Human rights in end of life care - England

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>
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<td>1</td>
<td>Review and rewrite all legislation, policies, protocols and guidelines relating to end of life care to ensure it is rights-based.</td>
<td>EOL care</td>
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<td>The economic case for a rights-based approach to end of life care should be made.</td>
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<td>Refreshed Ambitions Framework for Palliative and End of Life Care should have a human rights approach embedded throughout.</td>
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<td>4</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>Human rights in end of life care should be a core part of education for all pre-registration health and care staff.</td>
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<td>6</td>
<td>Process to be developed so that advance care planning or other mechanism is used to discuss end of life care choices.</td>
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A campaign to empower the public to understand and use their human rights should be carried out.

The National Curriculum should include human rights education.

Information on exercising human rights in relation to end of life care should automatically be provided in accessible format to patients and their carers.

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<td>General Government; DfE; NUT</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.

Using a human rights approach is seen as having a clear public benefit to health and social care, with the Care Quality Commission introducing a human rights-based approach to regulation in 2014. The Ambitions for Palliative and End of Life Care, a framework for the provision of end of life care in England, reflects human rights through some of its ambition statements: “each person is seen as an individual”, “each person gets fair access to care” and “maximising comfort and wellbeing”. And the NHS Long Term Plan, published in 2019, reflects the importance of this agenda by saying the NHS will “personalise care, to improve end of life care”.

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

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1 Funded by the Burdett Trust for Nursing for the first three years, now provided at cost by Sue Ryder
rights based or human rights education approach to healthcare\textsuperscript{3}. 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 of staff skills, and to some extent the issues within the theme of assertiveness of service users, additional action is required to address the issues within the other themes of 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 England with an interest in end of life care and/or an interest in human rights, as well as interrogating training evaluation findings.

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 organisational culture;
- Health and social care workers’ ability to balance both safeguarding and human rights principles;
- The multidisciplinary workforce.

**Barriers and ways to overcome them**

1. **Organisational culture needs to change**

   **The situation**

   - In some circumstances, health care organisations can have a culture of depersonalised care, mainly driven by their poor financial situations and external pressure to meet targets. This can worsen staff morale and risks compassion fatigue amongst clinicians.
   - Human rights embedded care is actually cost-effective in the long term but a high turnover of managers leads to a lack of long-sightedness or big picture thinking which can then trickle down through the whole organisation.

\textsuperscript{3} Newham R and Hewison A (2019) Human Rights Education in Palliative Care - A Critical Integrative Literature Review, University of Birmingham
• A strong focus on flow through hospitals due to pressure on beds can counter a person-centred approach. Patients are not always listened to in acute settings because clinicians are under too much pressure resulting from workforce shortages, time pressures, and a busy environment.
• This is a particular issue for older patients. Their human rights are not prioritised to the point that sometimes, rather than timely discharge under the frail and elderly or equivalent team, they are left in hospital beds and deteriorate so they then require palliative care.

Potential solutions

• Organisations should foster a culture of flexibility and creativity – a ‘can do’ attitude amongst staff. This requires simultaneous organisational and professional cultural change, as well as positive role modelling at every level.
• Clinicians should be supported to respect patients’ human rights: ‘Ask what matters to me; listen to what matters to me; do what matters to me’. However, safe staffing levels and time are critical for this to happen.
• More research is needed to build up the evidence base for organisation ‘buy-in’ i.e. to convince commissioners that a human rights based approach not only improves the quality of services but saves money. For instance, demonstrating costly litigation cases drop as a result.
• Ultimately, the culture of organisations and teams within the health and care system is influenced by the fact that human rights are not embedded in health and care legislation and guidelines. Therefore, these need to be reformed.

2. Health and social care workers prioritise safeguarding at the expense of human rights

The situation

• Clinicians are often risk-averse because of a lack of resources and an assumption that social services have no capacity; whilst the perception of a blame culture means clinicians fear litigation, exacerbating the issue.
• In health care settings, safeguarding is not about empowering clinicians to respect human rights and safely manage risks, but about crisis management, preventing deaths and major instances of abuse. Yet in reality, the majority of risks are low level.
• There can be a conflict between the autonomy of the service user and the clinical/organisational view of safe practice. Particularly when there are concerns the patient is making an ‘unwise’ or ‘risky’ decision which is detrimental to their health and safety. Organisational policies and professional codes of conduct require staff to maintain safety.

Potential solutions

• Clinicians should empower patients to make informed decisions regarding their care, including positive risk taking – it’s their decision.
• Balance is needed with a shift in attitude so that a human rights approach to clinical decision-making is viewed as an enabler of good care.
• Often, clinicians have the necessary expertise but need to be supported to feel they can take positive risks without fear of scapegoating. This cannot be addressed by a change in professional attitude alone, but needs transformation at management level, starting with increased organisational accountability, and at the political/policy level.
• Organisational change and workforce training need to be complemented by engagement activity with wider society, for example through a ‘social contract’ between clinicians and service users.

3. The multidisciplinary workforce requires development

The situation

• There is a lack of knowledge, understanding and awareness of human rights within the workforce. This can be traced to the few opportunities for students to learn about human rights.
• Many clinicians may be unaware of their duty under the Human Rights Act, resulting in a lack of advocacy for patients. Often patients at the end of life are vulnerable, meaning there is a significant power imbalance. The gap in public discussion around death and dying confounds efforts.
• There is little shared understanding across multi-disciplinary teams. Electronic records are not co-created, leading to a lack of collaboration between clinicians and ownership of the care their patients receive. It is easy to shift responsibility onto others (‘not my problem’).

Potential solutions

• We need transformation at a leadership level in our health and social care systems. For a start, care records must be co-created, collaborative and shared across health, social and community care workers – with input from patients themselves.
• 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. It should be also available post-registration and offered flexibly so that workers feel they can afford to take the time to complete it.
• For clinicians to fully understand the practical application of human rights, real life case studies need to be used. This is integral to realise the ambition of person-centred care.
• For the general public, human rights education should be part of the national curriculum in schools so that the power differential between patients and professionals becomes more balanced in the future.
Next steps for Sue Ryder (internal use only)

2. Lobby Ambitions Framework Partners
3. Contribute to NHSI ‘Equally Outstanding’ paper
4. Host fringe event on human rights at RCN Congress