UNIVERSITY OF LEICESTER

Institute for Policy

National Ethics Trust for dignified medical choices

Establishing a key independent body where patients can take their difficult medical prognosis for in-life and end-of-life care

Key Policy Recommendation

Create a National Ethics Trust (NET) to provide the necessary help and support for patients and their loved ones. This would:

- **Help make difficult choics with dignity** and **protect the patient's right to privacy**.
- **Assist those navigating the worst medical moments**, especially those with a difficult pain prognosis, and ensure people can make dignified choices in the UK.
- **Operate independently to the British court system – it would be staffed by a range of experts,** listening and meeting patients and their families in private.
- **Avoid families having to crowd fund** on social media because of a lack of legal aid in the British court system.

The impact of a National Ethics Trust (NET)

Current media debates about the ***Assisted Dying Bill*** have highlighted that the UK Court system cannot cope with taking on this highly sensitive and time-consuming workload in public ethics. Alternative proposals are being put forward as amendments to the Bill.

Whilst some GPs support the Bill, others would not want to be part of the medical process to end life. Many more in the GMC are neutral, waiting to see what Parliament enshrines in law. **This is one of the most sensitive areas of current public debate, an historic moment in the modern history of biomedicine in Britain.**

Yet, it is a medical fact that somewhere today is a patient at home, in a hospital ward, or hospice care, that cannot cope with the pain of their end-of-life prognosis. As they approach their tolerance level, they will need a **National Ethics Trust** – **NET** – to help them make important decisions nearing the end-of-life. We have the expertise in the UK to staff this new body and it could operate independently from the British court system.

The need for a National Ethics Trust (NET)

We live in a world where medical science has delivered wonderful **healthcare benefits** for everybody who has access to the **NHS** in Britain. Many people are living longer, but there is no medical guarantee that lengthening your lifespan will also deliver a good **quality of life** for everybody.

When patients, their families, and doctors disagree about end-of-life timings, treatments, and when to stop life support, medical disputes usually end up in court. But that legal requirement also can create a press and social media storm that is very stressful for all involved.

Currently, there is **little legal aid** to go to court and many families end up crowdfunding on social media to have a voice in medical decision-making, which means they lose their privacy in a storm of newspaper publicity.

In 2021, the House of Lords estimated some 350 people per year faced very harrowing end-of-life scenarios
(House of Lords Library, *Assisted Dying Bill (HL)*, 2021)

A new **national independent body** could help make difficult choices with dignity and protect the patient's right to privacy. It is a policy solution that works in parallel with the new ***Terminally Ill Adults (End of Life) Bill Private Members' Bill (Ballot Bill)* 2025**, what the media calls the ***Assisted Dying Bill*** in Parliament.

New legislation poses an ethical problem relevant to everyone, given the fact that life is finite, and we all will require access to medical care at some point in our lives.

Evidence Base

Research from the University of Leicster has addressed the following key questions regarding dignified medical choices:

- What happens when you are in so much pain at the end-of-life that it becomes unbearable?
- What if you face multiple health complications and a medical prognosis that will be agonising?
- What are the different pain thresholds people can cope with and how do they differ in patients?
- How do we know that the decisions people make in pain, are those they would still make out of pain?
- What happens when you are considered too young to decide for yourself what should happen if you have a fatal illness?
- How do we ensure that vulnerable people do not feel pressurised into taking assisted-dying decisions?

Experts at Leicester have also been researching what and when ***constitutes medical death*.** It is one of the greatest ethical challenges confronting us all today.

In a biomedical age when technology can trace the faintest signs of life, monitoring medical death is much more complicated. Recently the General Medical Council updated its GP guidelines in March 2022 on good practice in decision-making at the end-of-life, recognising **"difficult and challenging emotional decisions", not simply medical ones, that need to be better co-created between patients, practitioners, and family members.** For legally, anyone that assists someone to die with a terminal illness can be prosecuted under the Suicide Act (1961). Often loved ones die alone for this reason.

Implementation

There is one policy solution that would be holistic, both mediate ethics and formalise legal safe-guards, so necessary in a biomedical age, with the **establishment of a National Ethics Trust – the safety NET – we might all need in our future.**

Since the foundation of the NHS, we pay doctors from central taxation to decide what is in our best medical interests. If disagreements occur between the state and families, they can only be resolved by established principles written down in case law. But the Courts have little legal aid, and that causes long delays because of excessive workloads.

A National Ethics Trust would deliver a more ethical solution - an independent review process that could be conducted with **dignity**, **discretion**, and **decorum in private** avoiding the intense media spotlight in difficult and emotive cases.

The person in excessive pain (or their guardian, and/or carer) could ask to have a case review by the **National Ethics Trust – a safety NET** we might all need at the end-of-life. It would **meet three times** to ensure the person was not being persuaded by pain, loved ones, or other related personal issues, to make a decision, out of character.

Experts would all be very experienced in staffing sensitive case-loads and in 3 stages, check with relevant people involved at:

- A first half-day meeting, the medical ethics at the heart of the human situation.
- A second half-day meeting, would listen to the person's quality-of-life.
- A third half-day meeting, would check on potential coercion and the pain management prognosis.

For our **ageing population** further complicates everybody's future medical prognosis. The **Office for National Statistics** has highlighted that 'In 2015, there were around 901 million people aged 60 years, worldwide some 12.3% of the global population. By 2030, this will have increased to 1.4 billion (16.4%) and by 2050, it will have increased again to 2.1 billion (21.3%) of the global population.'

In the UK in the 'next 50 years, this means an additional 8.6 million people aged 65 years and over – a population increase roughly the size of London.' Legally many may have to die alone, to avoid a caring loved one being suspected of assisted dying when we reach our coping levels.

From 1st April 2009 to 31st March 2023, 182 cases recorded as assisted suicide were referred to CPS by police. Of these, 125 were not proceeded with by the CPS and 35 were withdrawn by the police.
(Crown Prosecution Service 2023)

Over the last 200 years, medicine has complicated what to do when we approach the deadline of our lives, which can now be monitored to the minutest degree by new biomedical technologies. The ***Terminally Ill Adults (End of Life) Bill Private Members' Bill (Ballot Bill)*** **2025**, proposes to change the law but **only a NET** works ethically, holistically, and practically for everybody.

This policy briefing paper was produced by Prof. Elizabeth Hurren, Chair in Modern History at the University of Leicester, with the support of the University of Leicester Institute for Policy.

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