Human rights in end of life care - Scotland

Why this is important

The World Health Organisation states: “Palliative care is explicitly recognized under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.” However, in the UK, this does not always translate into reality, with some people and families experiencing such poor end of life care that cases end up in the courts and in some cases, public inquiries. The controversy over the use of the Liverpool Care Pathway as an approach to end of life care highlighted the need to ensure that the individual rights and choices of people at the end of life need to be respected.

If there’s one thing that’s guaranteed, it’s that we will all die, and we will die just once. In the midst of the COVID-19 pandemic, the paramount importance of rights-respecting care at the end of life has never been clearer. With that in mind, it’s incredibly important that as a society, we do all that we can to ensure the person at the end of life has the best experience possible, in challenging and often confusing and changing circumstances and at a time of heightened emotion and sadness.

That is why Sue Ryder, in partnership with others, has undertaken extensive work in the area of human rights in end of life care. This paper sets out what we believe should now happen, and why.

Recommendations

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<th>Recommendation</th>
<th>Policy area</th>
<th>Who to</th>
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<td>1</td>
<td>Review and rewrite all legislation, policies, protocols and guidelines in relation to end of life care to ensure it is rights-based.</td>
<td>EOL care</td>
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<td>2</td>
<td>Future Human Rights Act for Scotland, or associated regulation/guidance, to include rights-based approach to end of life care.</td>
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<td>3</td>
<td>New/refreshed Strategic Framework for Action on Palliative and End of Life Care should have human rights approach embedded throughout.</td>
<td>EOL care</td>
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<td>4</td>
<td>The economic case for a rights-based approach to end of life care should be made.</td>
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<td>5</td>
<td>Human rights impact assessments should be mandatory for all new government (national and local) policies.</td>
<td>General</td>
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<td>6</td>
<td>Human rights in end of life care should be core part of education for all pre-registration health and care staff.</td>
<td>EOL care</td>
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### Background

In light of the Liverpool Care Pathway controversy and its ultimate demise, the British Institute of Human Rights (BIHR) invited Sue Ryder to co-produce a practical guide entitled ‘End of Life Care and Human Rights: A Practitioner’s Guide’, published in 2016. The guide addresses the challenges around ethical decision-making at the end of life.

In Scotland, Health and Care Standards published at the end of 2017 have at their heart the principle that the human rights of the individual must be upheld. All organisations providing care and support should work towards implementing these standards, and registration and inspection bodies use them to scrutinise the quality of care provided. In addition to this, Scotland’s [National Performance Framework](http://www.snaprights.info/action-areas/better-lives) explicitly recognises the obligation to respect, protect and fulfil international human rights, there are plans to pass a Human Rights Act for Scotland and the First Minister has appointed a taskforce to develop recent recommendations for a new human rights framework to improve people’s lives.

Independently of government, [Scotland’s National Action Plan for Human Rights (SNAP)](http://www.snaprights.info/action-areas/better-lives), was developed by a range of groups and led by the Scottish Human Rights Commission, and this has been taken forward since 2014. One of the three areas for priority action under ‘Better Lives’ is to “Enhance respect, protection and fulfilment of human rights to achieve high quality health and social care.”

Using a human rights approach is therefore seen as having clear public benefit to health and social care. As the Health and Social Care Alliance Scotland says, the aim is “to make these rights a reality – to move beyond simple compliance and embrace the spirit of this legislation, so that human rights become active considerations for those who deliver public services and are at the forefront of every interaction.”

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2 [http://www.snaprights.info/action-areas/better-lives](http://www.snaprights.info/action-areas/better-lives)
The Strategic Framework for Action on Palliative and End of Life Care, 2016-2021, states that palliative care “has proven value, is a human rights, public health and equalities issue, and the need for it is growing with the ageing population.”

For the past three years Sue Ryder has been providing training on human rights in end of life care to health and social care professionals, called What matters to me. The aim of the programme is to educate and empower the health and care workforce to feel confident in embracing human rights as key to good quality, person-led end of life care. Using established case law and real-life case studies, the training builds on participants’ existing knowledge and experience to increase awareness of how human rights can be used to aid decision-making, effect change and ensure compassion and dignity are at the heart of personalised care.

Feedback from course participants shows that while the training is used in practice, there are other barriers to taking forward a rights-based approach to end of life care that cannot be addressed by training. In addition to the course evaluation and additional feedback from participants, a literature review was commissioned from the University of Birmingham in order to examine the theoretical and empirical literature critically to set the What matters to me programme, and its evaluation, in a wider context.

The literature review identified four themes across published articles in this field: developing the skills of decision making of staff; developing assertiveness of patients and service users to improve services; embedding a human rights culture; and barriers to implementing a human rights based or human rights education approach to healthcare. It found that “there is no conclusive evidence to indicate that a national human rights culture in UK health and social care exists. The current political climate in the UK does not appear to be conducive to progress in this respect.” And went on to state “Evaluation of how such initiatives [human rights training programmes] change and become embedded in the organisation’s culture need to continue and focus on both process and outcome using robust qualitative and quantitative methodologies as appropriate.”

While Sue Ryder’s What matters to me training can help address the issues within the theme relating to skills of staff and to some extent the issues within the theme on assertiveness of service users, additional action is required to address the issues within the other themes on culture and barriers to implementation.

To explore the challenges identified in the in the literature review, Sue Ryder has worked with a range of stakeholders to build an understanding of the barriers to delivering human rights based end of life care, and determine ways in which these barriers can be overcome. To achieve this understanding, Sue Ryder engaged with a number of interested professionals through online consultation and a focus group with a range of professionals and organisations in Scotland with an interest in either end of life care and/or an interest in human rights, as well as interrogating training evaluation findings.

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4 Funded by the Burdett Trust for Nursing for the first three years, now provided at cost by Sue Ryder
This process has resulted in the identification of three areas for development if a rights-based approach to end of life care is to be truly embedded:

- Health and social care culture
- The multidisciplinary workforce
- Patients and carers’ understanding of human rights in end of life care

**Barriers and ways to overcome them**

1. **Organisational culture needs to change**

   *The situation*

- There can be contrasting professional and organisational cultures with regard to implementing a rights-based approach to end of life care. Therefore changes in attitudes and behaviour are necessary along with high level management support. We need transformation at a leadership level in our health and social care systems.
- The policies, legislation, protocols and guidelines on end of life care do not necessarily reflect a human rights based approach: this influences the culture of organisations and teams within the health and care system.
- Commissioners may need convincing that human rights education or human rights based approaches to healthcare make a difference and improve the quality of services and that they are equally if not more cost effective than other interventions.\(^7\)

   *Potential solutions*

- There will only be significant impact on the health system if there are changes in legislation, policies, protocols or guidelines. We should review policies and procedures to ensure human rights are embedded within them. Every strategic policy/guidance document on end of life care should be written in ‘rights respecting’ language so that it becomes the norm. To start, we need to encourage understanding of Adults with Incapacity (Scotland) Act 2000 in the context of human rights.
- A New Scottish Framework for Action on End of Life Care should refocus from a clinical to a clear human rights approach to end of life care, reflecting the Realistic Medicine agenda.
- Consideration should be given to developing a Charter for Human Rights in End of Life Care; and we need to influence the forthcoming legislation on human rights in Scotland so that it includes end of life care.
- Commission economic and social modelling to assess the cost of not respecting human rights
- Human rights impact assessments should be mandatory in the same way that we carry out Equality Impact Assessments

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\(^7\) Newham and Hewison 2019
2. **The multidisciplinary workforce requires development**

*The situation*

- There is a lack of knowledge, understanding and awareness of human rights within the MDT, and little shared understanding across the team.
- There can be a conflict between the autonomy of the service user and the clinical view of how to increase length of perceived quality of life, particularly when concerned the patient was seen to be making an ‘unwise’ or ‘risky’ decision.

*Potential solutions*

- Training and education in a human rights approach to end of life care needs to start at preregistration/undergraduate level, be mainstreamed across all disciplines and in all settings, regularly updated and ideally become mandatory. To include:
  - Realistic Medicine;
  - How to promote equality of access to human rights based end of life care, especially for those less likely to access care early/at all;
  - How to ensure changes in people’s wishes are acted upon.

3. **Patients and their carers should be supported to understand their human rights at the end of life**

*The situation*

- People requiring, or in receipt of, end of life care services and their carers do not necessarily know how human rights can enable them to make decisions.

*Potential solutions*

- Organisations and leaders should encourage and facilitate early conversations about end of life care across healthcare settings possibly connected with advanced decision making or power of attorney discussions.
- Empower the public through a charter and campaign to encourage conversations around human rights, end of life and what people want for themselves, so that the power differential between patients, professionals and their families becomes more balanced.
- Education should start at the earliest stage in schools, as part of other rights based education.
- Develop easy read information for families and carers that explains how decision making works, even for the unconscious person.