

RIGHTS

Made Real in Care Homes

Recognising, respecting and responding:

*promoting human rights
for residents of care
homes in Scotland*

Laurel's Lodge, Aberdeen

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 funding supported the development of seven 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 these 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.

In order to showcase good practice in the care homes, particularly in relation to observing and promoting people's human rights, we have produced a collection of stories from the projects which show 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.

This story is from Laurel's Lodge, Aberdeen

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 [Caring Conversations framework](#) 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.’

[Key Jar](#) 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

