

# What difference do human rights make to end of life care?

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**Abbreviated abstract:** There is consensus that everyone has the right to palliative or end of life care, but this does not always translate into end of life care that respects an individual's rights. In the midst of the Covid-19 pandemic the need to get end of life care right has been pushed to the forefront of many people's minds. Our poster will set a brief description of what we believe should be the next steps to ensure that everyone in Scotland who is at the end of life has care that upholds their human rights.

## **Related publications:**

Newham.R, Hewison. A. Graves. J, Boyal. A, Nursing Ethics, 19 June (2020)

<https://journals.sagepub.com/doi/10.1177/0969733020921512>

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palliative,  
neurological  
and bereavement  
support

# Previous work, challenge, and approach

- While there is consensus that everyone has the right to palliative or end of life care, this does not always translate into end of life care that respects an individual's rights
- 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 are respected
- Sue Ryder provides training in human rights in end of life care and feedback shows that there are barriers to the implementation of human rights-respecting end of life care
- A literature review was commissioned which found that a human rights approach is not embedded in training and education in wider healthcare
- Sue Ryder held a focus group with RCN Scotland to determine ways barriers to such an approach can be overcome
- What follows is a brief description of that work and what we believe should be the next steps to ensure that everyone in Scotland receives rights-respecting end of life care



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# Techniques and Methods

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
- barriers to implementing a human rights based or human rights education approach to healthcare.

To explore the challenges identified in the literature review Sue Ryder engaged with professionals through online consultation and a focus group which resulted in 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 worker's ability to balance both safeguarding and human rights principles
- the multi-disciplinary workforce.



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# Results and Conclusions

No.	Recommendation	Policy area	Who to
1	Review and rewrite all legislation, policies, protocols and guidelines relation to end of life care to ensure it is rights-based	EOL care	Scottish Government
2	Future Human Rights Act for Scotland, or associated regulation/guidance, to include rights-based approach to end of life care	EOL care	Scottish Government
3	Any new/refreshed Strategic Framework for Action on Palliative and End of Life Care should be rights-based	EOL care	Scottish Government
4	The economic case for a rights-based approach to end of life care should be made	EOL care	Stakeholders interested in human rights
5	Human rights impact assessments should be mandatory for all new government (national and local) policies	General	Scottish Government; COSLA; NHS; IJBs
6	Human rights in end of life care should be core part of education for all pre-registration health and care staff	EOL care	Scottish Government; NES; NMC; SSSC
7	Process to be developed so that anticipatory care planning or other mechanism is used to discuss end of life care choices	EOL care	HIS; IJBs
8	A campaign to empower the public to understand and use their human rights should be carried out	General	Scottish Government
9	Curriculum for Excellence should include human rights education	General	Scottish Government; Education Scotland; EIS
10	Information on exercising human rights in relation to end of life care should automatically be provided in accessible format to patients and their carers	EOL care	IJBs



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