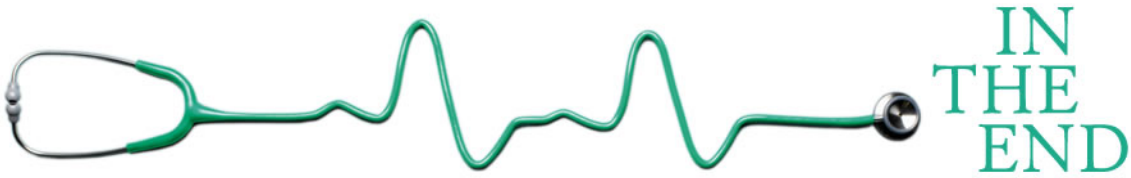

Discussion notes

IN THE END: About the film

Old people used to die at home, surrounded by their loved ones. Now they are ending up in intensive care, connected to machines and surrounded by strangers.

Intensive Care specialist Dr Charlie Corke is committed to give his elderly patients every chance to get better, but he knows that sometimes the treatment is only lengthening the dying process, causing discomfort and distress.

This documentary takes us on a journey of a doctor who is trying to balance his own enthusiasm for medical technology with an acceptance that, after a long and healthy life, it's OK to go.

IN THE END is a beautiful and profound film that follows the journey of patients, their families and their doctor dealing with a modern-day dilemma of our own making.

Director CHARLOTTE ROSEBY
Cinematographers MICHAEL WILLIAMS, JENNI MEANEY
Editor MARK ATKIN ASE
Sound Recordist MARK TARPEY
Composer MONIQUE DIMATTINA
Sound Designer GERALD MAIRDeveloped with the assistance of *SCREEN AUSTRALIA*.
Supported by the *STATE GOVERNMENT OF VICTORIA*.

Introduction

The Intensive Care Unit is the home of machines that are almost futuristic – life support technology designed to replace the functions of our vital organs while our bodies recover from injury, illness or trauma.

Very elderly people never used to be admitted to the intensive care ward. But nowadays in Australia and New Zealand nearly 15% of patients admitted to intensive care are aged over 80.

Intensive medical intervention can restore some people to their previous lives. These are the happy stories. But many elderly people arrive in intensive care already well along the path of dying. These people will never get back to the things they loved about life. And a long, painful and ultimately futile struggle ensues.

What makes it so distressing, says Dr Charlie Corke, a senior specialist working in intensive care, is that it takes an immense amount of invasive technology to try and support someone's failed organs. Not just a neat little intravenous drip, but an array of suction tubes, catheters, feeding tubes and breathing tubes surgically inserted. It can also mean sedating patients and tying their wrists to the bed to make sure that in their confusion they don't pull out all the tubes.

This can cause anguish for patients and their families. And it can be like this for weeks or months. There is always one more diagnostic test, one more round of the new antibiotics, one more procedure or one more surgical operation to try.

Charlie certainly doesn't believe in denying anyone treatment, but he asks: "Just because we have the diagnostic and therapeutic options available, should we always use them?"

The ability to extend life is a triumph of medical technology. But are we trying to cure when we should be trying to care?

Escalating Treatment, Diminishing Quality

It is easy for elderly people to "get stuck" on life support, not dying, but not getting better either.

In the past, writes Dr Charlie Corke in his recent book, Saving Life or Prolonging Death, most serious illnesses usually progressed rapidly to death despite medical intervention. "But now more effective medical interventions can support a longer road."

"What usually happens is that as each treatment fails we move to another that is usually more invasive and uncomfortable … Accepting that death is imminent is not easy and most patients, families and doctors hope that medical treatment can postpone this."

Progressive improvements in medical technology have provided many more ways of avoiding or delaying death and it is now unusual for anyone – families and doctors – to accept the inevitability of death until a significant amount of medical treatment has been tried and has failed.

This approach comes at a significant price and is far from what most of us say that we desire for our own end. When death is only accepted at the last moment, often just before death actually occurs – and often after unconsciousness – we miss the important opportunity to say goodbye.

Some medical intervention prevents death but fails to restore an independent existence, simply maintaining a situation that patients may consider to be excessively burdensome and undignified – at the worst a "living death", says Charlie Corke.

So why do we do it? Hope has a lot to do with it, and love. We also have unrealistic expectations of medical technology.

"It's no wonder that people think medicine always works," says Charlie. "It nearly always works on television, and that's where people mostly get their information. On TV, cardiopulmonary resuscitation – CPR – has an almost 100% success rate. But the truth is less than 10% of people survive resuscitation, and many do so with brain damage."

"Medicine has been portrayed as wonderful and able to vanquish death. But of course, 100% of people will die in the end."

"We cannot avoid death, but we can ensure the ends of our lives are comfortable and meaningful, and not excessively burdened with uncomfortable procedures that simply delay the inevitable."

Making The Difficult Decisions

There is a point where the increasing burden of medical intervention comes to outweigh the benefit. When the quality of life is very poor, the burden of treatment escalates, and when it offers little benefit, then the balance of harms and benefits may make a peaceful death the better choice.

But when exactly does the burden of the technology outweigh the benefit? The answer is different for every person; this is an intensely personal decision.

Elderly patients on breathing machines in intensive care can rarely make or communicate their own decisions. They are often unconscious and unable to speak for themselves.

People rarely leave clear instructions of how much medical intervention they would wish for at the end of their lives. Advance care planning, "not-for-resuscitation" agreements and living wills are a great idea, but people rarely have them.

If a patient leaves no guidance, what is the doctor or family to do? There are many decisions to be made. Operate? Intubate? Ventilate? Add more medical interventions? Withhold? Withdraw? Do we assume that a patient wants "everything" or should we assume that they might want what most others have said that they would want in a similar situation?

Many people think their own doctor can make the decisions on their behalf but, in hospitals, often the doctor in charge will be someone they have never met. And it's so hard for a doctor to know what is in the patient's best interest without knowing the patient or at least knowing where they are in their life's journey.

So it's usually left up to the family to work out how much treatment is too much. Without preparation and discussion beforehand, these can be agonising choices to make on someone else's behalf.

"Some doctors think that families shouldn't be burdened with making end-of-life decisions. But when our right to choose is removed we are often very dissatisfied, even when the choices made on our behalf appear reasonable," says Charlie. "You can see how important it is to write your wishes down using advance directives and advanced care planning."

From Fighting To Letting Go

Research shows that many families are demanding much more invasive technology than their elderly relative would actually wish for.

In a recent study Charlie presented families with a hypothetical end-of-life scenario. The results were clear: 83% of elderly subjects declined intensive treatment and 76% of their younger relatives also agreed that such treatment was inappropriate. However, when the relatives were presented with a hypothetical emergency situation and asked to make a decision about their parent's treatment, every one of them then elected to initiate intensive treatment.

Actually, says Charlie, most elderly people fear the process of dying far more than they do the thought of death itself. They don't want their death to be drawn out and uncomfortable.

But letting go is hard.

“The concepts of acceptance of death have many connotations that are weak … ‘throwing in the towel’, ‘giving up’, ‘not trying’,” says Charlie.

“If we give a family a one-in-whatever chance that a treatment might work – and that might be a thousand or two thousand or ten thousand – they’ll feel compelled to go to that. Unless we’re able to tell a family there is no chance at all, they often feel compelled to keep going.”

Doctors also often find it very difficult to accept death. Most doctors see their overriding role as that of saving life, rather than that of relieving symptoms. They feel death reflects their personal failure or inadequacy or that it simply confirms that they are not “the best”.

“It is enormously difficult to change from fighting like mad against death to stopping the fighting and accepting it,” says Charlie. “It’s difficult for doctors, it’s difficult for families, it’s difficult for patients. It’s difficult for everybody.”

Have We Forgotten How To Die?

These days most of us are protected from the realities of death and dying. We don’t see it around us, we don’t talk about it, and we don’t have to think about it.

There is plenty of death on TV. But this is mostly violent and unnatural. The natural process of ordinary dying in old age is generally absent from TV shows, and is concealed from our daily lives.

As recently as thirty years ago it was usual for people to die in their own homes, perhaps with a bed set up in the living room. Every child had seen a dead body – probably Grandma or Grandpa – laid out, with the family all around. Now, many people have never seen a dead person.

“We’ve lost the things that people associate with a good death: having your family around you and saying the final things – saying that you love them and hearing that they love you. Technology has taken that away from us,” says Charlie.

He wants a return to some old-fashioned values. He talks passionately in the film of a time, not long past, when “doing everything” for a dying elderly person involved doing special things for them like taking flowers, cooking favourite meals, or just being with them – not subjecting them to ventilation and an array of other invasive medical procedures until death becomes the preferred option.

Charlie believes the time has come for us to pause and consider our choices at the end of our lives. “If treatment can easily cure and restore, then we should take advantage of all that technology can offer. But if treatment will only delay the inevitable, causing discomfort and pain to the patient, with no prospect of a full recovery, then we should be able to let go. Patients, families and medical staff need to remember that ’it is OK to die’.”

Useful links

Erudite Medical Books
www.eruditemedicalbooks.com
Dr Charlie Corke's book Saving Life … or Prolonging Death: finding the way in a world of medical technology (Erudite Medical Books 2010) is available here. You can also find out about the "When Enough is Enough" course for junior doctors.

Respecting Patient Choices
www.respectingpatientchoices.org.au
There are two sections in this website: "Advance Care Planning for everyone" provides information about steps you can take to help you make plans for your future medical care.

The "Respecting Patient Choices for professionals" program provides training to doctors, nurses and allied health workers to enable them to discuss advance care planning helpfully and sensitively with patients and their families.

Palliative Care Australia
www.palliativecare.org.au
Palliative Care Australia is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all.

Music from *IN THE END*
www.moniquedimattina.com
Alongside Monique diMattina's original compositions in the soundtrack of IN THE END you'll also hear beautiful music from her recent solo piano album "Senses".

Ronin Films: *STILL BREATHING*
www.roninfilms.com.au
Read about and purchase a copy of Charlotte Roseby's previous film *STILL BREATHING* which also tackles difficult questions about life, death and dying.