



PRACTICE

WHAT YOUR PATIENT IS THINKING

Twitter helped me decide that I'm not for resuscitation

Discussions about your death will never be easy, but Keith Cass describes how social media was useful to him when thinking and talking about resuscitation decisions

Keith S Cass

When I first saw Mark—my palliative care consultant—in his clinic, we talked mainly about my pain, which was poorly controlled at that point. I have advanced prostate cancer, and it has spread to nearly all the bones in my body.

At my next visit the pain had improved substantially, and we talked about my wishes should I become more unwell.

When Mark first mentioned do not attempt cardiopulmonary resuscitation (DNACPR) decisions, and what my views on this topic might be, I was taken aback. Of course I want everything done. I don't feel so bad, so sign me up for full resuscitation please.

Using social media

Mark accepted my reaction, but it became clear that he thought that many people have a rose-tinted view of how successful cardiopulmonary resuscitation is, perhaps because of the way it is portrayed on television. He suggested I look at the TalkCPR website and videos on <http://talkcpr.wales> and search for the #TalkCPR hashtag he has set up on Twitter, to understand more about CPR in palliative care settings.

So off I went, followed Mark on Twitter, looked at some of the debates and the videos that he helped create with patients and carers. The first thing I took in was the low success rates of cardiopulmonary resuscitation for patients when the cancer has spread. And then of course I read about what cardiopulmonary resuscitation involves.

Changing my mind

At subsequent visits to see Mark, I gradually changed my mind. At first I thought that conditional cardiopulmonary resuscitation might be acceptable. We terminally ill cancer patients live in hope that a cure for our cancer will be found “tomorrow.”

But when I discussed it further and reflected on it as “just one procedure of many,” albeit an invasive and traumatic one which was unlikely to work, I asked for a DNACPR form to be filled in. I specified my views, in particular stating that I would still be keen to be considered for anticancer treatments such as chemotherapy. But when it comes to one particular intervention—cardiopulmonary resuscitation—I do not want it.

The main influence of my decision was the success rate and the possible damage to my physical body that would make survival with quality of life almost impossible.

Mark and his colleagues tell me that they still see many instances where the absence of a DNACPR or Advance Decision to Refuse Treatment form, means that healthcare workers start resuscitation by default, even in patients where a natural, irreversible dying process has started.

Talking to loved ones

It is not easy to contemplate your own death, but I approach it with some black humour, and my palliative care and oncology team are also good at sharing a laugh about some of the crazy things we discuss. I keep the form with me at all times, so healthcare professionals can be aware of my wishes, and I've told everyone around me about it. My (grown up) children were the first to know my decision at each stage and how I had arrived at my final decision of DNACPR.

I'd like doctors and nurses who have these discussions often to take the time to talk about the complex issues with patients and their loved ones to create a shared decision process.

Cardiopulmonary resuscitation in palliative care is difficult to discuss and some people may find it distressing, but doing so early means having informed patients who know the pros and cons and can have an intelligent conversation with their healthcare professional. Also they can explain their views to family and friends.

@redsockcampaign

Viewpoint from Mark Taubert, consultant in palliative medicine, Velindre Cancer Centre, Cardiff, Twitter @DrMarkTaubert

Keith was taken aback when I first broached advance care planning topics, but we talked about it and he took the time to look at cardiopulmonary resuscitation and make a decision as to whether this was something he would want considered if he became unresponsive. Like many people I meet, I thought that Keith was worried that having a DNACPR form might also preclude him from consideration for other, more standard treatments such as antibiotics, chemotherapy, and blood transfusions. But he has had his DNACPR form for some months now, and we both know that it has had no impact on other treatment decisions.

Keith was easy to talk to, but many people, especially patients' loved ones, find these conversations hard, which is not surprising. We hope that the TalkCPR website will get patients to approach their doctor saying: "We need to have a talk about resuscitation." In the future I would like patients to be in charge of treatment decisions. I hope that DNACPR forms, which are still filled in and signed by a healthcare professional, are gradually replaced by Advance Decision to Refuse Treatment (ADRT) forms, which are completed by informed patients and are legally binding.

What you need to know

- Doctors and nurses should take time to explain cardiopulmonary resuscitation and its limited success in palliative illness with their patients
- Resources such as a policy document, leaflet, and the TalkCPR videos can help supplement the conversation
- It is worth making DNACPR and ADRT conversations part of a broader chat about all treatments that can be refused, including simpler things such as blood transfusions and radiotherapy

Education into practice

- How do you discuss do not attempt cardiopulmonary resuscitation (DNACPR) decisions with your patients? Does this article offer you ideas on doing so differently?
- Which supporting resources do you direct patients and their carers to when discussing do not attempt cardiopulmonary resuscitation (DNACPR) decisions? What other resources might be available?
- Patients or doctors might bring up the topics of advance planning and resuscitation. How do conversations differ depending on who raises them? How could you alter the way you initiate or react to the discussion of these issues to achieve a better conversation?
- Is there anything else that you may think about or act on differently having read this article?

These questions were developed by the editors and reviewed by the patient author

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Mark Taubert is a collaborator on this article.

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