Book Review: Last Rights - The Case for Assisted Dying by Sarah Wootton and Lloyd Riley

The Covid-19 crisis has made many of us think more about end of life issues. Sadly, the crisis has resulted in many experiencing death in far from ideal circumstances. The renewed focus on end of life choices makes the timing of this book particularly relevant. It raises important questions:

- What kind of death would we want when our time comes?
- How will we be able to avoid levels of suffering that we find unacceptable, in whatever form that may take, when there is no realistic chance of a meaningful recovery?
- Who should be in control of our end of life choices us, our doctors, or the state?
- What planning should we be doing now, to achieve as good a death as is possible, given the current legal and medical constraints?
- How should the law be changed?

The book does an excellent job of explaining why the current law, which prevents assisted dying in England and Wales, is responsible for unnecessary suffering at the end of life. It argues convincingly that claims that the current law provides safeguards are bogus.

The claim that the law protects vulnerable people from coercion is exposed as false. Today vulnerable people can be coerced into ending their life by refusing life-sustaining treatment, or by refusal of food and liquid. Doctors routinely look out for evidence of such coercion and override this, with the aid of the courts if necessary, if it is believed that the person is not making their own decision, or lacks the mental capacity to make the decision. As doctors and courts can adequately safeguard against these existing risks today, there are no grounds to suppose that similar checks will not be adequate in the case of a person requesting a medically assisted death.

In cases where someone ends their own life, either with or without assistance, and with or without coercion, there is no opportunity for doctors to intervene. Vulnerable people are not protected by a law which drives people into covert, often premature, life-ending activity.

Case after case highlights the various ways in which the current law fails us:

 People feeling they have no choice but to make the difficult arrangements to travel to Switzerland for a legal medically assisted death there.

- People ending their lives too soon, without appropriate counselling and often violently, possibly traumatising those they leave behind.
- People trying but failing to end their own lives, due to lack of access to safe, peaceful medication. Instead they may end up in a worse state.
- People having to face prolonged legal investigation for compassionately helping a loved one end their life – adding to their grief at an already difficulty time.
- People refusing food and liquid as the only means they have available to end their lives.

The book builds on important evidence obtained through research carried out or commissioned by Dignity in Dying over the last few years. For example, estimating the number of terminally ill people who are driven to end their own life — a number that far exceeds, by a factor of at least 10, the number who travel to Switzerland for an assisted death there. Another report looks at the workings of our excellent palliative care system. While palliative care provides a good death to many, it requires more funding to ensure that it is available to all who could benefit from it. However, the evidence shows that even if everyone had access to the best available palliative care, 17 people per day would die in pain that cannot be adequately alleviated. Well-funded palliative care is certainly an important part of the solution to ensuring as many as possible have a good death, but it will never be a full solution.

MDMD joins Dignity in Dying in our demand for a public call for evidence on the failings of the current legislation and a change in the law on assisted dying.

Although the book has much to commend it, it leaves a huge elephant in the room. There is no meaningful discussion of the pros and cons of different ways of improving the law. The authors are the Chief Executive and the Policy and Research Manager of Dignity in Dying. Their organisation has much in common with MDMD but proposes a narrower solution, based on the law in Oregon, that would only be available to those with a life expectancy of six months or less. This would exclude those in early stage dementia before they lose mental capacity, and those who suffer incurably for a much longer time – such as with Multiple Sclerosis, locked-in syndrome, Multiple Systems Atrophy etc.

In its closing pages the book concludes: 'The issue of choice at the end of life is often presented as complex... It is not complex. It is very simple. We must respect the person who is dying. We must provide them with what they need to have the death they want.'

MDMD fully agrees that the autonomy of mentally competent people at the end of their life should be respected. But deciding how exactly this should be done is certainly not

'very simple'. Questions that need careful consideration, taking into account all available evidence, but which the book does not address include:

- What counts as "end of life" or "dying"? Evidence over the last few years shows
 that a fixed time limit on life-expectancy estimate is deeply problematic. More
 compassionate and flexible approaches are necessary, such as that used in
 Canada's Medical Assistance in Dying, (MAID), legislation. Within the UK there
 are already discussions regarding the difficulties surrounding a fixed time
 "terminal illness" definition in relation to benefits payments. Scotland has
 abandoned it, on the basis of medical advice. It is under review in England and
 Wales.
- What should the role of medical professionals be in providing people "with what they need to have the death they want"?
- Evidence shows that the most reliable, quick and painless method to provide a medically assisted death is to give a lethal drug intravenously, something that is not permitted in Oregon. In Canada and other countries, where the choice of oral or intravenous options are available, the evidence clearly indicates that most people choosing MAID want the drug to be administered intravenously. Should this be allowed in the UK? If not, why not, if it is the dying person's preference? If intravenous delivery is permitted, should it follow the Canadian model where doctors can administer it, or the Swiss system at Lifecircle where the person opens the valve to admit the drug themselves?
- Why should those who are incurably suffering be denied a choice to hasten their death? As Lord Neuberger pointed out in the Tony Nicklinson legal case: 'There seems to me to be significantly more justification in assisting people to die if they have the prospect of living for many years a life that they regarded as valueless, miserable and often painful, than if they have only a few months left to live.'

Instead of addressing these issues, the book frequently refers to the Oregon law without justification, or comparison with alternatives that have learnt from the limitations and problems with the Oregon model. In MDMD's view the Canadian model, with the currently proposed extensions, is the example that other countries, including the UK, should follow as it overcomes many problems of the Oregon law and learns from the experience of implementing MAID since it was introduced in 2016. This position is borne out in the recommendations from a parliamentary committee in Queensland Australia.