

COMPASSION IN DYING

ARE OUR WISHES RESPECTED AT THE END OF LIFE?

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A SYSTEMATIC
REVIEW OF RESEARCH EVIDENCE

"In the twenty-first century, people are living longer, ageing further and dying slower, with more degenerative disease, than ever before. The medicalisation of death has resulted in us dying away from home, in relative social isolation, often in a hospital where the first priority is to prevent death. We face an increasingly degenerative end to life, with less and less control over our own dying process."

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Guy Brown

Compassion in Dying trustee and author of 'the living end: the future of death, aging and immortality'

COMPASSION IN DYING

Compassion in Dying is a national charity that supports people at the end of life to have what they consider to be a good death by providing advice and information around their rights and choices. We also conduct and review research around rights and choices in end-of-life care. Our services are available to all those affected by the end of life; including patients, carers and healthcare professionals.

THE SYSTEMATIC REVIEW: ASSESSING EVIDENCE FROM RESEARCH

In order that Compassion in Dying could learn more about whether patient choices at the end of life are respected, we conducted a systematic review of relevant research evidence which asked *to what extent the medical treatment wishes laid out in preference tools are respected*¹.

THE UK CONTEXT: RIGHTS AT THE END-OF-LIFE

- The refusal of treatment is one of the few rights we have at the end of life if we have lost capacity. But this right must effectively be exercised before the individual loses capacity - by making an Advance Decision or giving a trusted person Lasting Powers of Attorney (LPA).
- An Advance Decision is a document which allows a person to set out treatment decisions in advance, in the event that they become unable to communicate or lose mental capacity. The refusal of medical treatment in an Advance Decision has statutory force under the Mental Capacity Act 2005 in England and Wales, and is binding in common law in Scotland and Northern Ireland. Advance Decisions are also commonly known as living wills and advance directives.
- The Mental Capacity Act 2005 also enables adults with capacity in England and Wales to make a Lasting Power of Attorney; this allows a person to appoint an individual(s) to make decisions on their behalf, should they lose capacity.
- **However, Advance Decisions and Lasting Powers of Attorney are not routinely used in the UK, and there is no evidence from the UK on the extent to which treatment preference tools and the decisions recorded in them are respected by healthcare professionals.**
- In July 2010 the General Medical Council published new guidelines for doctors in the UK on advance care planning for patients nearing the end of life². These have a clear emphasis on the importance of listening to patients and recording their wishes to help ensure that everyone involved in treating the patient can understand and follow their directions.

KEY FINDINGS FROM THE SYSTEMATIC REVIEW

01
Planned end-of-life care, combined with tools for recording treatment preferences plus buy-in of these tools from healthcare teams, significantly helps to ensure that patient wishes are respected.

Most of the research included in the systematic review took place in settings where end-of-life care is routinely practiced (such as hospices, nursing facilities and care homes), and care can be planned. The research indicates that the success of preference tools in ensuring patients' wishes are respected is as much about context of care, sophistication of care models and buy-in from staff, as the tool itself. However, there was some evidence to indicate that patient preference tools can have an effect in more general settings.

02 **UK practice needs to change**

The vast majority of evidence came from the United States (USA), where policy such as the Patient Self-Determination Act (which requires most health care institutions to provide information about advance directives to adult patients upon their admission to the healthcare facility) and locally-driven initiatives to record and act on patient wishes at the end of life have been in place over the past ten to twenty years. Patient wishes are recorded in the USA much more frequently than in the UK, and patients' end-of-life decision making has been on the agenda there for a lot longer. UK policy needs to change to ensure patients' wishes can be recorded, and existing practice (and any changes to practice) should be evaluated.

03

Example of good practice: POLST

One example of a successful tool for decision making is the Physician Orders for Life-Sustaining Treatment (POLST) which is used, to varying degrees, across the USA. The POLST is designed to convert patient preferences for life-sustaining treatments into immediately actionable medical orders, and to be transportable between care settings. This tool works in synergy with end-of-life programmes, where details are stored electronically in easily accessible patient records. POLST is specifically designed for people with progressive chronic illness or 'frailty', and its use has been widely supported by healthcare professionals, with training provided and strong uptake as a model for working.

04

Example of good practice: La Crosse

In another dedicated programme of work in La Crosse, Wisconsin, evidence shows that nearly 100% of patient decisions regarding hospital admittance were respected because questions about treatment options were asked in advance, and built into care plans and/or easily accessible in patients' records³. This planned, patient-centred approach has brought down La Crosse's end-of-life care costs. More importantly, it has ensured patients' wishes are respected so that they have a better end-of-life experience for less cost.

WHAT NEXT?

There is a clear need for research evidence from the UK. However, evidence from the systematic review demonstrates that in the USA medical treatment preference tools are an effective way of ensuring patients' wishes are respected, when used in the context of planned end-of-life care.

Compassion in Dying is committed to empowering individuals to exercise their right to make choices about the medical treatment they receive at the end of life.

COMPASSION IN DYING'S CURRENT WORK

- Compassion in Dying will continue providing Advance Decisions, guidance on their use, and information on wider end-of-life rights for both healthcare professionals and the general public, free of charge.
- Compassion in Dying is part of an Advance Decision Coalition which campaigns for a central register for Advance Decisions and Lasting Powers of Attorney⁴. This would ensure that patient wishes could be stored and accessed effectively, thereby making it much more likely that healthcare professionals will be aware of, and can act upon patient treatment wishes.
- Compassion in Dying is launching an information line which will provide expert information to enable people to make informed decisions about their care and treatment at the end of life.

FUTURE WORK NEEDED FROM COMPASSION IN DYING AND OTHERS

- Research in the UK is needed to evaluate the effectiveness of medical treatment preference tools in a variety of settings.
- A culture of respecting patient choice and having conversations about end-of life-preferences is essential to upholding patients' wishes. Therefore training and awareness raising for healthcare professionals on discussing and supporting patient choice under the Mental Capacity Act 2005 is vital.

In the context of planned end-of-life care, patient preference tools are an effective way of ensuring patient wishes are respected. However, to achieve this end we need cultural and systemic change. Patients and healthcare professionals must understand the choices they can make and how to make them. Health professionals must understand patients' end-of-life decision making rights as well as their own legal responsibilities. As well as these cultural changes, there must be technology in place to record patients' treatment preferences, to ensure that they are known about and respected.

PLEASE NOTE

THE FULL SYSTEMATIC REVIEW REPORT WILL BE AVAILABLE AT: WWW.COMPASSIONINDYING.ORG.UK FROM MARCH 2011.

STUDIES INCLUDED IN THE SYSTEMATIC REVIEW

Degenholtz HB, Rhee Y, Arnold RM (2004) Brief communication: the relationship between having a living will and dying in place *Annals of Internal Medicine* 141: 113-117

Hammes B, Rooney B, Gundrun J (2010) A comparative, retrospective, observational study of the prevalence, availability and specificity of advance care plans in a county that implemented an advance care planning microsystem *The American Geriatrics Society* 58: 1249-1255

Hickman SE, Nelson CA, Moss AH *et al* (2009) Use of the Physician Orders for Life-Sustaining Treatment (POLST) paradigm program in the hospice setting *Journal of Palliative Medicine* 12(2) 133-141

Hickman SE, Nelson CA, Perrin NA *et al* (2010) A comparison of methods to communicate treatment preferences in nursing facilities: traditional practices versus the Physician Orders for Life-Sustaining Treatment Program *The American Geriatrics Society* 58: 1241-1248

Molloy DW, Guyatt GH, Russo R *et al* (2000) Systematic implementation of an advance directive programme in nursing homes: a randomized controlled trial *Journal of the American Medical Association* 283(11): 1437-1444

Pekmezaris R, Breuer L, Zaballero A *et al* (2004) Predictors of site of death of end-of-life patients: the importance of specificity in advance directives *Journal of Palliative Medicine* 7(1): 9-17

Schamp R, Tenkku L (2006) Managed death in a PACE: Pathways in present and advance directives *American Medical Directors Association* 7: 339-344

Teno J, Gruneir A, Schwartz Z *et al* (2007) Association between advance directives and quality of end-of-life care: a national study *The American Geriatrics Society* 55: 189-194

FOOTNOTES

- 1 This is a sub-question from a larger question which proved too wide-reaching to conduct: What tools/activities are employed to support patient-informed decision making and choice in end-of-life care and what is known about their delivery and impact?
- 2 General Medical Council (2010) Treatment and care towards the end of life: good practice in decision making *General Medical Council*
- 3 Hammes B, Rooney B, Gundrun J (2010) A comparative, retrospective, observational study of the prevalence, availability and specificity of advance care plans in a country that implemented an advance care planning microsystem *The American Geriatrics Society* 58: 1249-1255
- 4 Lasting Powers of Attorney's are registered with the Office of Public Guardian, but doctors still need to be aware of their presence and be able to access them.

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