

## Dr Kathryn Mannix 29<sup>th</sup> March 2020 Facebook post

Today I was asked a great question about deciding whether or not a ventilator is the right treatment if someone has severe Corona virus infection. Is it better just to stay home? Will I die anyway? I gave my best answer, and tagged a very senior and experienced ICU specialist for her opinion, too. I thought the conversation might help lots of people who are discussing what treatments they would accept, and where they would draw the line, if they become very sick.

Remember: most of us will get better. Most of us won't need hospital. Hospital helps lots of people to survive. But some of us will become so sick that dying is possible, and at that point we'll be too unwell to tell people what we want. Here's the conversation in full, with the asker's name hidden because I haven't been able to ask her permission to quote her excellent question.

XX says: Ooh Kathryn! A difficult " chat " to have but I accept a necessary one ! 😞 Can you tell me that if I am recommended the need for ventilation in ICU I would be terminal? That would determine my preference would be to stay home!

Dr Kathryn Mannix: XX this is such a courageous and wise question. Here's how it works. Paging my ICU guru-pal Anna Batchelor to be sure I've got the details right. Most of us will catch the virus at some point and have a rough week or two before we get better. Many of us will struggle with a virus-induced lung inflammation that may be copable with at home. We'll cough, we'll have some breathlessness and it sounds like it hurts, too. But we'll get through. Some of us won't be able to breathe well enough to get sufficient oxygen for our needs. This is when making choices ahead of time starts to become important, because falling oxygen levels in our blood makes it hard to think clearly and hard to stay awake and make big decisions. (\*important point: being very sick with a body full of virus (think 'flu, or bad chicken pox) makes us sleepy too. Don't panic if you need lots of naps. That's normal. Not being able to waken fully between naps isn't normal).

People who are really struggling to breathe have choices: stay at home, even though they may be sick enough to die, or go to hospital. People who choose to stay at home can still have medications to ease their breathlessness. Our bodies handle the sensation of breathlessness very like pain, so the strong painkillers that ease pain also ease breathlessness. We can have those at home, keep our family around us (2 metres mostly, closer for helping us move, giving us drinks, then wash hands and back off again!) so at least we are with each other.

People who choose to go to hospital will probably have to be away from family. Visiting will be restricted or even banned to preserve health of staff and other patients who don't have Corona virus but need to be at the hospital. Hospital would use the same drugs as at home to manage breathlessness but can offer extra options, including oxygen by mask, oxygen by high-pressure mask or full ventilation with a tube down the throat and care in ICU. None of these treatments guarantees we will survive, but the staff will be honest about the chances. Not everybody will be offered ventilation, even if they are getting so sick their life is under threat.

Here's how it works:

1. If the ICU consultant believes the patient would tolerate ventilation, recover from their lung disease, be able to get back off the ventilator again, and recover fully from the viral lung damage and damage to other organs, then that person will be offered a ventilator. But of course, there's no guarantee that this treatment will succeed, it's about weighing up probabilities.
2. If the ICU consultant thinks that death is not avoidable, and that use of a ventilator won't save the person's life but might well make dying take longer and be more unpleasant, then that person won't be offered a ventilator.

3. Between these two scenarios, there's a tricky third scenario. The person is sick enough to die without a ventilator, but also so damaged either by the virus or by other conditions they already had, that have become worse because of this episode of being so unwell, that it's uncertain how well they would be if they survive. Problems might be: -They may never be able to breathe sufficiently again without a ventilator. - they may manage to get off the ventilator, but be so damaged that either they can't think clearly any more, or can't manage to live independently any more. For these people, it's really important for the ICU consultant to know whether the patient would accept that risk. But the patient won't be in any fit state to discuss it. THIS IS WHY WE NEED TO MAKE OUR WISHES KNOWN IN ADVANCE. The consultant will ask whether you've expressed opinions. You may have made a legally-binding Advance Decision to Refuse Treatment ADRT. If that's applicable to the current situation it will count as your decision, e.g. not to use a ventilator or not to go to ICU. You may have appointed a person/people with Lasting Power of Attorney for Health and Welfare (LPA-H&W). If so, they can agree or disagree with the offer of a ventilator on your behalf, as though they were you. So we need to make sure our LPAs know what we would and wouldn't agree to! Or if there is no ADRT and no LPA, there must be a consultation between the doctor who can offer a ventilator and people who know the patient well enough to say what the patient had said they would or wouldn't agree to. Then the doctor advising about treatment has to make a Best Interests decision that takes the patient's known wishes into account. This is very hard to do if they never expressed their wishes. I have relatives who have already said they would stay at home even if they were dying, in order to remain amongst family. I have met people who say they would agree to oxygen via a mask in hospital but would not want a ventilator. Their wishes are clear, so we can respect them.

So, finally to answer your question: if you are offered a ventilator it will be because you're sick enough to die without it, and the doctor thinks you can be helped. If the doctor thought you could not be saved, they wouldn't offer you a ventilator. But a ventilator doesn't guarantee survival, or survival with a decent quality of life. So our representatives need to be able to say 'She wouldn't want to survive if she could never think for herself again' or 'She'd rather not survive than only survive with no independence.' Have the conversation. Write it down. Review it every so often. Make an LPA or ADRT. Write a Will. Tell people you appreciate them. Mend old disagreements. Forgive old rifts. Tell people you love them. If we survive the pandemic, we may have kinder relationships and even more love in our lives than we had before. And if we don't, we won't leave a mess. It's the least we can do. Anna, please say if I made any errors in my 'essay' above. Anna Batchelor: it's a splendid essay. Being in ICU asleep on a ventilator for more than a week (which seems to be the going rate) is a "real kicking". You need to have a lot of reserve to get through that. No one bounces back from that quickly, and indeed many people will be less able and require more help afterwards than they did before. Patients who need help to get about or look after themselves (I'm not talking long term disability here that's a much more complicated discussion) but those who are slowing up and need help are those least likely to get back to how they were before. If you throw in some heart disease and a bad chest then going on a ventilator may just prolong your death not your life. One of the things doctors and nurses are finding distressing is patients dying without family present. It's important to know about restricted or no visiting. Now is definitely the time to make your own wishes known. Important to know you cannot choose to go on a ventilator...only choose not to. \*\*\*\*\* There's a lot to think about. It's not an easy conversation. But it's such a blessing for families (Anna and I have both seen it, many times) when they are certain that they know a very sick person's wishes, and can honour them. So have that conversation. Get your ideas, wishes, concerns, hopes, values written down. I'll talk about making formal statements in a future post. For now, just reward yourselves with a cuppa, whether you are in the same room or having a conversation by phone or screen. You deserve it.