A human rights approach to shared decision-making in end of life care

28 February 2018
Sue Hogston, Sue Ryder Associate
Aims for this session:

1. Understand the Sue Ryder human rights training programme and our offer to support you to improve shared decision-making at end of life.


3. Recognise the benefits of using a human rights framework to help shared decision-making to enable personalisation at end of life.
Background to training programme

• Sue Ryder worked with the British Institute of Human Rights to develop ‘End of Life Care and Human Rights: A practitioner’s guide’ published May 2016

• Sue Ryder secured a grant from the Burdett Trust for Nursing to deliver a 3-year training programme to embed this approach into practice
Three-tiered training programme

- Trainers
- Registered Workforce
- Non-registered Workforce
Aims of the training programme

1. Educate and empower more than 1350 individual registered and non-registered staff to feel more confident in embracing human rights as an integral component of shared decision-making at end of life care.

2. Train 360 Trainers to roll out the training in their place of work.
Objectives of the training programme

1. Build upon existing knowledge and experience.
2. Increase awareness of how human rights can be used to aid shared decision-making.
3. Affect change and ensure compassion and dignity are at the heart of personalised care.
# Intended learning outcomes

<table>
<thead>
<tr>
<th>Non-registered workforce</th>
<th>Registered workforce</th>
<th>Trainers</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1</strong></td>
<td>Understand the basic principles of the Human Rights Act</td>
<td>Initiate conversations in the workplace referring to human rights</td>
</tr>
<tr>
<td><strong>2</strong></td>
<td>Understand how to identify a human rights issue</td>
<td>Act as an advocate for human rights in the delivery of high quality end of life care</td>
</tr>
<tr>
<td><strong>3</strong></td>
<td>Understand how to challenge practice and refer human rights issues to a senior member of the team</td>
<td>Recognise the benefits of human rights framework to support balanced decision making</td>
</tr>
<tr>
<td><strong>4</strong></td>
<td>Recognise contribution to delivering personalised care</td>
<td>Use knowledge gained to deliver personalised care</td>
</tr>
</tbody>
</table>

So, what exactly are human rights?

- Human rights are basic rights that belong to every person in the world because we are human.

- They set the rule book for governments and how they should treat us.

- They are laid down in International and UK law.
Human rights values are......FREDA

F – Fairness
R – Respect
E – Equality
D – Dignity
A – Autonomy

Universal to everyone
More than just values….

“…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.”

Health and Social Care Alliance Scotland. (2016)
Quick Quiz
Supports National EoLC Strategy and Policy

• More Care, Less Pathway (2013)
• One Chance to Get it Right (2014)
• Ambitions for Palliative Care: A national framework for local action 2015-2020
• End of Life Care Training Strategy (Health Education England, 2015)
• Our Commitment to you for end of life care (DH, 2016)
• ReSPECT – Recommended Summary Plan for Emergency Care and Treatment (Resuscitation Council UK, Feb 2017)
CQC introduced a human rights approach to regulation in September 2014.

CQC staff have now gone through training on human rights and equality, with specific sessions for inspection and registration teams.

We are already seeing enforcement action where care providers are not respecting human rights.
Benefits to attendees and their employers

• Increases knowledge and confidence.
• Promotes the FREDA values.
• Prevents poor practice, neglect and abuse.
• Reduces risk of complaints and litigation in the longer term.
• Contributes to improved service performance and outcomes.
• Provides evidence for compliance with CQC regulation standards.
6 rights most relevant to EoLC

- Right to life (Article 2)
- Right to be free from inhuman or degrading treatment (Article 3)
- Right to liberty (Article 5)
- Right to private and family life, home and correspondence (Article 8)
- Right to freedom of thought, conscience and religion (Article 9)
- Right to enjoy all these human rights without discrimination (Article 14)
### Who has legal duties?

<table>
<thead>
<tr>
<th>Core public authorities</th>
<th>Functional/hybrid public authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public authorities, including courts and tribunals</td>
<td>Private or voluntary bodies performing public functions</td>
</tr>
</tbody>
</table>

**Not for profits**

Charities

Private companies
Your legal duty

RESPECT
(- ve)

PROTECT
(+ ve)

FULFILL
(procedural)
Types of rights

Absolute rights
– can **never** be restricted

Non-absolute rights
– can be restricted to protect the rights of others or in the wider interests of society
Activity

- Right to life
- Right to be free from torture, inhuman and degrading treatment
- Right to liberty
- Right to respect for private and family life
- Right to religion, belief and conscience
- Right to enjoy these rights without discrimination

Which human rights are absolute and which can be restricted?
Scenario 1

Brenda has MS. She recently suffered a bleed in her neck and now relies on ventilator support to breathe. Brenda has asked staff to stop her treatment.

What do you do?

A. Continue treatment because Brenda is not capable of making her own decisions.
B. Decide what to do based on Brenda’s wishes before her condition changed.
C. Withdraw ventilator support, knowing this will contribute to Brenda’s death.
Scenario 2

Dave is receiving palliative care in the last weeks of life. Dave is gay and is estranged from his family as a result of his sexuality. You need to speak to Dave’s next of kin about his deteriorating health.

What do you do?
A. Contact Dave’s partner, even though they are not married or in a civil partnership.
B. Contact Dave’s family without his consent because, legally, they are his next of kin.
C. Contact Dave’s family with his consent because, legally, they are his next of kin.
Sue Ryder offer to you:

1. Download the Practitioners Guide
2. Book onto one of our existing free workshops
3. Invite us to deliver a locally hosted workshop at your Trust for free (minimum of 12 staff)
4. Become a Trainer and deliver human rights training in your place of work

www.sueryder.org/humanrightstraining
### Outcomes: Mar 17-Sept 17

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Pre-workshop</th>
<th>Post-workshop</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge and understanding of human rights</td>
<td>36%</td>
<td>92%</td>
</tr>
<tr>
<td>Confident to use human rights to enable shared decision-making at EoL</td>
<td>30%</td>
<td>91%</td>
</tr>
</tbody>
</table>
Evaluation: Mar 17-Sept 17

Improving knowledge
• 92% of people rated their knowledge and understanding of human rights higher post course.
• 98% of people rated their knowledge about the relationship between human rights and national end of life care strategy and policy higher post course.
• 100% of people rated their knowledge of the UK Human Rights Act higher post course.

Improving Confidence
• 93% of people rated their confidence in explaining human rights to service users higher post course.
• 98% of people rated their confidence in using human rights as a way to enable shared decision-making at end of life care higher post course.
Practitioners trained – Mar 17-Sept 17

Total number of workshops delivered: 23
Total number of professionals trained: 256

- Doctors: 152
- HCAs: 35
- AHPs: 19
- Nurses: 32
- Others: 10
- Social workers: 8
Geographical reach – Mar 17-Sept 17

Locations
- Cheltenham
- Bristol
- Keighley
- Leeds
- Hitchin
- Taunton
- Aberdeen
- Reading
- Lichfield
- Sleaford
- Birkenhead
- Northampton
- Enfield
- Swindon
- Bradford
Impact of Training

“It would be helpful if this became mandatory training for all staff in the care sector.”

“I thought it was an excellent study day and really opened my eyes to a subject I had no knowledge of.”

“A really great workshop. Typically I found it a case of ‘you don’t know what you don’t know’ until I attended training.”
Thank you – questions?
For further information please visit our website:

www.sueryder.org/humanrightstraining

Or email us at:

humanrights@suerydercare.org