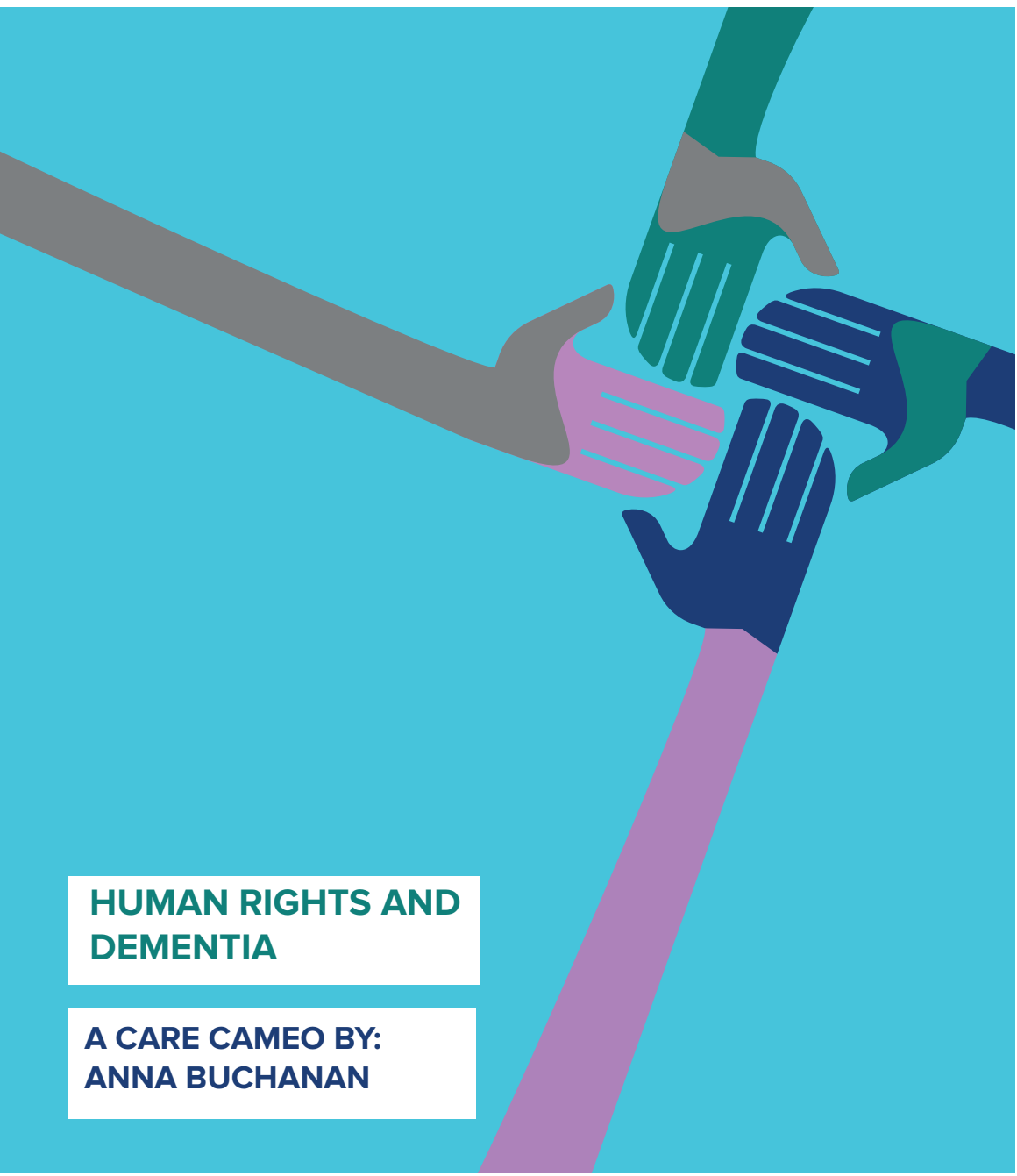




The *Care Cameos* series is designed to present short but challenging sketches of various issues and to provide a forum to encourage and foster debate on a whole range of issues important for the delivering of care and support for older individuals across Scotland.

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HUMAN RIGHTS AND DEMENTIA

**A CARE CAMEO BY:
ANNA BUCHANAN**



Preface

Welcome to the third of Scottish Care's Care Cameos.

The Care Cameos series is designed to present short but we hope challenging sketches of various issues and to provide a forum to encourage and foster debate on a whole range of issues important for the delivering of care and support for older individuals across Scotland.

I am delighted that this Cameo on dementia and human rights has been written by Anna Buchanan, who brings a unique perspective on the human rights issues facing individuals living in Scotland with dementia.

In this Cameo, Anna considers the potential of a human-rights based approach in the care and support of people living with dementia but goes much further than that in placing human rights at the heart of the whole life experience of people with dementia and their families.

Scotland has a strong recent history of articulating policies and strategies with human rights at their heart. However, such articulation on its own does not necessarily lead to an embedding of rights in day to day experience. Kofi Annan told the UN Human Rights Commission in 2005 that, '*the era of declaration is now giving way, as it should, to an era of implementation.*' We are still some way from that robust implementation of rights for people living with dementia in Scotland.

This Care Cameo is offered as a contribution to such a process. I hope you enjoy its challenges and considerations.

**Dr Donald Macaskill
CEO Scottish Care**

Introduction

I belong to a book club and we recently read the book 'Small Great Things' by Jodi Picoult. The book looks at racism in the context of the care of a newborn baby, and the story revolves around a quote from Martin Luther King Jr:

"If I cannot do great things, I can do small things in a great way".

There are few of us who can claim to have done 'great things' in the way that society defines as 'great'; but we can all do small things in a way that makes a huge difference to people we meet in the course of our day to day lives.

This Care Cameo is about human rights and dementia. Through it, I hope that I can encourage you to look at human rights in a slightly different way.

I am a lawyer and I love all the technicalities and intrigue of legislation and case law, but that is not the best place to start when considering human rights and dementia. Human rights are essentially about relationships between people; they are about our interactions with each other and the ways in which we attribute value to one another. They are based on the idea that every individual human being in the world should be treated with dignity and respect. Behind human rights is the symbolism of a 'spirit of worldwide community' that connects all human beings to each other.

This concept is based on a broad humanistic approach, advocating that shared humanity should supersede our differences.

"What is 'human rights'? It is everything - life, liberty, human dignity and justice. It encompasses all that which pertains

*to mankind in its universal context and is, therefore, universal in scope and application. To those who ascribe to the values of life only things material, this definition may appear esoteric. Beyond that, however, all that which touches upon the quality of life, in an inclusive sense, is ultimately a question of human rights."*¹

History - and current affairs - show us that the concept of human rights and the reality do not always coincide. Often human rights are *not* easily secured and retained, particularly by those who are in situations of vulnerability or are experiencing disadvantage for whatever reason. A key factor in taking a human rights-based approach is a solid understanding that a) human rights will often conflict, and b) they need to be balanced in the most equitable way possible. In current UK law there are, of course, absolute rights - the right to life, prohibition of torture or inhumane or degrading treatment, the right not to be held in slavery or servitude, and the right to no punishment without law². However, even these rights have grey areas and may occasionally need some balancing. The threshold for achieving these rights can be high, for example, what we may consider to be 'inhuman and degrading' may not be considered so by the courts - see *McDonald v United Kingdom*³.

The quashing of human rights can be systemic; it can be almost invisible, so we don't realise it is happening. There may be learned thinking or behaviour that goes unchallenged by those around us. This thinking can pave the way to outright discrimination or human rights violations.

Human rights in the UK are currently protected by legal instruments such as the Universal Declaration of Human Rights (international law), the European Convention on Human Rights (European law), the Human Rights Act 1998 (UK law) and The Charter of Fundamental Rights of the European Union (European law).

Legislation, conventions, declarations, charters and standards give us guidance on human rights and set standards and thresholds. Sometimes they provide people with the opportunity to challenge human rights violations through the courts, either directly or through judicial review. Sometimes they don't.

In Scotland there are a number of human rights-based documents that are relevant to the care of people with dementia, including:

- The Promoting Excellence Framework⁴
- The Charter of Rights for People with Dementia and their Carers in Scotland⁵
- The PANEL Principles - Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality⁶
- Scotland's National Action Plan for Human Rights (SNAP)⁷
- The Standards of Care for Dementia in Scotland⁸
- Scotland's National Dementia Strategies (although the third Strategy published in June 2017 makes no real mention of human rights)⁹

- Health and Social Care Standards: My support, my life¹⁰

Scottish citizens with dementia who face discrimination or a breach of their human rights may have legal recourse through the Human Rights Act 1998, the Equality Act 2010, other civil action and judicial review. There is some legislation in Scotland that sounds as if it should provide direct legal recourse, but doesn't. For example, the Patient Rights (Scotland) Act 2011 does not provide a route for seeking redress through the legal system if a person considers that their rights, as set out in the Act, have not been met. Another is the Apologies (Scotland) Act 2015 which is less about the right to an apology when things go wrong and more about making it possible for service providers to apologise without fear of prejudicing the person making the apology, or the apology being used to attribute blame in litigation. Receiving an apology can go a long way to resolving situations where something has gone wrong.

There are also a number of institutions that regulate and/or provide guidance on the care that people living with dementia should receive, for example:

- The Mental Welfare Commission
- The Scottish Human Rights Commission
- The Equality and Human Rights Commission
- The Scottish Public Services Ombudsman
- The Care Inspectorate

In Scotland we are, therefore, well-endowed with opportunities to learn about and promote human rights for people living with dementia and challenge abuse of those rights.

At an international level, the UK as a whole is a signatory to the United Nations Convention on the Rights of Persons with Disabilities. The Convention enables the UN Committee on the Rights of Person with Disabilities to conduct inquiries, such as the inquiry which took place in 2015 to examine the effects of social security policy changes on disabled people. The published inquiry report¹¹ was critical of the UK Government and highlighted, in particular, the lack of proper equality impact assessment when considering policy changes. An equality impact assessment is a process designed to ensure that a policy, project or scheme does not discriminate against any disadvantaged or vulnerable people. The UN Committee felt that robust equality impact assessment would have better shown the effect that the policy changes could have on people who are disabled. The Committee also suggested that a cumulative equality impact assessment - looking at the impact of *all* policy changes when taken together - should have been undertaken to determine the overall impact on disabled people. The UK government disagreed, saying it was not technically feasible, and the UN Committee does not have the power to enforce its recommendations.

The Convention on the Rights of Persons with Disabilities is highly relevant to people living with dementia as it states, *"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 clear that the use of the term 'include' should not be interpreted as excluding those who have short term or fluctuating conditions. The Convention adopts a social model of disability, recognising *"...that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others"*. However, in its consideration of UK policy changes and their effect on disabled people, the UN Committee made no mention of dementia.

DEEP¹² (Dementia Engagement and Empowerment Project) is a network that brings together groups of people with dementia from across the UK to try to change services and policies that affect the lives of people with dementia. Some members from the network were invited to present their views to the UN Committee on the Rights of Persons with Disabilities in Geneva in August 2017. DEEP produced a report¹³ which had input from people with dementia living in Scotland, Wales, England and Northern Ireland. This report highlighted issues with stereotypes and prejudice, accessible transport, independent living, community inclusion, accessible care, and being able to work. DEEP has also published a booklet entitled 'Our Dementia, Our Rights'¹⁴. It is hoped that dementia will become more of a focus for the UN going forward.

Human rights in practice

In May 2016, Dementia Alliance International published 'The Human Rights of People Living with Dementia: from Rhetoric to Reality'¹⁵. The publication has a strong foreword by Kate Swaffer, CEO and co-founder of Dementia Action Alliance. Kate also has dementia. Her voice is clear as she writes about people with dementia reaching beyond the PANEL Principles, using enforceable legislation and seeing the UN Convention on the Rights of Persons with Disabilities become more relevant to people living with dementia. She advocates for a future Convention on the Rights of Older People, which is an aspiration that has been held by many for some time.

It is absolutely essential that people living with dementia, and their unpaid carers, have a robust and distinct voice on the human rights issues that affect them, their families and friends. It is important that they are supported, listened to and their advice acted upon. We see this happening in Scotland through the work of the DEEP network and the Alzheimer Scotland Scottish Dementia Working Group¹⁶; through the Alzheimer Scotland National Dementia Carers Action Network¹⁷; through the *tide* (Together In Dementia Everyday) carers network¹⁸; and through numerous dementia friendly communities¹⁹. Without the input of people who are experts in dementia through lived experience, including unpaid carers, we will never properly understand the human rights issues that are at stake.

There are, though, many people with

dementia who cannot participate in such networks or groups. Their connection with human rights is far less about policy and much more about what they are experiencing on a day-to-day basis in their home, care home or elsewhere.

From 2009 until 2014 I worked for the Older People's Commissioner for Wales and led a team that provided support to older people - many of whom had dementia - whose rights were being disregarded, or were at risk of being disregarded. Occasionally a case would end up in court, or there might be a judicial review, but on the whole the law is a fairly expensive and time-consuming instrument. For anyone working in the field of dementia and human rights, an excellent understanding of equality and human rights legislation is necessary in order to pinpoint any breaches of the law; but in order to deal with many situations where human rights are at risk - or there is discriminatory behaviour - tact, diplomacy and excellent negotiation skills are as important because human rights are primarily about relationships.

Human rights and dementia in Scotland is about relationships and power dynamics. Almost no-one sets out to deliberately trample the rights of someone with dementia. Human rights tend to be breached as a consequence of imbalanced power dynamics to some degree or another. For example, when the perspective of one person is weighed against the perspective of another, and the person with the most power uses their position to make a decision with little discussion,

consideration or understanding of the other person's perspective. Or the person in the weaker position has no voice at all. Sometimes a person who wants to do what is right cannot because they feel they do not have authority to act or may be reprimanded for doing so.

A person in the stronger position may not realise that they are depriving someone of their human rights; they may feel that they are coping with a difficult situation or fixing a problem. They may even set a precedent that others follow because it seems to be the best approach. They also have the opportunity to set a course for a human rights-based approach that secures human rights for the person in the weaker position. Let me share some examples based on true life situations.

The right to hold a belief

William had been a vegetarian for 33 years. It was a belief that he held to quietly but firmly. In older age he developed Alzheimer's disease and was eventually admitted to a care home when he could no longer live with support in his family home. William's family made it clear that he was vegetarian and this was recorded in his care plan. For the first two months, the kitchen staff prepared vegetarian meals for him.

In the third month there was a change of kitchen staff and the number of cooks was also reduced. William's daughter, who visited her father most days, was present at dinner time and noticed that her father was served mashed food that seemed to contain meat. When she asked what was in the food, the carer who was serving it replied, *"It's what I was given by the*

kitchen". William's daughter spoke with the kitchen and discovered that although the kitchen staff were aware of her father's dietary requirements they had decided it was easier to just give him the same food that everyone else was eating. When she asked why they had not left out the meat, the daughter was informed that, *"he probably needs some protein"*.

William's belief in vegetarianism would likely be protected under Article 9 of the European Convention of Human Rights (freedom of thought, conscience and religion), and if he had not had Alzheimer's he would likely have noticed the meat and refused to eat it. Alzheimer's had placed him in a situation of vulnerability which led to the kitchen staff being able to override his previously expressed wishes. The balance of power lay with the staff.

In the 'balance of rights' equation the staff had very little to do to uphold William's rights, but they failed to do it.

The right to family life

Dorothy and Jim had been placed together in a care home where they had lived for just over a year. They had a room together and did everything together. They had made friends with other residents and often went on day trips in the care home's minibus. Dorothy had early stage dementia but after a year in the care home this developed to become much more severe. The care home informed Jim and Dorothy's son that they were not registered to deal with dementia to the extent that Dorothy was experiencing it. She would have to be moved to another care home, about 40 miles away and in a rural area.

Jim's son was consulted and, because

he wanted the best care for his mother, he agreed; but Jim was distraught at the prospect of being parted from Dorothy, his wife of more than 60 years. He cried every day and would not let Dorothy out of his sight. The care home staff were very concerned about Jim and his mental wellbeing. They enquired as to whether Jim could move to the new care home with Dorothy but were told that no places were available.

The manager of the care home phoned social services and asked if any support could be put in place so that Jim could visit his wife. Social services asked why Jim's son could not drive him there. The manager pointed out that Jim's son had a disability and could not drive. She was also very concerned that the son would be unable to visit due to the lack of bus service.

This situation engaged the Article 8 rights of all three family members (right to private and family life). The manager met with Jim, his son and an allocated social worker to try and find a solution. Jim's son was in receipt of direct payments and so an increase to his direct payment was authorised so he could visit his mother and take his father with him in a taxi. The manager pointed out that this did not allow Jim to visit his wife alone. The social worker said that it was the most she could do because a direct payment for Jim would not be authorised and he had no money of his own.

Jim visited his wife once a week, with his son, for almost a year until she passed away. The care home staff took extra care to make the visits special, ensuring that Jim was dressed smartly. They took time to talk about Dorothy and helped Jim through the grief of no longer having her with him

all the time. A volunteer befriender helped Jim make a memory book which not only gave him a chance to talk about Dorothy, but also to re-engage with his love of fishing. The befriender was able to take Jim fishing on three occasions.

The 'balance of rights' in this scenario shows that the staff a) saw the bigger picture, b) sought a solution, and c) mitigated some of the impact. They made every effort to ensure that Jim's rights were protected. What is not so clear is how Dorothy fared in the new care home and whether she felt the impact of being away from Jim. There is also a question as to why Jim could not be supported through direct payments.

When balancing human rights in the context of dementia, one factor to consider is whether a person has the capacity to decide what is in their own best interests or whether a point has been reached where someone must do this for them. We know that it is often not a simple thing to declare that a person 'has no capacity' to make decisions.

The law in Scotland generally presumes that people over the age of 16 are capable of making personal decisions for themselves and of managing their own affairs. The starting point is a presumption of capacity and this can only be overturned where there is medical evidence stating otherwise.

For the purposes of the Adults with Incapacity (Scotland) Act 2000, a person is "incapable" of making decisions if they are incapable of:

- acting; or
- making decisions; or
- communicating decisions; or

- understanding decisions; or
- retaining the memory of decisions,

... in relation to any particular matter due to mental disorder or inability to communicate because of physical disability.

This is not an ‘all or nothing’ definition as the Act recognises that an individual may lack capacity to make certain decisions relating to their affairs but might have capacity to make other decisions. For example, someone may have capacity to deal with small sums of money but might need some help in making decisions about dealing with their bank account²⁰.

The Act aims to protect people who lack capacity to make particular decisions, but also to support their involvement in making decisions about their own lives as far as they are able to do so. Anyone authorised to make decisions or take actions on behalf of someone with impaired capacity must apply the following principles:

Principle 1 - benefit

Any action or decision taken must benefit the person and only be taken when that benefit cannot reasonably be achieved without it.

Principle 2 - least restrictive option

Any action or decision taken should be the minimum necessary to achieve the purpose. It should be the option that restricts the person's freedom as little as possible.

Principle 3 - take account of the wishes of the person

In deciding if an action or decision is to be made, and what that should be, account must be taken of the present and past wishes and feelings of the person, as far as these may be ascertained. Some adults will be able

to express their wishes and feelings clearly, even although they would not be capable of taking the action or decision which you are considering. For example, he/she may continue to have opinions about a particular item of household expenditure without being able to carry out the transaction personally.

The person must be offered help to communicate his or her views. This might mean using memory aids, pictures, non-verbal communication, advice from a speech and language therapist or support from an independent advocate.

Principle 4 - consultation with relevant others

Take account of the views of others with an interest in the person's welfare. The Act lists those who should be consulted whenever practicable and reasonable. It includes the person's primary carer, nearest relative, named person, attorney or guardian (if there is one).

Principle 5 - encourage the person to use existing skills and develop new skills

Encouraging and allowing the adult to make their own decisions and manage their own affairs as much as possible and to develop the skills needed to do so²¹.

Although not a Scottish case, *Cardiff Council v Peggy Ross (2011)*²² was a case that looked at the balance of liberty versus security. The case revolved around a) whether or not Mrs Ross had the capacity to decide for herself whether she embarked on a 16 day cruise in the Mediterranean, and b) whether such a cruise was in her best interests. Mrs Ross, aged 82, had lived in a care home in Cardiff for three months and had a severe degree

of microvascular disease and bilateral hippocampal atrophy indicative of a mixed dementia.

For 20 years Mrs Ross had been in a close relationship with Mr Davies, who was 81, and they had spent these years alternating between their two homes. Additionally they enjoyed around 50 cruise holidays together during those years. Before Mrs Ross moved into the care home they had decided to book, and pay for, a cruise. When told about the plans for the cruise, just several weeks before it was due to take place, the care home staff were concerned and undertook an assessment of whether or not Mrs Ross had capacity to decide to go on the cruise.

The care home manager and Mrs Ross's social worker undertook an assessment of Mrs Ross's capacity and found that she lacked capacity to make a decision about going on the cruise:

However, Mr Davies disagreed saying that he knew how much Mrs Ross enjoyed these holidays and that she was comfortable with the cruise ship environment. Cardiff County Council took the case to the Court of Protection. It was felt by the Court that the assessment and associated conversations were driven by the social worker and care home manager's desire to do the right thing for Mrs Ross. However, excessive emphasis was placed on Mrs Ross's safety and what might go wrong. The social worker had had a particular concern that Mrs Ross would be left alone on the ship, wander off and come to harm. The Judge reached the following conclusion:

"(There were concerns) that Mrs Ross might 'wander' (as she undoubtedly has in the past when living alone) on the ship and go over the side. It was suggested, not without some force in

my view, that this smacked of saying that her best interests were best served by taking every precaution to avoid any possible danger without carrying out the balancing exercise of considering the benefit to Mrs Ross of what, sadly, may be her last opportunity to enjoy such a holiday with Mr Davies. This led, in my view, to trying to find reasons why Mrs Ross should not go on this holiday rather than finding reasons why she should...

On the evidence put before me I concluded that:

(a) Mrs Ross was, on balance, at the very least willing to go on this cruise despite her somewhat ambiguous utterances.

(b) If one 're-winds' to a year ago, and for many years before that, it was part of Mrs Ross's lifestyle to take cruises on a regular basis each year in Mr Davies's company from which it must be inferred that she was happy to do so. Without the intervention of her dementia the probability is that she would have wanted to go on this cruise.

(c) Mr Davies, who knows her well, supports this view.

(d) As already mentioned, this could be their last opportunity to extract enjoyment from such a holiday.

(e) Looked at in a positive light, the concerns about her safety on board appear to have been given disproportionate emphasis. Mr Davies, who has proved able to care for Mrs Ross at weekends, will be with her for the duration of the cruise, sharing her cabin and in a position to keep a watchful eye on her and attend to her needs.

(f) Concerns about her 'wandering' are largely, if not wholly, met by the

fact that a cruise ship is a 'confined space' such that she cannot wander far. During the night Mr Davies has formulated strategies to ensure she does not leave the cabin without him becoming aware.

(g) The suggestion of a carer to accompany the couple was put forward but is unnecessary, too costly and impractical. It is difficult to see how a carer could do any more than Mr Davies can do.

(h) Lastly, Mrs Ross is familiar with the pattern of life on a cruise ship, has travelled on this particular ship in the past and will be with Mr Davies who has her best interests at heart, such that she fears that Mrs Ross might find the new environment disruptive and therefore distressing are seemingly allayed.

For these primary reasons I concluded that it was in Mrs Ross's best interests to embark on this cruise."

This case is a good example of the real 'rough and tumble' of human rights, where perceptions conflict and something that may have seemed straightforward has become a bigger issue. Given a different set of facts the case might have been decided differently. No-one in this scenario was deliberately trying to deprive Mrs Ross of the right to go on holiday with her partner. The care home was likely fearful of any adverse repercussions for Mrs Ross, and for them, if anything went wrong on the cruise. Management of risk, however, needs to be enabling to the fullest extent possible.

Risk management can be difficult, particularly if there are staff shortages due to financial or other constraints. Care staff sometimes find themselves in a situation where resources (time,

money, material and human resources) are limited. Care staff also have human rights and there will be times where their rights - such as their right to work in a safe environment, their employment rights and their right to a private and family life - have to be secured.

Ensuring that the care workforce is sufficiently skilled, supported and trained will always be a priority and it is important that staff are given time and resources to learn and develop. This is as important for the many unpaid carers in Scotland who care for relatives and friends with dementia but who have less protection under the law. Dementia Carer Training, such as that provided by Alzheimer Scotland²³, can give family members the confidence to care. Given that unpaid carers save the UK economy a staggering £56.9 billion a year (£11.6 billion saved by unpaid dementia carers)²⁴, these types of training course are well worth government funding.

The third National Dementia Strategy for Scotland (2017-20) contains an excellent foreword written by the National Dementia Carers Action Network, but the Strategy itself contains no commitments specifically for unpaid carers of people with dementia. These carers will say that caring for someone with dementia can be very different to caring for a person without dementia and comes with its own unique challenges. The Carers (Scotland) Act 2016²⁵, which commences on 1 April 2018 will, amongst other things, require local authorities to provide support to carers, based on the carer's identified needs which meet the local eligibility criteria. A specific Adult Carer Support Plan or Young Carer Statement should be put in place that identifies carers' needs

and personal outcomes. Each local authority will be required to have its own information and advice service for carers which must provide information and advice on emergency and future care planning, advocacy, income

maximisation and carers' rights. Part 6 of the Act states that information must be provided about education and training opportunities for carers [s.34(2)(c)].

Making rights real

There are many examples of excellent practice in care settings in Scotland and the fact that there is national commitment to securing and retaining rights should spur us on to even greater things. One example is the work of My Home Life²⁶.

My Home Life is an initiative that promotes quality of life and delivers positive change in care homes for older people. This involves work with care homes, statutory bodies, community organisations and others to co-create new ways of meeting the needs of older people, relatives and staff. My Home Life places emphasis on the importance of relationships in the care home and with the wider community; it is an enabling model and helps staff to take an appreciative inquiry approach by asking *"what is working now and what more do we need to do to make it even better?"*. This approach promotes better understanding of the balance of rights and is empowering for practitioners, who are able to examine what they are doing with a sense of positivity.

Residents and family members of Campbell Snowden House in Bridge of Weir contributed to 'Come On In', a pocket-sized guide which aims to help friends and family of people living in care homes make the most of time

spent together²⁷. It recognises the right that residents and family have to continuing relationships with family and friends. The booklet acknowledges that people can feel awkward when they visit a care home because it is an unknown environment and possibly the person they are visiting has changed because of a condition they have, such as dementia. It gives ideas and suggestions for having a good visit and it also helps people understand the resident's perspective.

"I was upset the last time, I came back with my relative and I had to visit the bathroom, they left without me saying goodbye. I like to walk them to the front door, as I would have at home, it's important for me to say goodbye."

Arora Dementia Friendly Community²⁸, is run by the An Lanntair arts centre on the Isle of Lewis. They work with a number of care homes, hospitals and the wider community to help people with dementia reconnect with their lives and their culture. They do this through story-telling, hand memory²⁹, song, dance, memory boxes and other means. By allowing space for freedom of expression, there can be a reconnection with who a person is and what is important to them. Projects like this work from the premise that when people with dementia are losing

a sense of personal identity it is up to us to try and help them find it again, if even for a short while. By doing this we are reminded of that person's humanity, personality and place in this world.

These projects might seem as if they are a million miles away from legislation, conventions, charters and standards. But, in fact, they put flesh on the bones of the black letter law and bring rights to life. They are the 'small great things'. They allow relationships to flourish; they help restore a sense of identity and purposefulness; they help us see beyond dementia and see the person; they guide us when we have to balance human rights; they teach us to understand that one day we may be the person living with dementia.

The new Health and Social Care Standards³⁰ are designed to help health, social care and social work services in Scotland uphold human rights. They are a helpful bridge between the law and practice. For example, Standard 2 *"I am fully involved in all decisions about my care*

and support" sets out standards that, if met, will ensure that people receiving care or health services will be enabled to be as independent as possible, provided with an independent advocate where needed, and supported to express their views.

The Standards provide a fresh opportunity for service providers to explore new ways of securing and retaining human rights for those they serve. The Life Changes Trust³¹ is working in partnership with Scottish Care to support projects in care homes in Scotland that will enhance and uphold the human rights of people living with dementia. From November 2017 until March 2018 the Life Changes Trust is receiving applications for small grants. The grants are for a maximum of £20,000 for human rights-based projects in care homes. The purpose of these grants is to develop exemplary good practice models that can be adopted, or built upon, by other care homes/care settings. Each successful applicant will have shown which human rights and Health and Social Care Standards are being upheld as a result of the project.

Call to action

1. We need to move away from talking about human rights in the abstract and develop a better understanding of how human rights impact our day-to-day work.

This does not mean that we should ignore the law, conventions, charters and standards - far from it - but it does mean that we should not fool ourselves into thinking that just because we have head knowledge about human rights then all is well. It is necessary, but not sufficient.

The oft-quoted words of Eleanor Roosevelt are relevant:

"Where, after all, do universal human rights begin? In small places, close to home - so close and so small that they cannot be seen on any maps of the world. Yet they are the world of the individual person; the neighbourhood he lives in; the school or college he attends; the factory, farm, or office where he works. Such are the places where every man, woman, and child seeks equal justice, equal opportunity, equal dignity without discrimination.

Unless these rights have meaning there, they have little meaning anywhere. Without concerted citizen action to uphold them close to home, we shall look in vain for progress in the larger world."

Unless human rights have meaning in care homes, hospitals, day centres and people's own homes, they will have little meaning anywhere for people living with dementia and their unpaid carers.

2. Let's see the new Health and Social Care Standards as a 'fresh start' in our thinking.

The worst thing that could happen is that the new Standards are seen as yet another layer of bureaucracy and reporting requirements. Yes, they will be part of inspection and regulation processes but individuals can choose to make the Standards a source of motivation rather than a cause of consternation.

If you are a leader by role or personality in your sphere of influence

- no matter how small that sphere is - your attitude towards human rights will mould that of others. So lead well.

3. Consider what the 'balance of rights' means for you.

This Care Cameo may have encouraged, challenged or annoyed you. It may just have been mildly interesting. If you care for someone with dementia, paid or unpaid, it is highly likely that this week you will face a situation in which you need to balance rights and make the best decision you can make.

Sometimes these decisions are very difficult, but they are easier to approach if you have at least considered and discussed human rights principles before you are in the middle of a complex situation. You might want to consider some scenarios with your staff team, or with other unpaid carers with whom you meet for peer support. A good starting point could be the Scottish Human Rights Commission's Care About Rights training if you have not already used it.

In conclusion

Few of us will do 'great things' as society defines 'great'. We won't be famous, we won't write a bestseller or star in a film. We won't draft important legislation or conventions, but we *will* always have the opportunity to influence the world in which we find ourselves. That world may be very small for some of us - it might be the family home or a small care home; it might be an office desk from which we commission health and social care

support and services. It does not matter.

Human rights are about the relationships we have with each other. They are about ensuring that statutory processes are truly human rights-based. They are about learning to resolve difficult situations. For human rights to work well those rights should be the foundation of the approach we are building in Scotland, not the décor.

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1. Mahmoud Cherif Bassiouni, Emeritus Professor of Law at DePaul University, Chicago, USA, and tireless advocate for those seeking justice for grave human rights abuses (b. 9/12/1937, d. 25/9/2017)
2. See the European Convention on Human Rights, Articles 2, 3, 4(1) and 7 http://www.echr.coe.int/Documents/Convention_ENG.pdf
3. McDonald v United Kingdom (judgment given in 2014) [https://hudoc.echr.coe.int/eng?i=001-60448#{"docname":\["McDonald"\],"itemid":\["001-144115"\]}](https://hudoc.echr.coe.int/eng?i=001-60448#{)
4. Promoting Excellence Framework <http://www.gov.scot/resource/doc/350174/0117211.pdf>
5. Charter of Rights https://www.alzscot.org/assets/0000/2678/Charter_of_Rights.pdf
6. Human Rights Based Approach http://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf
7. Scotland's National Action Plan for Human Rights <http://www.snaprights.info/what-is-snap>
8. The Standards of Care for Dementia in Scotland <http://www.gov.scot/Resource/Doc/350188/0117212.pdf>
9. Scotland's Third National Dementia Strategy <http://www.gov.scot/Publications/2017/06/7735>
10. Health and Social Care Standards <http://www.gov.scot/Publications/2017/06/1327>
11. For the full Inquiry report and the UK Government's response see <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7367#fullreport>
12. For more information about DEEP see <http://dementiavoices.org.uk/>
13. UNCRPD Alternative Report http://dementiavoices.org.uk/wp-content/uploads/2017/07/Our-Lived-Experience-270717_1.pdf
14. Our Dementia, Our Rights <http://dementiavoices.org.uk/deep-groups-news/our-dementia-our-rights/>
15. From Rhetoric to Reality, Dementia Alliance International <https://www.dementiaallianceinternational.org/wp-content/uploads/2016/05/Human-Rights-for-People-Living-with-Dementia-Rhetoric-to-Reality.pdf>
16. Scottish Dementia Working Group <http://www.sdwg.org.uk/>
17. National Dementia Carers Action Network <https://www.alzscot.org/ndcan>
18. tide <http://tide.uk.net/our-work-in-scotland/>
19. Life Changes Trust Dementia Friendly Communities <http://www.lifechangestrust.org.uk/projects/dementia-friendly-communities>
20. Adults with Incapacity (Scotland) Act 2000 [http://www.publicguardian-scotland.gov.uk/adults-with-incapacity-\(scotland\)-act/definition-of-incapacity](http://www.publicguardian-scotland.gov.uk/adults-with-incapacity-(scotland)-act/definition-of-incapacity)

21. For a helpful overview of the Adults with Incapacity (Scotland) Act 2000, see the Mental Welfare Commission's website: <http://www.mwscot.org.uk/the-law/adults-with-incapacity-act/>
22. Cardiff Council v Peggy Ross (2011) COP 28/10/11 12063905. See [http://www.mentalhealthlaw.co.uk/Cardiff_Council_v_Peggy_Ross_\(2011\)_COP_28/10/11_12063905](http://www.mentalhealthlaw.co.uk/Cardiff_Council_v_Peggy_Ross_(2011)_COP_28/10/11_12063905)
23. Alzheimer Scotland Dementia Carer Training Courses https://www.alzscot.org/information_and_resources/information_sheet/2310_carer_training_courses
24. See Alzheimer's Society report 10/7/17 https://www.alzheimers.org.uk/news/article/219/ons_reports_unpaid_carers_provide_social_care_worth_57_billion_alzheimer_s_society_comments
25. Carers (Scotland) Act 2016 <http://www.legislation.gov.uk/asp/2016/9/contents/enacted>
26. My home life <http://myhomelife.org.uk/>
27. Come on In http://www.lifechangestrust.org.uk/sites/default/files/Come_on_in_-_Staying_connected_0.pdf
28. Arora Dementia Friendly Community <https://dfclanntair.wordpress.com/>
29. Hand Memory <https://dfclanntair.wordpress.com/2016/01/26/hand-memory-by-jon-macleod/>
30. Health and Social Care Standards <http://www.gov.scot/Publications/2017/06/1327>
31. Life Changes Trust <http://www.lifechangestrust.org.uk/>
32. Care about Rights, Scottish Human Rights Commission <http://careaboutrights.scottishhumanrights.com/>



About the Author

Before returning to Scotland, Anna Buchanan worked for the Older People's Commissioner for Wales as Director of Protection, Scrutiny and Human Rights. In this role she oversaw the Commissioner's work on equality and human rights. She also led the Commissioner's complex casework team and advised on the use of the Commissioner's statutory functions.

She joined the Life Changes Trust in April 2014 as Director of the People Affected by Dementia Programme. The Life Changes Trust was established by the Big Lottery in April 2013 with a ten year endowment of £50 million to support transformational improvements in the quality of life, well-being, empowerment and inclusion of people affected by dementia and young people with experience of being in care.

Anna has a degree in Public Administration from the Robert Gordon University in Aberdeen, and a law degree from Cardiff University Law School. She was called to the Bar of England and Wales by the Honourable Society of the Middle Temple, London. Anna has a broad interest in human rights and has lectured and written on religious rights and freedoms, particularly in the context of education law.

