

Secretary of State for Health and Social Care

Cc: Merry Varney of Leigh Day, solicitor for Kate Masters

21st May 2020

Dear Sirs,

In support of the proposed application R (on the application of Kate Masters) v Secretary of State for Health and Social Care

Compassion in Dying is a national charity that helps people prepare for the end of life, including how to talk about it, plan for it, and record their wishes. We are the UK's leading provider of Advance Decisions to Refuse Treatment and specialise in supporting people to complete these forms in line with the Mental Capacity Act 2005. This enables them to make decisions according to their goals and priorities when living with a life-changing illness.

Compassion in Dying has supported over 56,000 people to plan ahead. Between 2017 and 2019, approximately 7% of the queries received by our free information line related to Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) forms and Cardio Pulmonary Resuscitation (CPR) decisions.

The experiences and issues faced by our callers in relation to DNACPR are summarised below. The problems and difficulties identified are ongoing issues: the coronavirus pandemic has not created them but it has highlighted them. The volume and nature of queries we receive on DNACPR inform our support for Ms Kate Masters in her request that the Secretary of State improves the availability of accurate and accessible national guidance regarding CPR, including what the law requires, what the CPR procedure entails and how decisions as to whether to attempt CPR are made. The current reality faced by the people we support indicates plainly that the provision of easily accessible and clear information, as Ms Masters is requesting, would significantly improve those people's experience of medical treatment and care, and furthermore would reduce distress felt by both patients and their loved ones.

Experiences of the people we support

A) Patients are distressed when doctors do not comply with the law

Despite the law set out in the Tracey Judgment [2015] QB 543, [2014] EWCA Civ 822, we are often contacted by distressed individuals and family members who want to understand why a DNACPR decision was not discussed with them. These callers are not necessarily in disagreement with the decision but rather want to understand why the decision was taken and what its implications are. As such we have known for some time that the communication skills of healthcare professionals discussing DNACPR with people varies widely, and we see the emotional impact created by this variance on patients and their loved ones.

"My mum is in a care home and the GP placed a DNAR on her records. No one spoke with me and I don't know what it means."

Compassion in Dying Information Line caller

B) Patients feel abandoned when their treatment preferences are ignored by healthcare professionals

The people who call us often want our help to ensure they have some control at the end of life. However, we have received numerous reports from callers feeling abandoned or not taken seriously by healthcare professionals when they initiate a conversation about their future treatment preferences, including when they have requested a DNACPR for themselves. They feel 'in the dark' and anxious because they don't know what their rights are in terms of requesting or demanding DNACPR orders if they wish to not be resuscitated. This highlights a very serious lack of understanding by some healthcare professionals of individuals' rights to refuse treatment in advance as set out in the Mental Capacity Act 2005, which could result in patients being subjected to treatment they do not wish to receive, with lasting effects on their quality of life and wellbeing.

"Caller is 84. She has an irregular heart beat and had been resuscitated many years ago - she was told she was very lucky to have survived, her recovery was painful and took a long time, and she knows it will be different now that she is much older. A few months ago she went to the GP to talk about this and get a DNACPR form. He said that she didn't need to refuse CPR because she is very healthy and refused to give her a DNACPR form. She has been very worried ever since."

Compassion in Dying Information Line call record

C) Lack of clarity about the different advance care planning tools leads to disjointed and inefficient care

Compassion in Dying also regularly receives calls from health and care professionals seeking clarity on local implementation of advance care plans and DNACPR forms. Examples of questions raised, to which nationally applicable answers are currently either unavailable or hidden in inaccessible PDFs rather than presented in a way that clinicians and the public can find, read and interpret, include: whether someone needs both an Advance Decision and a DNACPR form; whether the DNACPR form travels with the patient to different care settings and whether CPR should be performed on someone with a DNACPR form while waiting for an ambulance.

"Caller works at a GP surgery. One of their patients has a DNAR form and has moved into residential care. The care home said the GP has to do another form with the correct address. GP thinks the form should travel with the patient so doesn't think she needs a new form, and wants to know what they should do."

Compassion in Dying Information Line call record

D) Developing a shared understanding of the decision not to attempt CPR contributes to a better end-of-life experience

Our callers tell us that done well, DNACPR conversations help people understand what is likely to happen if they become unwell and give them the opportunity to ask questions and explain what matters to them. Good conversations also focus on what treatment and care will be given, not just on the fact that CPR will not be attempted. Once the reality of the situation is explained, people who are already very unwell or frail often do not want to receive treatment that is likely to be painful and distressing, only to keep them alive with a quality of life that they would not personally find acceptable. Finally, we hear that when treatment decisions are made in line with a person's goals and priorities, it enables families and carers to have a better bereavement experience.

"My father, 63, with terminal cancer and father-in-law, 83 with Parkinson's and other disorders, had frank, compassionate discussions with their doctors, who

included us, as carers, in their decision-making. This ensured that they were able to accomplish a beautiful death, at home, comfortable, without pain and surrounded by their loved ones."

Compassion in Dying Information Line caller

E) There is a lack of clarity around systems for recording DNACPR orders

Some of the questions we are asked by healthcare professionals set out in point C) above reflect confusion over local systems for recording DNACPRs, as well as uncertainty over their implementation. Similarly, many of the patients and families who contact us express concern that healthcare professionals will be not be aware of their decisions and preferences about treatment, even if they are recorded in an Advance Decision and they have DNACPR. If healthcare professionals are not aware of DNACPRs because they have not been properly recorded, they obviously cannot observe the decisions set out in them. Ms Masters' case is an opportunity to provide clear, accessible national level guidance on principles for the recording of DNACPRs, alongside or as part of national guidance regarding DNACPR, what the law requires, what CPR entails and how decisions as to whether to attempt CPR should be made.

Caller's mother is dying and has moved into a care home. She had made a DNAR with her GP but only has a copy, not the original. The care home says they need the original form otherwise they will phone for an ambulance if her mother goes into cardiac arrest. Caller wants to know who should issue the DNACPR, who should hold it and how it should be recorded so that if an ambulance is called or her mother has to go into hospital the DNACPR will be recognised and accepted.

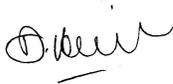
Compassion in Dying Information Line call record

The coronavirus pandemic has highlighted an urgent need for an honest and transparent approach to supporting people's understanding of what CPR is, why it may not be clinically appropriate, and what can be done to ensure people are treated with respect and dignity. Examples of blanket DNACPR decisions being applied are deeply concerning and highlight, in some areas, existing problems around local leadership on DNACPR decisions and poor communication by healthcare professionals: it is perhaps not surprising that at a time of great stress on the healthcare system and when doctors are working under intense pressure, the problems of variation in interpreting the law and poor communication have been exacerbated.

The remedy sought by Ms Masters presents an important opportunity to demystify CPR decisions and to ensure patients, families and healthcare professionals share a good understanding of people's rights, and the importance of these vital conversations. We believe that this opportunity to show national leadership is more important now than ever and must not be missed.

Compassion in Dying strongly supports Ms Masters' proposed application. We look forward to hearing your response.

Yours faithfully



Davina Hehir
Director of Policy and Legal Strategy
Compassion in Dying