Picture the scene. You’re working on a general medical ward in a busy hospital. A patient, Sonia, wants to refuse hydration and nutrition through her gastronomy tube. She has decision-making capacity and understands her life may be shortened as a result.

As her nurse, what do you do? Should you persuade her family to convince her to continue her gastronomy feeding at all costs? Should you refuse to accept her choice, and continue to feed her against her will? Or should you accept that while you feel that Sonia’s decision is unwise, she has the right to make this choice?

Complex situations like this are playing out every day. Nurses face dilemmas about how to support patients and service users, their families and loved ones, in what are often distressing circumstances. It can be difficult to know what to do.

That’s where taking a human rights approach to health can help, says Jacqui Graves, human rights lead with the charity Sue Ryder. The organisation, working with the British Institute of Human Rights, is offering free training on human rights and end of life care to support care workers to navigate these often difficult issues.

The training, called What Matters to Me, aims to empower health and social care professionals to deliver personalised, compassionate and dignified end of life care.

It provides a comprehensive introduction to the Human Rights Act (1998) and a framework for shared decision-making, using case law and case studies such as Sonia’s story above, to bring it to life.

‘Human rights are based on the shared values of fairness, respect,
When human rights law and real-life practice collide

Dave is receiving palliative care in the last weeks of life. Dave is gay and lives with his partner. He is estranged from family members as a result of his sexuality. You need to speak to those important to Dave about his deteriorating health.

What do you do?

» A: Speak to Dave’s partner

» B: Contact Dave’s biological family without his consent

» C: Decide not to speak to anyone

The answer is A, because the right to private and family life – Article 8 of the Human Rights Act – supports Dave in identifying who he sees as his ‘family’. For Dave, his family is his partner. It makes no difference whether they are in a civil partnership or married.

Dave has expressed clearly that his partner is his family and next of kin. Therefore no one should contact his biological next of kin unless Dave changes his mind and makes it clear he now wishes them to be contacted.

Following Dave’s death, it is the responsibility of his partner to decide whether he will contact the biological kin or not.

Source: Sue Ryder and the British Institute of Human Rights
Human rights in end of life care

» Everyone has human rights, including staff
» Human rights set the minimum standards for care
» The Human Rights Act, 1998, protects 16 rights in UK law
» Those working in health and care must respect and protect these 16 rights
» Those who are being cared for can use human rights to talk about their care and treatment

...the emotion out of the issue,’ says Ms Graves.

‘She can explain to the family she understands how they feel, but that under the Human Rights Act she has a legal duty to respect their mum’s rights, and that no one has a right to demand treatment.’

What is important is that the training is practical and pragmatic, she adds. ‘It asks what does this mean for me and my practice – how can I stay on the right side of the law? It uses case studies based on real-life cases to make it real, and grounded in practice.’

Personalised care

Kath Keogh, a Sue Ryder practice educator based at Leckhampton Court Hospice in Gloucestershire, has taken part in the human rights and the train the trainer courses.

She admits to having been surprised by how much she got out of it. ‘At first I thought it might be quite dry, but it certainly wasn’t dry and I came out really enthused,’ she says.

‘It was a subject I didn’t know much about. I mean, I’d heard of human rights, but hadn’t really thought about what it meant, and how to apply it in practice.

‘From a teaching point of view, human rights is part of ethics and it has helped me communicate that so that people can understand what might be threatening someone’s human rights, such as their right to privacy. It can be small things, like who they want around them, but they all add up. It’s all about personalised care.’

Ms Keogh, who was previously a palliative care specialist nurse in an acute hospital, says it would have been useful to learn more about a human rights approach in that role. She and colleagues regularly apply what they learned from the course to their hospice-based work.

‘There was one lady who was supposed to be admitted to die, but it came out in the telephone conversation that she actually wanted to die at home. So we had to consider how we could uphold her rights and make sure her care was person-centred. We put in hospice-at-home care. In that instance, avoiding admission was the human rights approach.’

Capacity and autonomy

As for the case of Sonia (top), the correct answer, taking a human rights approach, would be to accept that while you may feel her decision is unwise, she has the right to make this choice.

Article 8 of the Human Rights Act – the right to privacy and family life – supports Sonia because it is all about autonomy. Sonia has decision-making capacity and has the right to refuse treatment as long as she is able to understand the consequences of her decision.

In law, clinically assisted hydration and nutrition are, like ventilation, seen as treatment. Anyone with decision-making capacity can refuse treatment but they cannot demand it, so Sonia is perfectly within her rights to make that choice.

Jennifer Trueland is a health journalist

Sue Ryder human rights training tinyurl.com/humanrights-workshops