Anderson's when they first walked through its doors. Common descriptions were homely with a warm atmosphere, and staff who appeared welcoming and caring.

A round of interviews followed with residents, staff and volunteers in an attempt to capture the essence of Anderson's from multiple perspectives. Another pop-up event, this time in the foyer of a local hospital, gathered views of care homes in general. Most were negative, although where interviewees had experience of a care home, opinions tended to be more nuanced and realistic.

Several workshops were then planned where thoughts and ideas around music were explored with residents, family members and others. The suggestion of a programme of community music sessions evolved from a workshop involving volunteers at Anderson's. The result was three full days of music activities to try out all the ideas to emerge from the three workshops.

'The goal was to explore the role of music in the care home and to give people a different, more meaningful experience when participating in music activities,' Yoni says.

Those three activity days were intense but offered the opportunity to work in small groups across Anderson's five separate units.

'The small group sessions were great,' says Sarah. 'All of a sudden, residents were up and dancing. It was an amazing thing to see just how happy people were.' The sessions also helped Anderson's cement its reputation as a home rather than a care home, she adds.

The project then delved further into stories regarding music and its place in the lives of individuals resident in Anderson's. Yoni says: 'We did one-to-one sessions about 'music and me", where we asked, 'What are your top three songs? Can you share your memories of those songs and how they make you feel?" These sessions enabled us to explore with residents the personal meaning of songs on a deeper level.'

She adds: 'One of the things we had figured out is that Anderson's is really integrated into the local community already. But an added value of critically reflecting on the role of music was to consider how we could make those interactions with the community more meaningful.

'For example, instead of asking people to come to the home to perform their songs, why not ask them to perform songs that are actually related to specific residents, or which can trigger certain kinds of memories?'

From that came an idea to map old songs of Scotland – I Belong to Glasgow and The Northern Lights of Old Aberdeen, for example – which linked residents to places significant to them.

Often care home residents can seem like passive audience members in musical activities – being performed to and with little input into the structure of the session. But the project team strove to ensure that music activities in Anderson's became much more interactive as well as meaningful.

Yoni explains that children coming into a residential home can sometimes feel a little awkward if they know none of the residents and the residents don't know them. At Anderson's they tried different approaches to encourage interactivity, with children and residents working together to make percussion instruments, for example, or the children singing songs based on randomly chosen items picked from a basket by residents.

A highlight of the three-day musical programme was a performance by 'The Wandering Scotsman'. Musician Bill Mullen lives in America but grew up in Dundee and his wife has a relative in Anderson's. He responded to a social media post where the home asked anyone interested in being involved in the music project to get in touch.

Sarah says: 'It was an absolute honour to have him play. Everybody was just blown away by the atmosphere and was so happy.'

In a post on his website, Bill wrote: 'From the first song the whole place was filled with song and laughter. It was fantastic. I was so impressed.'

The success of the project has prompted Yoni and Tara to produce the <u>REMIX Toolkit</u>, a resource that describes music-based activities designed to enhance and explore the role of music in a care home.

Yoni says: 'Using these tools can help staff and volunteers to build empathy and understand a person's background and life story. We want to share it now for everyone to use.'

Although much has been achieved as a result of the project, there's no question of Anderson's losing momentum.

'It's great to see how much has gone on as a result of the project,' Sarah says.'But we're still only at the start, I think. It's been a long journey to this point but we're definitely on to something special.'

#### **Rights secured:**

✓ Right to freedom of expression
Article 10, European Convention on Human Rights

"...I can direct my own play and activities in the way that I choose, and freely access a wide range of experiences and resources suitable for my age and stage, which stimulate my natural curiosity, learning and creativity." Note that this Standard is written for children, however, it is equally applicable to adults.

Health and Social Care Standards, 2.27

✓ "I get the most out of life because the people and organisation who support and care for me have an enabling attitude and believe in my potential."

Health and Social Care Standards, 1.3

√ "I can maintain and develop my interests, activities and what matters to me in the way that I like."

Health and social care standards, 2.22

#### This is normal life

#### North East Angus Care Home Improvement Group

Ivan Cornford learned early in life that nothing should get in the way of aspiration.

'I was brought up at the time of punk rock,' he says. 'So I believe you can do anything without the slightest bit of knowledge. I played in a band once and couldn't play guitar, couldn't even tune it, but that was our band.'

Ivan brought this ne'er-say-die approach to a project focusing on promoting the human rights of residents in a group of care homes in northeast Angus.

Ivan works through Scottish Care and put the project together in the five care homes, all of which belong to different organisations within the North East Angus Care Home Improvement Group. Three remain with the project, two in Montrose and one in Brechin.

The project is looking widely at the human right of participation and how everyone can be supported to meet their full potential.

'It's about assisting services to move towards developing participation and inclusion strategies that focus on individual needs,' Ivan explains. 'It recognises that no single process will provide a one-size-fits-all solution to the issues of participation and inclusion – a range of approaches will be needed.'

A major part of the project will be to develop practices that do not require care homes to take on extra staff or bring in extra resources, or be asked to do anything unrealistic. 'The focus is on changing the culture of care to embed the right to participation and inclusion in everyday work,' Ivan says. 'It will challenge the notion that participation and inclusion are add-ons to normal activities.'

The project adopts the five headline outcomes of the health and social care standards as its principles.

'We feel the principles about residents being included in wider decisions and recruitment and selection are particularly important for us,' Ivan says. 'We like those ideas, and we use them as a springboard to move into other areas.'

An initial audit looked at how people were involved in all aspects of the homes, from activity to recruitment and selection, and in day-to-day and community decisions.

'We found that levels of participation were quite limited and depended on individuals' abilities and capabilities,' Ivan says. 'All of the homes involved residents to some degree in recruitment and selection, for instance, but it was restricted to residents the staff felt had the capability to take part in interviews. Staff couldn't see how they could involve everybody in the process of recruitment and selection, or get beyond the issue of capability.'

Based on findings from the initial audit, the project currently is drilling down to look at three specific areas for improvement – staff supervision, staff recruitment and care planning. Each care home is focusing on one of them, defining how they can support full involvement for as many residents as possible in that area. Ivan arranged workshops on improvement work to support the staff.

Residents' involvement in staff recruitment is a particular source of interest for Ivan.

'Residents need to be involved in appraising the people who'll be looking after them,' he says. 'They have the right to be able to size up people's levels of caring and compassion. That is our starting point.'

'We were talking to some of the residents in one home about what they felt about the staff there,' Ivan continues. 'They said they liked them because they all had good manners. So that home is now thinking that this will be part of their person spec for job applications. The person spec is going to be designed by the residents – they like it when staff say please and thank you, so that's a criterion future staff will need to meet. It's simple things like this that the project is helping us to learn.'

Even though the project is very much about human rights, it has a strong link – at least metaphorically – to gardening. Gardens have become something of a vehicle in the project to enable the teams to look at culture change more generally. This was accentuated by the experience of a garden design company Ivan invited in to support the project.

'We asked a group that specialises in creating therapeutic garden spaces to come and speak to us about culture change,' Ivan says. 'The company told us about how they had been paid a lot of money to create new gardens in care homes. When they went back to revisit the homes six months after completion, they found the gardens hadn't been used. The doors to the outdoor spaces were still locked, so no one could get into them.

'They realised that all their carefully thought-through work didn't matter unless there was culture change within the organisation. Somebody had to unlock the door and let the residents into the garden.'

On another occasion, the company had wanted to help out a care home whose garden was full of weeds.

'They asked the home if they could help,' Ivan recounts. 'But the staff said no – they needed the weeds. Why, the company asked, a bit bamboozled? Because the residents like to do the weeding, was the answer – no weeds, no weeding. And sure enough, later that afternoon, a resident was seen to go out into the space and start weeding.'

The lesson from all this, Ivan believes, is that it's the culture of the home that is the most important element in determining the possibility of change. This extends to all aspects of how a home functions.

'It's as if we need to have someone to come into our homes to look at them completely differently, almost like an alien,' he says. 'And then start talking to residents about what they like and don't like about the home and the staff, and how involved they feel in how the home is run.'

Ivan's project is still in its relatively early stages, and he does not expect to see the full results of what has been learned from it for some months yet.

'It's taken us about eight months to get to this place, and hopefully we will have a clearer idea of the outcomes in about six months' time,' he says.

'Key learning so far has been about engaging with and starting conversations with residents, which was the focus of our first improvement workshop.'

A second workshop with the organisation Ketso, which specialises in helping people to work together more inclusively and effectively to develop creative solutions to the challenges they face, and staff from Health Improvement Scotland will take place shortly. After this, Ivan and his colleagues will put their new learning into practice across the three chosen areas of focus.

'The really interesting question is about what's stopping us from getting people as involved as they can be in recruiting and selection', Ivan says. 'Then we want to apply what we learn as widely as possible to help people be involved in different ways. It's about throwing things at the issue to see what works and trying different options. That's the bit we will come to next – it should be quite exciting.'

And gardens will continue to play a part in how the project develops.

'What stops residents going out to the garden when it's raining?' Ivan asks. 'Is it because they don't want to get wet? Or are staffing stopping them because, well, it's raining? Rain's never hurt us. We just put on a coat and wellies and off we go. Someone can pick up an umbrella, walk out that open door and go round the garden. This is normal life. This is what it's about.'

#### **Rights secured:**

√ Right to liberty and security

Article 5, European Convention on Human Rights

✓ "I am supported to participate fully and actively in my community."

Health and Social Care Standards, Principles

✓ "I can maintain and develop my interests, activities and what matters to me in the way that I like."

Health and social care standards, 2.22

"I know who provides my care and support on a day to day basis and what they are expected to do. If possible, I can have a say on who provides my care and support."

Health and Social Care Standards, 3.11

✓ "I benefit from a culture of continuous improvement, with the organisation having robust and transparent quality assurance processes."

Health and Social Care Standards, 4.19

#### **Changing habits**

#### Fairfield Care

The quashing of someone's human rights in a care home can happen in full sight. It does not need to be the result of conspiratorial actions. It can happen simply through the act of enforcing habits – the result of habitual thinking and behaviour that may be barely noticed and go unremarked and unchallenged.

Sandra McCombie, business support manager for Fairfield Care, recounts how habitual thinking and behaviour looks in practice.

'One of our homes is in a very rural setting, with beautiful views. But the staff close the blinds, meaning the residents can't see the views. We asked, why do you do that – why deny the residents such a lovely sight? And the answer was – it's a habit. It's done "just because". And there are so many habits like this one that have formed in care homes "just because".

Moving beyond habitual thinking and behaviour requires effort and support. And that is at the hub of a project taken forward within homes owned by Fairfield Care.

The project is using the Learning and Innovating from Everyday Excellence (LIFE) approach from the My Home Life programme for care homes.

'There's nothing wrong with some habits,' says Professor Belinda Dewar of the University of the West of Scotland, who has been supporting the project. 'But we wanted to help people to talk more about them. We wanted them to be curious about the habits they want to keep, and work out what to do with those they wanted to move on from.'

Belinda explains that LIFE sessions really tap into what matters to people and help them to take forward the cause of human rights in care homes.

'They use short snippets of conversations and stories about life in care homes to help explore more deeply what matters and what is valued,' she says. 'The stories use the experience of residents, their relatives, managers and staff of care homes and the wider community to help us talk about our ideals and practical ideas that can be taken forward to benefit everyone who lives in, works at or visits the home.'

Belinda's colleague Cathy Sharp (from Research for Real), adds: 'We do not need long stories or conversations. Just a few lines about life in care homes to help us explore what people value, what matters to everybody in the home community – what we want to have more of, and what practical ideas we can take forward to everybody's benefit.'

The LIFE session process starts with hearing or reading a story.

'Then we go through a process of questions,' says Cathy. 'We talk about what is there to celebrate in this story? People chip in with their views. Then we move on to talking about any surprises and puzzles that emerged, before turning to identifying what people would like to happen more of the time, and what can each of us do that feels real and possible?'

Once the questions are completed, the group considers what learning has emerged from the process, noting what's worked well so it can be used on another occasion. 'We've learned a huge amount by following this process consistently throughout,' Cathy says. 'There's always something new. We're always surprised and there's always learning every time we've had a LIFE session.'

A LIFE session story looks something like this one, from a resident.

"I didn't like it here at first. I was wary of the staff. I didn't know them. I didn't really trust them. I've managed to make friends. People can be funny at times. After being here, I notice that the staff seem to be genuinely interested in me. They ask me the funny questions and get a bit of a laugh. I feel protected here. I look forward to the lovely meals and sitting here in the lounge watching the world go by, you can just sit here in peace and quiet. I like to talk to my daughter on the phone. She has been off on holiday so I look forward to hearing from her."

'So from this story, we'd work through the questions – what is there to celebrate, what are the surprises and puzzles, and what can we do from here on in?' explains Belinda. 'It's amazing what we come up with. Yes, we might think we need to ensure more opportunities for phone calls with the daughter, but many other things can spin off as well.

'The importance of peace and quiet, for instance,' Belinda continues. 'Where are the spaces in the home for peace and quiet? We have activities coordinators, but should we think about having a peace and quiet coordinator as well? The most obvious route from the story might not be the one we end up pursuing.'

Typical issues that come up for discussion in the sessions include supporting night staff to ask specific questions about hopes and what matters to them and residents, asking people what helps them to feel safe and protected, discussing the concept of activity with the Care Inspectorate, and being more aware of how people can be supported to make connections and form friendships.

To ensure learning from the sessions can be shared among those who are unable to attend, the team have developed a set of cards that carry some of the questions and topics discussed.

'The cards are kept inside a brightly ornamented container called 'Chatterbox",' Sandra explains. 'It's all very well having a LIFE session with five or six people in the room, but what about the rest of the staff in the care home? How can we spread our learning, curiosities and puzzles more widely? The Chatterbox is the answer.'

Questions might be things like: It's the day of your funeral; what would you like people to be saying?, Who would you like to get to know better? and Who makes you laugh? As well as using the cards with people who haven't been to a session, they can also be used within sessions to raise another topic of discussion if conversation dries up.

For Belinda, an important issue is that it is the Chatterbox – not professional staff – that determines the questions.

'So it isn't about staff asking residents questions, which is the traditional approach, perhaps. It isn't an interview – it's an engagement. There is something quite levelling about that process.'

'The big thing about LIFE sessions is that you don't really get it until you do it,' Cathy says. 'Lots of people haven't really understood it until they've actually tried it out and have been part of it. And then perceptions change.'

That was certainly Sandra's experience.

'I remember saying to Belinda, well, you can come and do this, but we know our residents really well – you're not going to improve much. That was a bit arrogant. It's only when you peel back at the sessions you find out how much you didn't know, not just about the residents, but also about yourself. I never realised that I wanted everybody to laugh at my funeral – how fun is that!'

And now, Sandra is seeing the tangible effects of the LIFE sessions.

'A resident used one of the sessions to tell her story about the care home that pulled the blinds down and obscured the lovely views outside,' she recounts:

'About two weeks ago, she came up to me and said, "do you know, the blinds were opened and I got to see the sunset. It was beautiful and I wished you were there, and I could have taken a picture for you."

That lady made us face up to and challenge our habits with her story. That's culture change in action for me.'

The LIFE sessions and the cards are still evolving, and Sandra is confident that they will continue to gain momentum as time passes.

'The important thing for us is that the LIFE sessions are still ongoing,' she says. 'I see them as being a bit like a lemon drizzle cake – you know that when you put the lemon on the top of the cake, it will take a wee while to filter down to the base. At the moment, I'd say the lemon's probably halfway down the cake.'

Belinda is also optimistic about the future of the project in the homes.

'One of the lovely things about the LIFE sessions is that it's not Sandra or any other staff member who's taking it forward – it's actually all the people in the session. All of them – staff, residents, relatives – are progressing different bits of the change process. So if we ask who are the innovators in our day-to-day practice – actually, it's all of us.'

#### **Rights secured:**

- ✓ Right to respect for private and family life Article 8
  European Convention on Human Rights
- ✓ "I benefit from a culture of continuous improvement, with the organisation having robust and transparent quality assurance processes."

Health and Social Care Standards, 4.19

✓ "I am included in wider decisions about the way
the service is provided, and my suggestions,
feedback and concerns are considered."

Health and Social Care Standards, Principles

√ "I am supported to discuss significant changes in my life, including death or dying, and this is handled sensitively."

Health and Social Care Standards, 1.7

✓ "I am encouraged and supported to make and keep friendships."

Health and Social Care Standards, 2.19

#### Thinking about the future

#### Laurel's Lodge, Aberdeen

People of all ages have concerns about what happens if they become ill and are no longer able to control their lives. The idea of anticipatory care planning (ACP) – through which individuals can think ahead, understand the health issues they may or do face and plan accordingly – arose as a result of these concerns.

ACP undoubtedly has many benefits for people. But it can pose challenges for care workers, especially those in care homes, who find they need to have difficult conversations with people they have known for some time and have strong relationships with.

Jill Will, a lecturer at Robert Gordon University, has been facilitating a research project at Laurel's Lodge care home in Aberdeen that looks at the issues around ACP in care-home settings.

'The care-home staff were keen to do something to try and address ACP,' Jill says. 'ACP was being directed by GP services, who were asking care-home staff to find out where people wanted to die, where their preferred place of care was, did they have a 'do not resuscitate" order in place, and was the family aware. Often, this was carried out as part of residents' six-monthly care reviews, where staff would discuss care plans and maybe speak a bit about the future in terms of end-of-life care.'

The project aimed to help staff think about how they could have ACP-related conversations, particularly for people with dementia.

'It was about finding out what people really want,' Jill says. 'How do we help staff to explore the issues? And how do we have those conversations in a way that's really meaningful?'



A human rights approach was central to the project, particularly in areas around freedom of expression and allowing people to really be themselves. The health and social care standards were also a significant underpinning, with the project linking to issues about discussing 'significant changes in my life', including death and dying.

The project began by asking the care home team what they thought about ACP.

'We wanted to get an idea of where they were at on ACP,' Jill recalls.

'There was an overwhelming feeling about ACP conversations being really difficult, quite intimidating and something that's tricky to get right. And there was a real nervousness about getting it wrong – the team were hoping to protect the relationships they'd built with residents and families and didn't want to do anything that could impact on that negatively.'

But there was also a sense that staff saw ACP as a really important area.

'Staff were also speaking about wanting to go deeper, to have conversations that really helped them to understand and get beyond just scratching the surface.'

Discussing where ACP sat in care reviews was the main catalyst for change, Jill believes.

'This was the first kind of real lightbulb moment the staff had,' she says. 'At an early workshop, somebody said they would usually start an ACP-related conversation with a resident or relative by saying, "this isn't something either of us really wants to talk about." Fronting up that this is going to be a difficult conversation immediately puts people on the back foot. We discussed as a group about how that approach might land with people on the receiving end, and realised – how can we expect them to engage in a conversation that neither of us wants to have?'

The first approach, then, was to flip the language around.

'This was one of the biggest changes in our project.' Jill says. 'We got round to saying that, actually, this is a conversation that's really important for us to have, and it's a conversation we really value. It doesn't have to happen in one go, but it's something we need to begin to think about.'

The <u>Caring Conversations framework</u> and tools from My Home Life Scotland, part of an international initiative that promotes quality of life and delivers positive change in care homes for older people, were used to progress the project, and further workshops were set up for staff.

'We used the Caring Conversations principles of becoming courageous, celebrating, connecting emotionally, being genuinely curious, considering other perspectives, collaborating and compromising to explore how the discussion could go with residents and relatives,' Jill says.

From there, a different structure was applied to the review process.

'Reviews had been directed by paperwork that was standardised across the care home company,' she recalls. 'So we said, let's have a think about how we have that conversation – let's think less about what's on paper and more about the people in front of us.'

<u>Key Jar</u> questions – where people pick a question randomly from a jar, then read out and answer the question – were used to support staff to share a happy memory or something they admired about a resident.

'Lots of lovely stories emerged, then we moved on to creating a kind of "day in the life" of the person. That was really, really powerful, because rather than focusing solely on activities of daily living like eating and sleeping, we saw what Mrs Smith's whole day looks like – these are the things she enjoys and here is why they are important to her.

'I was really struck when we did that,' Jill continues. 'The staff members were so, so knowledgeable about the person they were discussing.'

The focus then moved from "thinking about ACP" to "thinking about the future".

'The staff felt these conversations about the future would enable them to really have eye contact with the person and focus more on emotion than the practicalities,' Jill says. 'So it became much more about connection rather than getting information.'

Questions were designed not only to find out where the person would want to be, but also to find out what might bring them comfort.

'One of the staff said the change in approach had helped her to focus on who the resident was now,' Jill says. 'It wasn't all about looking back to the past. People change – their tastes change, their interests change – so it was about valuing people for who they are now and not just what they used to be.'

Staff continued to feel a bit awkward in generating the conversations in the early stages, but the positive responses they got from residents and relatives helped them to move deeper.

'Relatives who may have been reluctant to discuss end of life before were now inviting staff to talk about it, sometimes even before staff were at that stage in their heads,' Jill says. 'They were able to speak openly and honestly about how they perceived their loved one's condition, and that was an invitation for staff to ask more – the relatives were ready for it.

'The relatives also said they surprised themselves – they were saying things that they'd never even really thought about before,'
Jill continues. 'I guess that's the beauty of having carefully crafted questions that are quite open and that people can steer – they can sit in the driving seat and take it to where they want it to go.'

A key part of the project was to try to capture how we can know about what is important to someone who can't verbalise and who cannot be part of formal review meetings.

'It was really important to think about how we hear what people want,' Jill says. 'So we spoke a lot about people's facial expressions, hand movements and gestures. We discussed what we knew from experience of working with the person. And we spoke with relatives about what works with the person, what doesn't, and how we would know it.'

A second set of workshops allowed staff to reflect on what had been learned, which led to the development of a toolbox and an 'unfolding story', as Jill explains.

'We had a celebration event where we listened to people's stories and came up with this collective.'

#### The staff said:

'I used to think anticipatory care plans were difficult conversations to have about people who are already at the end of life. But now I know that anticipatory care plans are an ongoing conversation that helps us to get to know about everyone's future wishes. When I think about human rights towards the end of someone's life, it should be a journey where they are involved in making choices about what they would like. Going forward, the thing I'd like to notch up is my confidence. I'd love to find out about the person's wishes and whether these conversations make a difference to them. One thing that puzzles me is if I'm doing it right. The thing that I've learned that I'd most like to share with other care homes is that you can do it with the toolbox.'

Embedding ACP into six-monthly reviews and changing the conversation around ACP are notable achievements, but moving forward, Jill wants more.

'We need to look at how we make this part of everyday conversations and how it can build on and inform what people want for their future,' she says. 'We also need to try to involve relatives more. I've been absolutely blown away by some of the relatives in the project and the lengths they go to try and help people to enjoy the things that matter to them, so I'd really like to focus on this a wee bit more.'

### **Rights secured:**

- ✓ Right to freedom of expression
  Article 10, European Convention on Human Rights
- ✓ Right to respect for private and family life Article 8, European Convention on Human Rights
- ✓ "I am supported to discuss significant changes in my life, including death or dying, and this is handled sensitively."

Health and Social Care Standards, 1.7

✓ "My future care and support needs are anticipated...My personal plan sometimes referred to as a care plan is right for me because it sets out how my needs will be met, as well as my wishes and choices."

Health and Social Care Standards, 1.14 and 1.15

## A garden for the isles

Tigh a 'Rudha, Tiree



It seems strange that residents of a care home in Tiree, one of the most beautiful of Scotland's islands, should not have an outdoor space from which they can safely enjoy the outdoors and all its splendours. But that is how it was for residents of Tigh a 'Rudha, a small local authority care home for older people and the only care home on the island.

Tigh a' Rudha (Scots Gaelic for House on the Point) sits in a beautiful spot with spectacular sea views. But the windows in most of the rooms are too high for people in wheelchairs to see out of, and the main lounge faces not the sea, but the car park.

This was a situation Jane MacDonald, assistant social care worker attached to the care home, was determined to rectify.

Inspired by older people's right to have access to a garden and safe, independently accessible outdoor space enshrined in the new Health and Social Care Standards, she made a successful application to the Rights Made Real in Care Homes funding to get things sorted.

'We wanted to enable people with dementia to exercise their right to access a garden,' she says. 'The aim was to ensure that people with dementia would have the freedom to choose to go outside when they wished and would experience the physical and psychological health benefits of spending time outside. We hoped that people with dementia, whose world so often shrinks, would feel that the garden had significantly expanded their world.'

Jane recognised that the care home residents, most of whom had lived all or most of their lives on the island, would have led predominantly outdoor lives when they were younger. She wanted to help them maintain or re-establish those connections with the outdoors.

Staff at the home had done their best to create an outdoor sitting area for residents, but it was not really doing justice to the surrounding landscape.

'The lounge has a patio door and we had created a small pavement area outside,' Jane explains. 'But although we did our best to brighten it up with tubs and planters, it was never in good repair and was separated from the car park only by a small kerb. It wasn't safe for residents to access on their own. And while it could be sunny in the afternoon, it lacked proper shelter, which meant that it was vulnerable to the prevailing southerly winds. We could only use it on still days, and you don't get many of those on Tiree!'

Jane's plan was to take this sitting area together with an under-used part of the car park and create a sheltered and attractive sensory garden suitable for people with dementia. In designing it, she followed the guidelines for creating dementia-friendly outdoor spaces from the University of Stirling's Dementia Services Development Centre.

'The garden is being paved to form a safe and level surface with the minimum possible threshold between the lounge and the garden,' Jane says. 'We'll have seating areas and space for wheelchairs, with a wide path looping around a central raised bed and back to the door.

'The raised bed is being filled with plants chosen for their scent, colour and different leaf shapes and textures. There will be calming greenery but also more stimulating colours and scents, as well as plants that sway in the breeze. We're choosing plants that thrive on Tiree and will make sure we don't include anything potentially harmful.'

The far end of the bed will have a gentle water feature flowing over pebbles, creating an interesting stopping place on the journey round the garden. Wheelchair-accessible planters will be placed along one of the boundaries to encourage residents to grow salads, flowers, strawberries and herbs.

And the residents and their families are not the only ones who will benefit – the local wildlife will thrive too.

'We've created a wildflower meadow beyond the garden boundary, sown with flowers and grasses native to Tiree,' Jane says. 'This makes good use of what would otherwise be a dead space once the garden is fully constructed and will also provide a habitat for wildlife, including the great yellow bumble bee, a native species of Tiree that is now endangered.'

Residents and their families have had their say on the design of the garden, as have staff.

'The staff pointed out that when residents have been able to sit outside, they've enjoyed being able to see who is going in and out of the building, who is passing by on the road, and watching the sheep and cattle on the machair,' Jane explains. 'We've therefore, asked for "windows" or lower areas to be incorporated into the garden fence so that people can see what's going on. Similar "windows" will frame views out to the sea.'

Securing the funding was just the first part of a long process of bringing the garden dream to reality.

'There was, and is, so much to consider.' Jean says. 'The safety elements, the costs and the natural elements are but three. We of course have done everything we can to plan safety into every phase, and the budget is being monitored constantly, but there isn't much we can do about the weather! We painted the central plant bed, for instance, only to find it rained before the paint dried – so it will need to be done all over again.

'The garden is nearly, nearly finished, but this is why I've given up on predicting completion dates!'

The largest of the two raised beds has been planted and the wildflower meadow has been sown. Pavers are now going down and a new level-threshold patio door has been ordered, after which the access ramp can be completed and the gates hung.

The first planting day caused great excitement in the home.

'I did the planting with a friend whose mother, who is a keen gardener, is a resident,' Jane says. 'We opened the patio door while we were working to give residents and staff a sense of what it might look like once the garden is finished. It meant people could feel included in the process and my friend could discuss with her mother what plants we were putting in and where.'

The idea of inclusion was further extended through workshops Jane organised for staff to enable them to make some attractive objects for the garden.

'I think staff members enjoyed the chance to create things and also the opportunity to contribute something to the garden,' she says. 'We made a combination of word tiles in English and Gaelic collected from a previous 'Tiree in Your Words" community project and from a word-collection box at the home, and also some tactile, decorative shapes. The idea is to group the shapes at intervals along the rim of the central bed. If we have any left over, we may mount them on small boards or put them in a little cloth bag for people to touch as everyone – staff and residents alike – seems to enjoy handling the samples. They are so beautiful and tactile.'

Jane is conscious, though, that while several residents are or were keen gardeners, not everyone is interested in plants and flowers. She therefore has shifted her thinking towards alternative uses for the outdoor space.

'I was looking at my own garden and realised that I have got old floats, a lifebelt, creels and other objects I've picked up on the beach dotted around, as have many gardens on the island,' she says. 'We could include some of these in our garden – these artifacts would mean something to residents and would maybe prompt memories. This is just one of the ways in which people might like the garden to develop.'

Because Tiree is a small and geographically isolated island community, people with dementia who live there can lack access to many of the services and groups available to people in larger communities or on the mainland. Residents are close to their families and communities but have fewer opportunities to participate in the kinds of group activities and other creative pastimes that might lead to a richer and more fulfilling life. Jane and her colleagues hope the garden will go some way to filling those gaps.

'We hope that creating the dementiafriendly sensory garden will help people to re-engage with the outdoor world that once was so important to them, to use the outdoor space to spend time with family, friends and the wider community, and to be able once again to experience some of the wonderful sights of our beautiful island.'

## **Rights secured:**

√ Right to liberty and security

Article 5, European Convention on Human Rights

✓ "I can choose to have an active life and participate in a range of recreational, social, creative, physical and learning activities every day, both indoors and outdoors."

Health and Social Care Standards, 1.25

√ "If I live in a care home, I can use a private garden."

Health and Social Care Standards, 5.23

✓ "I receive and understand information and advice in a format or language that is right for me."

Health and Social Care Standards, 2.9

√ "I can use an appropriate mix of private and communal areas, including accessible outdoor space, because the premises have been designed or adapted for high quality care and support."

Health and Social Care Standards, 5.1

# Comment by the Chief Executive of Scottish Care

As someone who once worked in a longstay institution in which people with disability were forgotten, not heard and not recognised, it is a joy to read of the



developments in recognising, respecting and responding to people's human rights that are being taken forward in the project care homes.

At the heart of the projects is the idea of true person-centred planning. Person-centred planning essentially is all about imagining something better, as are human rights.

The term realisation of rights is often used in legal circles. Technically it means that all human rights law and activity directs itself towards enabling people's rights to come to fruition, be realised, come to pass. Through their actions in the projects, the care home teams and their colleagues from academia are realising people's human rights.

The question now is, what is the future for human rights in care homes, for residents, their families and staff? And how are we going to realise that future?

The first step of 'imagining better' is to imagine. It's not wishful thinking. It's not daydreaming. It's about rooting our desire and vision of a future into the present.

Do we have a vision for care homes? Have we started to utilise the tools of the imagination? It's not just about plans and strategies – it's also about the music and the amazing work done at Anderson's in Elgin, the foresight to set up a bar where people can meet, chat and enjoy the company of others at Jenny's Well in Paisley, the vision to turn the fifth floor of a home into a roof garden where residents can grow their own

food at Bankhall Court, the sheer audacity of aspiration that is driving culture change in the North East Angus Care Home Improvement Group, the impressive array of tools and techniques that are supporting residents and staff in Fairfield Care homes to explore and define what they really want, the gentle but so positive way that anticipatory care needs are being identified at Laurel's Lodge in Aberdeen, and the determination of staff of Tigh a 'Rudha in Tiree to ensure older people with dementia can enjoy the basic right to experience the outdoor splendour of their wonderful island.

Let's use our creative senses. Let's use all those aspects of who we are as human beings to first imagine, then realise, a future that is better. That's the message of the projects for me.

There are some dramatic developments in human rights going on in Scotland. The First Minister has set up a human rights taskforce that includes people who really understand the world of health and social care. The aim is to create a human rights act for Scotland and potentially to incorporate the human right to health in law.

This gives those of us who are determined to progress human rights in care-home settings a huge opportunity not only to influence the legislation, but also to ensure that practice is properly resourced and the right to health is understood as being more than just the right to clinical health; it is also the right to wellbeing, the right to access social care and the right to receive palliative care and bereavement support when the time comes. We need to grasp this opportunity.

These projects are imagining human rights not as something of interest only to lawyers and specialists, but as the vehicle for changing our relationships and our communication and, importantly, advocating for those who currently have no voice.

The projects, and our mission, are far from over. Human rights is a journey, not a destination. Let's all imagine better, imagine different.

#### **Donald Macaskill**

Chief Executive Officer, Scottish Care