

October 2019 Written by Dr Gordon Caldwell

For our October blog post, we wanted to share Dr Gordon Caldwell's thought provoking reality of DNACPR decisions. Would you be surprised if your patient died in the next year? Use the question to prompt your own discussions around treatment escalation and advance planning.

#### My Reality of Do Not Attempt Cardio-pulmonary Resuscitation Decisions

A Story of what CPR is like when it should not have been done

There was a frail old man struggling with his breathing in the first bed on the right as our team entered the six bedded bay to see our patient in the next bed. I think there was a nurse with him, but that may just be wishful thinking to salve my conscience. Our night doctors had been busy and needed to get away from their 13 hours shift, to grab some sleep before starting again that evening. We went to see our patient, and of course to maintain dignity and a semblance of confidentiality, we pulled the curtains around his bed. I was concentrating on our patient's problems and was aware of disturbance from the next bed. Our Registrar left to help out. Soon the whole cardiac arrest team arrived and started cardiopulmonary resuscitation (CPR) on the frail old man. The bay filled up with more staff, as usually happens during daytime cardiac arrest calls. We finished the consultation with our patient, reassured him as much as we could, and after checking our help was not needed, left to see the remaining patients. Later I went back to ask Sister what had happened. The man had died. The CPR attempt was called off after about 10 minutes.

When the admission notes were read out, he had been admitted from a nursing home in the small hours of the morning. He had severe emphysema and poor mobility. I asked the year 3 doctor about his thinking when he had admitted the patient. He thought that the patient was probably dying, but felt he was too junior to make that decision. He chose to wait until the Consultant round in the morning, thinking that the Consultant would make the "Do not attempt cardiopulmonary resuscitation" (DNACPR) decision. The patient suffered an undignified death, with one doctor doing chest compressions, another attempting to intubate his airway and a host of clinical staff looking on. The atmosphere in the ward was one of shock. The other patients in the bay were clearly distressed as were the nurses, who had wanted to provide kind care to a frail old man as he died. The doctors in the cardiac arrest team were also subdued. I felt that I should not have gone to see our patient, but dealt with the frail old man, although he was under the care of another Consultant. What he needed was a nurse to sit with him and hold his hand as he died; probably he needed some oral morphine to relieve the distress of breathlessness. He certainly did not need CPR.



I have told this story, warts and all, because it encapsulates our dilemmas in hospital about DNACPR decisions. Of course, you can criticise all of us in the story. The year 3 doctor should have spoken to the night Registrar, but maybe the Registrar was busy transferring another patient to the Intensive Care Unit. So the year 3 doctor should have phoned the Consultant in the middle of the night to get the decision, but maybe he thought the patient would make it through to the ward round, or maybe he was frightened to phone a Consultant at night. Very likely the year 3 doctor had a host of other patients and tasks to see to, with his bleep going off all the time. When Sister came on at 7 am, perhaps she should have called the Consultant, but it is possible she had not even had time to see the patient and had only had a verbal handover. I could have stepped aside and attended the patient. The Nursing Home staff or General Practitioner could have discussed this with the man, and made an advanced care plan. The man himself could have thought this through, if he still had capacity.

Some of my thinking about this story

Unless a DNACPR order is in place the nurses have to call the cardiac arrest team when a patient suddenly collapses, or is found collapsed or in extremis.

All of these potential criticisms are true, and what also is true is that right now, every day, hospital doctors face this sort of problem. I think it will be many more years, before we get to the stage where most people with very frail health have had these CPR issues resolved prior to arriving in hospital. In the meantime hospital clinicians are in an unenviable position. In 2014 there is a steady stream of frail, usually elderly frail, patients arriving in hospitals. Some are inevitably dying and the others despite their frailty will survive this admission, but are at a small risk of unanticipated sudden decline.

Talking with a frail patient who is inevitably dying and with his family is emotional and draining, but straightforward. The decision about DNACPR is also usually straightforward, because most patients want to die with the family around them, in comfort, and with "no heroics". Discussions with frail patients who will probably survive the admission are complex, emotional and take a long time, but the diseases in all our cohort of patients are running ahead around us. Most acute clinicians do not have the time for these discussions, yet we don't want to see out patients dying like the frail old man. Why don't we have the time? Last Saturday I saw 20 acute admissions, of which I thought that 15 had sufficiently frail health that they could not survive a CPR, although none looked as if they were imminently dying. The work of diagnosis, investigation, treatment, documentation, explanation and handover took 8 hours. Another 15 hours of discussion about CPR status, would leave 1 hour before starting to see the next 20 patients that I had to see on Sunday morning. As a clinical team we have to make a judgement that the frail patients, in the event of a sudden unanticipated deterioration, would not survive a CPR, to save them from a violent and undignified death, distressing to patient, family, other patients and hospital staff, who went into their careers to provide intelligently kind care.



### Words and Meanings

George Orwell was passionate about the meaning of words. In the book 1984 he showed a society in which words lost their meaning. In 2014 we live in a world in which "wicked" can mean a really great experience. The meaning of the words in this debate really matter.

Cardio-pulmonary Resuscitation (CPR)

A defibrillator is a device that delivers an electric shock across the skin and through the heart. The shock is like the Alt Ctrl Delete key combination, shutting a Windows computer down, in the hope that it will reboot successfully. The electric shock to the heart stops the heart's electrical timing activity in the hope that the heart will reset itself into the right rhythm (sinus rhythm, SR). Defibrillators came into use in the 1960s to treat ventricular fibrillation (VF) and ventricular tachycardia (VT) in patients who had had a coronary thrombosis.

Coronary Thrombosis, Ventricular Fibrillation (VF), Ventricular Tachycardia (VT), Asystole and Pulseless Electrical Activity (PEA)

A coronary thrombosis or myocardial infarction (the words mean the same) is commonly called a "heart attack". One of the arteries supplying blood carrying oxygen and glucose to the heart gets blocked by a blood clot. Usually the patient experiences severe crushing pain or tightness in the middle of chest.

When parts of the heart are starved of oxygen and glucose, the heart muscle eventually dies and turns to fibrous tissue. These days, with early interventions, the damage can often be limited. In the early minutes after the blood clot has blocked the artery, in a few patients, the heart rhythm becomes very unstable and the patient suddenly collapses into unconsciousness. Here is one place where words really matter. This collapse can also be called a "heart attack" by patients and the media, whereas doctors would call this a "cardiac arrest". In a cardiac arrest a patient suffering a coronary thrombosis develops unstable electrical activity so that the heart stops pumping blood. Unless urgent action is taken, the patient will die.

The unstable electrical activity can be VF, VT, asystole or PEA.

In VF the ventricles, the main pumping chambers of the heart, develop a totally chaotic electrical activity. In VT the ventricles beat so fast that the heart scarcely pumps any blood at all.

In asystole the electrical activity stops completely. In PEA the electrical activity continues, but the signalling between the electrical activity and the heart muscle is broken.



The defibrillator is more effective in VF and VT than in asystole and PEA. In VF and VT, the electrical shocks can reset the timing processes and sometimes the heart starts beating again in the normal rhythm. When this happens it can be really exciting and dramatic. I have seen patients collapse unconscious in front of me, and the heart is in VF. In a coronary care unit it is possible to charge up the defibrillator and apply a shock very quickly, so that the patient comes round almost at once. On rare occasions the patient can even resume the sentence he was speaking. Without a defibrillator he would have died. Sometimes the shocks do not work, it is impossible to get the heart rhythm reset and the patient dies. I can recall many, many more failed defibrillations than successful ones.

During a coronary thrombosis asystole and PEA are very difficult to treat and the prognosis (chance of success) for restarting the heart is far worse.

After the introduction of the defibrillator it soon became apparent that permanent brain damage can ensue unless a good blood flow from the heart beat is established, in adults, within a few minutes. Some blood can be pushed around the body by cardiac compressions. In cardiac compressions, provided the patient is on a firm surface, compression of the sternum by forceful downwards pressure of the hands, blood gets squeezed out of the heart to the brain and other vital organs. The force required is substantial – much more than kneading bread, perhaps more like using a large bilge pump on a boat. The amount of blood squeezed out is more if the lungs get filled and emptied of air. During CPR it is common to intubate the trachea and use a bag to force extra oxygen into the lungs, and also so that if the patient vomits, the vomit does not go down into the lungs. Cardiac compressions are forceful and can cause damage. Post mortem studies after failed CPR commonly show fractures of the sternum and ribs, and these are inevitable in old people with osteoporosis. The injuries are similar to hitting a steering wheel in a car crash in the days before seat belts and airbags. I can right now, as I type, still feel from many years ago that peculiar sensation with the first compression as the sternum gives way and a number of ribs crack.

In the 1960s Cardiac Arrest Teams were trained to do cardiac compression and intubation with ventilation, whilst the defibrillator was brought along in the hope of correcting the heart rhythm. Some patients with coronary thrombosis, who would otherwise have died, were brought back to life. This led to the development of coronary care units (CCU). Then the cardiac arrest teams started going out on "crash calls" to patients who collapsed abruptly on the general wards. The success rate on the wards was far less, mainly because these patients were not suffering a coronary thrombosis, but dying of other conditions like blood clot to the lungs (pulmonary embolism), pneumonia or cancer. In all deaths the heart stops, but in very few deaths is the cause a myocardial infarction and potentially reversible VF or VT. Nonetheless by the 1980s, in some hospitals, it had almost got to the point where a patient could not die without a crash call and a CPR attempt. This may have been one of the reasons for the development of Hospices; to save patients from the traumatic CPR death. I was involved in many crash calls in the 1980s, and I am ashamed to admit that many of us took the opportunity to use these to learn how to place central lines or practice draining a cardiac tamponade. For junior anaesthetists it was a chance to hone skills in urgent intubation. Thank goodness we now have good simulation suites.



Then someone thought that it would be good to try using defibrillators outside hospital in "Out of hospital cardiac arrests". Again in some circumstances this worked and lives are being saved every day. You can see defibrillators at railway stations, airports, and popular tourist destinations. In general these were used on people very different from those in general wards in hospitals. In the 1980s if you had reached Victoria Station and as you rushed to the Tube, had a coronary thrombosis complicated by VF, in medical terms you were a medically fit person. "Medically fit" these days pretty much means you can go up one flight of stairs at a good pace, and that every day you usually walk outside your house under your own steam. So CPR on Victoria station in the 1980s was only being done on a selected group of medically fit people. In 2014 with electric buggies people who are "medically not fit", can get all the way around the world!

In broad terms, and clinicians are well aware of all the other causes of VT and VF, CPR was developed to try to reverse chaotic heart rhythms during a coronary thrombosis. Success was much more likely the earlier defibrillation was done, and was much more likely in patients under 70 years of age. Significant brain damage occurs in an important proportion of survivors. CPR and defibrillation was very unsuccessful in "medically not fit" patients on the wards, but had limited success in out of hospital cardiac arrests.

### Medical Emergency Team (MET)

However some patients really benefitted from the cardiac arrest team's arrival. A lot of "crash calls" were not for patients with a cardiac arrest, and viewed as false alarms. Some had epileptic convulsions, some had major haemorrhages, low blood glucose levels, obstructed breathing, or sepsis. Today many hospitals have Medical Emergency Teams (MET) or outreach teams from the Intensive Care Unit. If a patient is listed as DNACPR, he must not be automatically excluded from MET or outreach calls. Many frail patients can benefit from fairly invasive treatments provided by a MET, and may even need to go to a high dependency unit. Being listed for DNACPR must not mean "do not attempt any clinical care".

### **Respiratory Problems**

I heard a story that a patient with an obstructed airway was allowed to die by paramedics, because the patient had a DNACPR in place. Once again words really matter. Interventions to restore breathing are in general far less traumatic than cardiac compressions. A very simple suction device can remove sputum that a frail patient cannot cough up, or a lump of meat that has gone down the wrong way. It may be far better to have a code for "Do not attempt cardiac compressions" (DNACC) than "DNACPR". Obstructed breathing is extremely unpleasant and should nearly always be actively relieved.



### Frailty

I have mentioned frailty many times, without defining it. Physical frailty has little to do with quality of life, it is to do with physical quantity of function of the body. Of course someone with very little physical function can enjoy a "good" quality of life, enjoying family, reading, TV, even getting out of the house. Many Junior Doctors seem to think that because someone is a "nice" person, can play bridge and read a book, they should be listed for CPR, because he has a good quality of life!

I try to explain this concept of quantity of function of the body in terms of Jenga bricks. Imagine in the tower of bricks there are four labelled "Heart", four "Breathing", four "Brain", four "Kidneys", four "Skin" and so on for all the vital organs and processes, and four bricks for "Cancer". Now imagine you are 80 years old and are playing Jenga with your grandson and you each have your own Jenga tower. Please don't do this, its far too morbid!. Of course you want him to win, so you allow him to remove bricks from the top of his tower, but you have to take bricks from the lower half of your tower. Even losing 2 Heart bricks for the youngster hardly matters e.g. hole in the heart repaired, his tower stands firm. However your tower becomes wobbly after a heart (heart attack), lung (emphysema), diabetes, kidney, and brain (minor stroke) brick have been removed. Eventually even a little jiggle of the table e.g. a urine infection, is enough to bring your whole tower down. If someone came along with a hammer (CPR) your tower would inevitably fall. Ageism is inappropriate in many areas of medical practice, but not in relation to CPR. The chances of survival after a CPR attempt diminish progressively with age.

So if you are 80 years old and being treated for angina and heart failure, emphysema, diabetes, kidney disease, have had an operation for bowel cancer, and arthritis so bad you cannot get out of your house, your health is frail. Some younger people can also have very frail health, a few very old people have robust health. Mobility really matters, so if a relative of yours is 85 and spending 50% of daytime hours in bed day in, day out, health is frail.

Of course our population is getting older. Dementia is becoming more common. This means that a large proportion of patients admitted to hospital as emergencies are now in frail health. If they have advanced dementia or delirium then they may no longer have the capacity to make decisions about treatment or choosing not to have treatment. I strongly suspect an important proportion of frail patients don't want all the tests and treatments a big modern hospital processes them through in obedience to guidelines and pathways. Very few of them are admitted having a coronary thrombosis, and thus at risk of VF or VT. Even if they did, with their frail health, the treatment simply would not work.



### Resuscitation

This is the word that causes huge misunderstanding.

By Resuscitation Doctors mean "Cardiac compressions, intubation, ventilation and attempts to restart the heart, when the heart is in VF, VT, asystole or PEA, because of heart disease". So "DNACPR" should mean just that and still do everything else that is appropriate, but do not attempt an invasive process that is doomed to fail and serves no one any good at all.

Unfortunately even nursing staff can interpret DNACPR as "we are not really trying any more with this patient".

For the patient and carers "Do not resuscitate" can also sound like "Oh they are not going to look after me anymore" and of course easily becomes "I must be about to die very soon, and they won't care for me."

Are you baffled now? I am feeling baffled. How did we get to the point that almost by law and certainly by recommendation of the General Medical Council (GMC) Doctors are meant to actively discuss DNACPR decisions with patients are relatives. CPR "works" in very specific circumstances of a coronary thrombosis (and a few other conditions) complicated by VF or VT, and even then is far from universally successful. (I know there are other circumstances in which it works like primary VF). In other circumstances, in simple terms, CPR does not work, and it certainly does not work in frail elderly people. There are many other treatments that do "work" in frail elderly (see MET above), and much we can and ethically must do for these frail patients.

So what's the problem, Gordon?

The patient who is inevitably dying

If the patient is inevitably dying there is usually no need, other than the GMC and law's orders, to discuss CPR status. In full open discussion with the patient, carers and clinical team the patient's wishes are explored. Commonly patients envisage dying surrounded by caring people, as the patient is kept pain free, warm and clean. No mention is made of wanting a cardiac arrest team to arrive as the patient slips into death. So why do we have to actively explain CPR to the patient and carers, to say we are not going to do something that they don't want and won't work? The use of the words "not resuscitate" in this emotional and difficult conversation can easily be misinterpreted as "They are saying that there is nothing they can do, they are going to abandon me". Even worse we doctors often say "There is nothing we can do", when we mean "Your cancer had caught up with you, you are dying, we are going to be with you through this, come to you, help you, talk, relieve your pain, laugh and cry with you."



The frail patient who slowly deteriorates after admission

Again this situation is straightforward, even if painful and emotional. The main problem now in hospital with shift working and lack of continuity of supervision is spotting that they patient is inexorably deteriorating. Sometimes we also forget to review the CPR status, as time slips by. However once the clinicians recognise the inexorable deterioration, this leads to conversations about death and dying. As above unless the patient or carers raise the issue, I cannot see that discussion about not using a futile invasive treatment that the patients does not envisage, is helpful in any way. Of course sometimes patients or carers raise the issue and then it is all straightforward, as everyone agrees "No heroics". Should the patient or carers ask for or demand CPR a very ugly situation ensues. By law and by medical ethics it is clear that such a demand does not have to be fulfilled. So why do we pretend to offer a choice, when should the patient say "I want it" we then have to say "No"! The outcome is usually then that the patient gets relisted as "For CPR" and at the moment of death the cardiac arrest

team comes, the family are rushed out of the room and the team undertakes a cursory attempt at CPR. Someone in the team reads out "78 years old, bedbound for the last 6 months with metastatic cancer" and the leader calls "Stop".

The frail patient who is expected to recover and go home, but who would not survive a CPR

So, finally to the nub of the problem. The majority of patients admitted under my care are over 80 years old, or over 75 years with multiple health problems so that their condition can be described as "medically frail". I am not a Geriatrician, I am a General Physician and this has been a major demographic change since I qualified in 1980.

Although these patients are "frail elderly" only about 3% die during an admission under my care. Most of these cases are inevitable deaths from advanced cancer or advanced dementia with immobility. You could argue that they should not come to hospital at all, but they do! As I described above, the care is straightforward but challenging and can be very rewarding.



However a small proportion of frail patients expected to survive to discharge from hospital, suffer an unexpected major deterioration, and whilst the patient is dying the cardiac arrest team will be called unless a DNACPR is put in place. This deterioration can happen any time after admission, so to save the patient invasive futile harmful treatment the clinical team has to decide "DNACPR" very shortly after admission, at the very same time as the team is most in demand for acute care of a cohort of patients. Even for the patient in question there will be a lot to do – start the antibiotics for pneumonia, explain that there may be a lung cancer on the X ray, arrange blood tests for the next day, speak to the partner who is worried at home, write a referral to physio and OT etc. Then there are all the other patients to be seen, for example there may be a patient with meningitis or another with a major bleed from a duodenal ulcer, in need of urgent treatment. Would it be right to spend an hour agreeing a DNACPR, maybe with a relative on the other side of the world, in a patient who probably won't deteriorate, whilst we leave two acutely ill patients with treatable conditions, to deteriorate? The clinical team cannot get it right; it is in an impossible situation and one that neither the patient nor the clinical team should be in. For the clinical teams on our general wards it is now both everyday and ordinary. As I said, last weekend I was responsible for about 40 admissions over 2 days. The majority of whom would not survive a CPR, but most of whom survived to discharge. They need a protective DNACPR decision, whilst we do all their complex difficult clinical care of diagnosis, treatment, review and all the time with lots of communication!

The experience of CPR discussions can be disturbing for the frail patient. For example our team may review a patient and she is told she has pneumonia, emphysema, weight loss, diabetes, some temporary damage to the way the kidneys work, and of course she knows she had a stroke and a heart attack last year. We are treating her with 48 hours of intravenous antibiotics, and hope she will be good to go home in 4 days time, if the physios help her back onto her feet. Then we are meant to have the discussion about CPR. So I will dramatise the conversation "Oh yes, and in the meantime, should your heart stop, would you like us to have a go at restarting it? Personally I would not recommend it", "No", "Ok lets sign the red form" (I have heard conversations not much different from that!). Then the patient is left asking herself "Did they say I am going home in 4 days, or that my heart is going to stop and I will be left to die?" I know because a patient told me this a few months ago, after someone had had the CPR talk with her. You could say "Well the nurse will explain it all to her after the round." For 65% of my bedside reviews there is now no nurse there to hear the conversation, to then be able to explain what was said. This is the reality of working life on General Wards in many NHS Hospitals. It is far better on specialist units.

What lies ahead, is there any hope?

The hope is that society and individuals wake up to the fact that death is eventually inevitable and increasingly likely after the age of 80 in previously fit people and in those over 75 with "frail health".



We need to learn to think ahead to how we would like to die, when the time comes. Most doctors would relish patients and carers who come wanting help and advice on this. Medical professionals also need to learn to be straightforward in communication as well as curious about patient's actual understanding. For example oncologists tend to be optimistic people and communicate to patients receiving palliative chemotherapy that it is a treatment. Patients take this to meant "a curative treatment" whilst the oncologist thinks he has communicated "This is quite a toxic and time consuming treatment that may prolong your life a bit". It can be a great shock to these patients when they arrive in hospital and we give a prognosis of days. However it can be difficult for Doctors to give advice about CPR, because the number of CPR calls is falling, so they may not have any first hand experience of what a CPR is like. The numbers are falling because we are getting better at recognising frailty and better at discussing impending end of life and so avoid futile CPR.

GPs using the "Gold Service Framework" are taught to ask "Would I be surprised if this patient died in the next year?" If the answer is "No, I would not be surprised", this can provide the GP with a prompt to open up discussions. We should do this much more in hospital, but time pressures are a major barrier. All hospital doctors have ward patients, clinic lists, and possibly operating lists. Most already have completely full days, and are working beyond hours, often with few breaks. We could take on this important aspect of patient care, if we had the time. Senior nurses are as capable (more capable?) at these conversations, but are also under huge pressure. We know from Mid Staffs that nurses can be so task saturated that even their humanity can be eroded. A nurse frustrated that she does not have enough time to provide basic human care, is not going to be in the right frame of mind for an emotional one hour conversation about DNACPR. So, as ever, it is mainly in the hands of our patients and carers to prepare themselves. Failing to prepare is preparing to fail. The emotional traumas of dying and death can be lessened by anticipation and

planning. Advanced care directives talked through with a trusted doctor or nurse and validated by a lawyer can be very helpful. Have the courage to ask your Doctors about prognosis. If you don't want heroics, even if you want to cut down your huge list of medications, talk with your family, talk with us.

I believe when you ask us to "Do everything, Doc" what you really mean is "Do everything that you as an ethical medical professional believe is wise, likely to work and kind and not cause unnecessary suffering." I say that because when a patient dies the very first question the relative usually asks is "He didn't suffer, did he doctor?" A death under CPR inevitably causes suffering.

That frail old man in the first bed could have died quietly with one of our lovely nurses holding his hand and talking with him. It is misunderstandings about words and their meaning that robbed him of a calm end of life.