



## **Conversation with Dr Kathryn Mannix, 12<sup>th</sup> June 2020.**

### **Jane Duncan Rogers:**

Hello, everyone. I am Jane Duncan Rogers of Before I Go Solutions, where we encourage people to make good end of life plans. Today, I have a very special guest to talk to, Dr. Kathryn Mannix, who is a palliative care doctor, and actually, Kathryn, why don't you say something about yourself?

### **Kathryn Mannix:**

Oh, thank you. Hello, everybody. So, I am or I was a palliative care doctor for more than 30 years. I took early retirement from medicine to try and campaign for better public understanding about dying. I wasn't quite sure what that was going to be when I took early retirement, but it turned out it was this. So, I wrote a book about dying, which is people's stories. It's been lovely for me to spend time in their company writing about them, and I thought it would be in a few libraries, but what I didn't expect was what actually happened as a consequence of writing the book, and it's been fantastic.

### **Jane:**

Tell us a little bit more now you've given us that teaser! Tell us about what happened.

### **Kathryn:**

Well, it became a bestseller. It's been translated into 12 languages so far. It was shortlisted for the Wellcome Book Prize. I just really didn't expect any of that, but what that did was opened lots of doors and it's helped me to have lots of platforms from which to communicate, literally, platforms, stages to speak in public, but also this kind of conversation where through the work I've met so many fantastic like-minded individuals, and there are so many of us now all trying to support getting people more aware, getting people less afraid, and then what you're doing - to actually get people then to engage in doing some very positive definite planning, and it's all so important.

### **Jane:**

Yes. That's right. I was delighted when I discovered your book because I read it, first of all, (and if you haven't got a copy, I really recommend it because it's a wonderful read) and because it's so important to talk about end of life, death, whatever it is you want to call it. I think we're perhaps more likely to call it death now. I'm not absolutely sure about that, but talking about it whatever name it is, is really important, and then there's a second step, and that is acting on it. That's why I think you and I are a great team.

### **Kathryn:**

Indeed.

### **Jane:**

So, today, what we're going to do is we're going to have a conversation. Some people have sent in questions. So, we're going to base our conversation around those questions. Some of them are

pretty interesting questions. The first one leads on from this thing about talking because a really common question that I get asked is, well, first of all, how do you talk about it, but, certainly, how do you talk about death or end of life or anything to do with the end of life with somebody who really doesn't want to?

For example, Isabel said, "When someone absolutely refuses to engage in such conversation, even if they have a terminal diagnosis, how do you go about making decisions for them, especially if there's no power of attorney in place?" Perhaps you can explain a little bit about the power of attorney or decisions first as we haven't talked about that yet.

**Kathryn:**

Great question, isn't it? Yeah. Thanks, Isabel. I'm sorry if you found yourself in that situation because it's terribly difficult, and particularly if it's somebody who you're very, very fond of. It can be heartbreaking.

So, let's think a little bit. There are two parts to that question, somebody who doesn't want to talk, and then there's the decision making and how legally decisions can be made if the person themselves doesn't want to be involved in discussions about their treatment or the management of their wellbeing. Let's do the legal bit first because that's actually a little bit easier.

The law is slightly different in Scotland from England and Wales, and a bit different again in Northern Ireland. So, no surprises there. So, both England and Wales allow for us to nominate an attorney. That's a person who is allowed to speak on our behalf if we are unable or unwilling to make medical and welfare decisions.

What surprises a lot of people is unless you're actually taking steps to fill in the forms and make that a legally valid contract between you and the person or the people you nominate to be your attorney or your attorneys, it doesn't matter how close your relationship is with somebody. Legally, they cannot speak for you. You have no voice unless you've nominated somebody to be your voice.

**Jane:**

When I first heard that, I was really shocked because I just assumed that my partner, my husband would be able to act on my behalf because we are married. When I was told that that wasn't true, I just couldn't believe it. This was from a talk from a lawyer. Actually, I heard her give the same talk a year later, and it had taken me a year to really process this, and to understand that that's the case. That's why we have to get acts together about that, isn't it?

**Kathryn:**

Yeah. It's not a complicated thing to do, but it's a time-consuming thing to do because, for example, I and my siblings and each of my parents are the attorneys for the other parent. So, we're empowered to act together or for some things just one of us, the person who's handy can make a decision, but for the big decisions, we have to act together. So, you can stipulate that.

So, I said, "Well, if we're going to do this, then we have to sit down together and understand what it is that you would like to happen, Dad or what you would like to happen, Mum."

What was really interesting was our Dad made the assumption that whatever he had thought through and wanted, obviously, he's known his wife for a long time, they've been married for decades, Mum will want pretty much the same thing, and she did, but there were certain really important differences. So, we did have to just unpick it and think about.

"Dad, what if you got hit by a bus or you had big stroke, you're completely unconscious and they want to know - would you want to go in an intensive care unit, would you want to be on a ventilator, those sorts of things?"

You can't guess the answers to those things. Now, sometimes people will say to you, "Okay. You know me well enough to pull the information that the doctors and nurses are giving you together at that time, and make a judgment that you think things like the best judgment, and I trust you to do that."

So, there, it's giving us the list of instructions. What they're really doing is saying, "These are my values in life." So, it's really important to know what that person values, how long they would live, more than how comfortably and well they would live - or will it be the other way around? "If I can't live comfortably and well, please don't prolong my living." So, it involves some really important questions if you're going to be somebody's attorney.

Then the other thing that people can do is they write what some people refer to as a living will. Again, they've got slightly different names, but it's an advance decision to refuse treatment because we can't demand treatment. All of us who'd been along to GP with a sore throat-

**Jane:**

Hang on just a minute - you just said a really important thing. We can't demand treatment.

**Kathryn:**

Yes, everybody's been to the GP with a sore throat thinking that you need antibiotics and the GP looks at your throat and says, "That's not bacteria. That's a viral sore throat. Antibiotics won't make any difference."

"Oh, but I always had antibiotics. It makes me better faster."

"It's not an appropriate treatment for you. I am not going to prescribe it, and you cannot demand it. You have no right in law to demand a treatment that isn't appropriate for the illness that you've got."

**Jane:**

Okay.

**Kathryn:**

So, the same thing applies with the very end of life. If we're not well enough for an operation, we can't demand to have that operation. If the anaesthetist says, "This person's chest is so terrible, we can't do the abdominal surgery that they need," you can't demand that operation.

So, we can't request and demand treatments, but we do have every right to refuse any treatment that might be appropriate, or the doctors or nurses might want to offer to us, but for any reason at all, it doesn't even have to be a sensible reason, if you just don't like the sound of that, you're allowed to say no, and you can write an advance decision to refuse treatment.

There are certain legal things that have to be fulfilled, so you've got to write it, you've got to sign it, you've got to date it. Somebody has to witness that you've signed it. They don't need to read it. They just need to witness your signature. In the future, if something happens to you, and you can't speak for yourself when people look at that document, then if the document is talking about things you said you didn't want under particular circumstances and the circumstances match, then in law, it is

valid and applicable. So, valid means it's properly written, it's signed, it's dated, and applicable means it applies to these particular circumstances with a pretty good match.

So, there was a case before the court of protection in England and Wales just a couple of weeks ago, where somebody had an advance decision to refuse treatment because they did not want to live permanently with a bowel stoma opening onto their abdominal wall, and then they ended up having surgery during which a stoma was made on the abdominal wall because the surgeons had no choice once they got in there, and they had to remove so much of the bowel that it wasn't reversible.

This actually contravened the person's right to refuse to live with a permanent stoma, and the court of protection found that, actually, the reason that the decision wasn't respected was that the person had written it, but it wasn't properly signed, and dated, and witnessed. So, it wasn't valid even though it absolutely applied to the circumstance.

So, the patient was somehow persuaded to have the operation, and then the judge of the court of protection ruled that it was permissible to not wake this person up from their anesthetic and allow them to withdraw feeding and fluids and not wake up again because he was so clear that he didn't want to live with a stoma. Having lived with a stoma before, he knew what he was talking about, and this was now validated by the judge.

**Jane:**

Interesting. Wow. Okay. Quite a few things in here, aren't there? They're really important. We'll come back to the other part of the question from Isabel about when somebody doesn't want to engage in a conversation. Tell us more about the advance decision. It's called a decision in England and Wales, and a directive in Scotland, but it's the same thing, living will, it's more or less the same thing.

I know that because of the people that I work with that it's really difficult to go through all these different scenarios that you might have. Who wants to do that? Let's face it, who wants to look at the end of their life and think, "Oh, my God, it might be like this"? Nobody wants to do it.

Actually, just a little tip there. If you are doing that or if you're think about doing this as a result of this conversation, you can say to yourself, "If I were in this situation yesterday, this situation where I cannot speak for myself,, what would I want to have happened?"

You can go through it by imagining that I had happened yesterday. It's a little bit less challenging than imagining it's going to happen in the future. So, when people have made an advance decision, is that something that the doctors want? Because that's what I've been hearing?

**Kathryn:**

Well, what's always fantastic when a person is not able to speak for themselves is that the people who love them know the answer to the question I now need to ask them, which is, "What would this person who you love say to me now if I could sit them up for 10 minutes and have 10 minutes clear conversation with them about their situation? What would they tell me?"

Because it's really important that people aren't left feeling that because their partner wouldn't want to have a ventilator (so we don't use a ventilator,) that in some way they refused the ventilator and, therefore, their partner died. What they're saying is, "No, he would refuse the ventilator."

So, it's a medical decision. It's not a family decision. It's a medical decision between a doctor and a patient who is allowed to refuse and express their opinions. What we're doing is we're substituting the conversation, the patient's part of the conversation to try and understand what they would say.

So, they might have made an advance decision to refuse treatment, and it might be about this specific treatment, but it might very well be that what they've written about themselves and their wishes, and their wish not to be messed around if they're sick enough to die, helps us to know what their wishes, what their values would be because their advance directive doesn't match the situation, so it's not applicable, now it becomes a medical decision. It has to be made in best interest.

So, best interest decisions are really important principle in medicine. It doesn't mean the doctor decides what I think is best. What the doctor is obliged to do by law is to work out which of the alternative treatments could be useful for this person, which of those would restrict their ability to be the best - they could be the least - and then to discuss those options with people who know that person well enough to say, "Well, he would definitely not want that," or "He always did say that it was a choice between this and that. That's what he would go for."

So, we're trying to bring the person's wishes into the room, so that what they would least like to happen IS the least likely thing to happen, and the thing that will restrict them least is, as far as we can make possible, the MOST likely thing to happen. So, that's best interest decision.

**Jane:**

Okay. So, to me then, it's obvious that we need to be talking about this beforehand, before we get into any kind of situation like this. Of course, we hope it's not going to happen, but it is a little bit like an insurance policy. We're familiar with insurance. We pay for insurance, don't we? We hope the house is never going to burn down or whatever, but we don't think about it like that with this. But actually, it's the same principle. We hope that it's not going to happen, and we get our ducks in a row or whatever it is the analogy in case.

**Kathryn:**

Yeah. Absolutely.

**Jane:**

Yeah. Okay. So, if as a doctor you're in a situation where there is nobody who has made an advance decision and there's nobody who is a power of attorney, what happens? I mean, that just means that the whole decision is on your shoulders. Is that correct?

**Kathryn:**

Well, that's what you're naming. There's no previous discussion. Nobody knows what the person thinks. There's no pieces of paper to tell us, is usually what happens because most people haven't filled any paperwork or had any conversation. So, it turns out that, interestingly, more of us have planned our funerals than have planned our dying, even though we're going to be much more involved in our dying than we are in our funeral.

So, what has to happen under those circumstances is this best interest decision making process. It's a consultative process. Now, somebody is in front of you and they're going to die if you don't do something quick, so you do something to stop them dying unless there's very clear evidence that they would not want that thing to happen. The most important example of that is if somebody's heart stops beating, do you do CPR to keep the blood with oxygen and circulating around their brain, because your brain will be dead within six minutes of not getting an oxygenated blood supply. Do

you start that CPR while you find out whether the person didn't want it or not, which actually is I think another one of the questions that somebody asked us about, isn't it?

**Jane:**

Yeah.

**Kathryn:**

So, that's a really tricky situation because, actually, CPR is a very particular treatment. It's a treatment that you use when somebody's got an otherwise healthy body, and for some particular sudden reason their heart stops beating. So, maybe they've just quietly had a heart attack and nobody was expecting it. Maybe they've been struck by lightning. Before their heart stopped beating, their kidneys are working reasonably well, and their liver was in good order, and their brain worked, and their circulation worked.

So, if that happens to somebody and you can keep them going until you get them into a hospital, keeping that blood circulating by pushing really quite hard to keep that blood circulating, then they've got, somewhere between a 5% and a 10% chance of surviving it, if they are not in hospital. So, the chance is small, but it's there.

The way people talk about this depends very much on whether they're a glass half full or they're a glass half empty person, or a glass 10% full or 90% empty type person. Certainly, if that person was a teenager playing sport and she's playing football and she collapses, and her heart is not doing what it should, obviously, you would start CPR and you try and get that person to a hospital and save their life, and sometimes you will succeed.

The other time that somebody's heart might stop, though, is when they are so sick that their body is starting to die. Gradually, all of the different organs are starting to just not work so well. That's what dying is about, isn't it? The body is gradually starting to fail.

Depending on what illness or illnesses we've got, some organs will fail before others. Eventually, we're at that very last part of life where we're very weary, we're mainly in bed, we're coming in and out of unconsciousness. Gradually, the brain is shutting down department by department till the only bit that's still working is this bit at the back that manages our breathing. The heart, of course, isn't worked by the brain. The heart is just pumping automatically. That's what it does.

So, eventually, the breathing becomes uneven and irregular, and there are pauses, and then it becomes very gentle, and then it stops. That's what ordinary dying looks like. A few minutes after the last breath, the heart will no longer have enough oxygen in its blood supply to keep beating. So, in fact, although what we notice is the last breath as the moment of death, that's what we usually would call it. That's the moment of death. If the heart will carry on, usually its very, very low pressure. You can't feel the pulse. If you had an electrical thing on, you'd be able to determine the heart was still beating maybe for a few more minutes.

But in a cardiac arrest, the heart stops first. Everything else is still working and you can keep everything else working by making do, by pressing the chest to substitute for the heartbeat to keep the blood circulating.

In ordinary dying, the heart stops last and CPR is not going to reverse it. It just can't help, but it can mean that families are pushed out of the way, there are people jumping up and down on the chest, displacing all of that gentleness and tenderness there was around the bed.

It's a hard work procedure. You want somebody pressing very hard on that chest. Those of us who've done CPR, all of us have had that sense of somebody's ribs breaking as we press hard enough to press the sternum against the heart to keep the blood circulating. So, it's not something that we want to happen as the last thing that happens as we're dying when we were expecting to die, but it is a very important first aid procedure for somebody who shouldn't be dying but whose heart has stopped.

**Jane:**

Okay. That's really clearly explained. Thank you so much. So interesting because if you're not at all from a medical background, you don't come across this thing. Normally, we're not learning about this.

**Kathryn:**

No, of course. The difficulty is when you're looking after an elderly relative or you're visiting a friend who you know is terminally ill and you're popping in and out, you may be the person who's with them at the time when their breathing starts to slow down. Sometimes that makes funny noises because the other thing about not being awake anymore is you don't swallow, you don't cough to clear the fluid from the back of your throat. So, it gets a bit noisy.

All of that noise is a sign that the person is in fact completely unconscious, but it sometimes troubles families. Sometimes they panic. Sometimes they call an ambulance. So, an ambulance crew now comes and they find a person who's got almost no pulse or possibly no pulse at all, is this a cardiac arrest or is this a death?

Unless they know definitely that this is a death and it's an anticipated death, they're obliged to start cardiopulmonary resuscitation because they don't know otherwise. So, a DNACPR order, do not attempt CPR, cardiopulmonary resuscitation order is simply an instruction to say, "This person's heart stopped. Don't do CPR." It doesn't mean don't do CPR OR anything else.

So, you can have a DNACPR order and you can still have major surgery. You can have your hip replaced because you've fallen over and broken it. It doesn't mean don't feed somebody. It doesn't mean don't give somebody antibiotics. It doesn't mean don't offer any of the treatment. It only means don't do CPR. Don't make the mistake of thinking when this person's heart stops that they want you to jump up and down on their chest.

**Jane:**

Yeah. Very interesting.

**Kathryn:**

That might be because it won't work or it might because they don't want you to do that. So, I don't want you to do that. I don't want that 10% chance of survival, that 90% chance of death because the 10% chance of survival also comes with a very high percentage of brain damage.

I know there are people who live very meaningful lives with brain damage, but I haven't got enough living left to do to get used to living with brain damage. So, I choose to have a DNACPR order and not have somebody jump up and down on my chest, but if I break my hip and I go in to a hospital, I have got to have my hip replaced, and I know that while sometimes things go a bit wrong under an anesthetic, I'm well enough to go and have my hip replaced. In that case, I might actually tear up my DNACPR order for the period of time when I'm in hospital having my surgery, because if my heart

stops in the middle of the operation, you better get it going again, boys! And then, of course, when I'm well, I can change my mind back again because now I'm outside the hospital, and chances of surviving (a heart attack) would be very low, and chances of brain damage would be very high. I would go back to having my DNACPR order.

So, none of these things is carved in stone. It's a flexible fluid thing to follow us through our lives as we age and have illnesses and get better from them, or get illnesses that we're not going to get better from.

**Jane:**

So, just while we're on the DNR, its sometimes called a DNR, as well as DNACPR, you have to get that from your doctor. Is that correct?

**Kathryn:**

So, it's a medical certificate. It says either that for this person, even if you start CPR, it wouldn't help. So, that's a futility criterion. Or it says, "I've talked this over with this person and I'm convinced that they are convinced that they don't want it."

So, it's really just an instruction from one clinician to another clinician to say, "It's okay. You don't need to start and I've got your back here."

Now, as we become more and more involved in our own healthcare because, of course, these orders started in the 1960s when the only people who ever got CPR anyway were people who were in a cardiac unit. It wasn't a thing that you learned as first aid. It wasn't a thing that bystanders in the street could start pumping on your chest. People wouldn't know apart from specialists in a hospital. It would have been a note, really, from one doctor to another doctor to say, "This person's heart condition has gone past the point where CPR would be helpful for them now."

So, this started off as medical notes. Now, we have much more autonomous uses of health services. There isn't a space for the person to sign the form, and people get upset about that, but it's actually because the form hasn't caught up with the way we live our lives anymore. It started as a note from one doctor to another. We haven't really modernized it enough yet, I don't think. I think it would be nice to invite people to say, "Yes, I've understood why we're doing this, and I agree." I think families would feel better about it as well.

**Jane:**

Okay. So, two more things on that, and then we'll go along to another question. So, I'm perfectly healthy. Can I just go to the doctor and say, "I would like to have one of these in place?" Are they obliged to do that?

**Kathryn:**

Yeah, yeah. So, you go along to the doctor and say, "I've been thinking about it. I've realized that the chances of it working are not very high. The chances of it bringing me back to the way I like to live my life now are even lower than that. I don't want to take that chance, and I know that the only way I can have a DNACPR order." And by the way, I'm really keen that we don't call them DNR orders.

**Jane:**

Oh, why is that?



**Kathryn:**

Because do not resuscitate sounds like I could flick a switch and resuscitate you and I'm choosing not to.

**Jane**

Ah, good point.

**Kathryn**

So, attempt is the really important word in it. It's do not ATTEMPT cardiopulmonary resuscitation because of the 90% fail rate - we are only ever attempting.

**Jane:**

Right. Thank you for highlighting that. That's really important, that I didn't know about. So, that will be something that will get revised in the next edition of my own book.! So, another Jane asked a question about, "What do doctors think when people have made a DNR statement? Are they relieved? Are they disappointed? Do they like the fact that that's happened?"

**Kathryn:**

I'm fascinated by this question, Jane. So, thank you for asking it. I think that the fact that there is a form says this person has thought about it, and that's a real relief for those of us who work in palliative and end of life care. I'm obliged to say here for all of the pallists who are listening - palliative care isn't only about dying. In fact, it's mainly NOT about dying. It's mainly about good symptom management during an illness that probably can't be cured anymore, but you don't want to be suffering from it, which means that a lot of people who we look after do move towards the end of their lives, and often, they will die in our care, but we're not there because they're dying. We're there because we're managing their symptoms.

Sometimes the symptoms are emotional symptoms, like they're worried about lack of control as the end of their life approaches. So, we might talk about what you expect to happen. Of course, they all think it looks like what's on the television, which it doesn't. So talking about what normal dying looks like can be very, very helpful, but so also is the distinction between heart stops first, cardiac arrest; heart stops last, normal dying,. But if an ambulance crew arrives and actually don't know the difference, you can help them to know the difference by saying, "This is already written, waiting for this moment."

So, our sense is not that we have a particular opinion about the form. It's much more about the fact that the person has got the form, has thought things through, and had conversations. Therefore, the conversations we have to have with their families, and I'm using the word family. When I was in New Zealand, I learnt this lovely word [foreign language 00:31:35] which is your village. It's all of the cousins and the aunties, and the people who belong to you who may or may not be related to you. So, yeah, your family, your village.

They know, and if we've got to talk to them because you're not well enough to talk about what you would want, they know, "She always said this. She talked to us about that. She was really insistent that this or that didn't happen." That's so helpful for us, particularly when we're working in the emergency room and it might surprise people to think the palliative care team is in the emergency room, but, of course, people come in sick enough to die, and it might be that, in fact, they can be made well again, but over that precarious day, two days, three days, where it could go either way,

you also want their symptoms very well managed. So, you might be getting a little bit of both over that period of time.

We're talking to families about uncertainty, "This could go either way. How aggressive would your relative like us to be with our treatment? Where would they draw a line?" These are conversations we can have with our beloved now about ... I love your idea they talk about it as though if this had happened yesterday, what I should be saying to the doctor about it for you today? That's a really great way of doing it.

### **Jane**

Yeah. It really works. Actually, I do talk to people about we need to take responsibility for our life and our death. If we can help the professionals, because we haven't done the training, we don't know all the details that you've been telling us, but if we can help you because of our lives and our knowledge, if we can help you make that decision, then I think we have a responsibility to do that. So, that's why I encourage people.

So, another question: "If a person is worried that their previously made DNACPR, "may not have been communicated to healthcare professionals, and they may not be articulate enough to give it themselves because of the situation they're in, would it help if they had a tattoo across their chest?"

### **Kathryn:**

Now, isn't that a really great question? So, the easy answer is no, it wouldn't because it's actually the piece of paper that's the legal document. But the actor Greg Wise is very funny about this. He says he's going to have DNACPR tattooed across his chest, and he's going to have PTO tattooed across his back. Actually, if there was a way in which we could let people know that there's a certificate to protect me from CPR, is a really lovely way of looking at it, isn't it? CPR is very intrusive, and this is a protection certificate from it like a medical alert bracelet, for example. Wouldn't that be a useful thing? We don't at the moment have anything like that.

So, one of the things that's really important is when your doctor makes the form out for you, you carry the original. You have it with you. In my part of England, people are asked to carry it in a really, really bright yellow envelope that gets given to them at the same time, startlingly yellow.

It's too big for a small handbag. It's far too big for a man's suit pocket, and that's a shame. So, we need to think about the design a little bit, but it means it's there if you collapse. It's quite easy to find. In the house, where do you keep it? Because if the paramedics dash in and somebody says, "Oh, it's in the drawer," so how many drawers do you think you have in your house?

So, one of the things that we say to people is think about sticking it on a fridge magnet because most houses only have one fridge. Stick it on the door of the fridge, and then put it in your pocket every time you go out.

When your doctor makes the certificate, ask the doctor to be sure to let the out of hours general practice know and the out of hours emergency services know, so your local ambulances, for example. And it might be that your local 111 system, the NHS dial in system, is also able to note that there is a certificate of some sort associated with your care. It might be that it's a DNACPR. It might be an advance decision to refuse treatment.

It might be something that can be really useful rather than all of these instructions, which are about what NOT to do. Some places also have emergency care and treatment plans, or emergency healthcare plans or in some parts a Respect form. They give a little bit about what not to do, but

they also say, "So, this person's got lung cancer, and this is where it spread to. Sometimes they get breathless. If they get really breathless, do this, and then if that doesn't work, do this. If they get a pain in their hip because we know they've got a bone secondary there, do this, and then do this. Also, this person has already decided that CPR is not going to be helpful for them, so find their DNACPR form. It's probably in the same envelope as this form, but if it is not, find it."

So, actually, getting the emergency services to know that those forms are around and need to be looked for is really important.

**Jane:**

I guess, ideally, there would be a completely joined up computer system where you press all the information in at one end and it goes to all relevant places, but I don't think we quite have that yet. Is that correct?

**Kathryn:**

That's absolutely correct. It's a real problem. It's partly about the public objecting to very big computer systems with personal data on them because it's a breach of confidentiality if something goes wrong. So, the smaller the system is, the safer people feel. So, we've got a kind of conflict between civil liberties rights, which are about maintaining our confidentiality and then our right to have the most appropriate medical treatment already negotiated with this doctor or that nurse, but they're not known about by this other practitioner when we meet them in an emergency.

So, it's quite a difficult dilemma, really. There are no really easy answers to that. I guess the other challenge is that if you've got an online system, even when it's completely joined up, if I change my mind, say about my DNACPR form, I've got to make an appointment with my doctor who's got to then go into the system and resend it or re-enable it, depending on which way I'm changing my mind. So, actually, if the person carries the original, the current, the valid document, it will always be the valid document.

**Jane**

Okay. So, now, at the moment when we're beginning slowly in the different countries to come out of lockdown, I can imagine that people would be thinking, "I can't just go to the doctor to get this," but would you recommend that they do that?

**Kathryn:**

Well, COVID's been really interesting, hasn't it? Because it's been so hard for so many people, and there are a lot of bereaved families. There are a lot of people who has a consequence of being bereaved or are really thinking about their mortality like, this could happen to any of us in a way that I don't think we've really thought about in a generation or more. People are starting to think about, "What would my family need to know if I was so sick, if I was too breathless to speak?"

So, now is the time when actually general practitioners are trying to encourage people to have those very conversations. There've been some critical media coverage about GPs trying to instigate those conversations. Sometimes that has been a little bit clumsily done, I will agree, but it hasn't been with bad intent. It hasn't been with an intent to place the DNACPR order on everybody in the care home, for example. It's been to make sure that there's been a conversation to offer the opportunity to discuss whether or not CPR would help you in order to protect you if you get so sick and the ambulance crew rushes in and they stop CPR.

Because we have to do it in high volume, I think that's been really difficult for people. So, now, we've got a bit of a breather. The numbers of COVID transmission are dropping. The number of people who are sick with it is dropping. Now, we've got time to just think and, of course, a lot of GPs are seeing people by video call, so a conversation with a GP would be absolutely fine. They're seeing the people. If you need to look at a rash or you need to examine a lump on somebody's leg, you need to go there, but this is a conversation that could easily be had by phone.

I think, largely, GPs would welcome it because what they're seeing is that one of the unexpected benefits of this really difficult situation is people are talking about how we might die as though we're actually mortal, as though it might happen to all of us.

**Jane:**

Yes, when the statistics show that 100% of us are going to die.

**Kathryn:**

Yeah. The rates are very, very bad in Britain. 100% death rate, joint worse in the whole world.

**Jane**

Yeah. That's right. It's completely bonkers, isn't it, that we don't want to talk about this, which, of course, is why you and I are talking about it and, hopefully, people listening will understand that, yes, we actually do need to do this. So, I also know that many of the people I come across have really good intentions to have a conversation, want to take an action knowing that they need to do it, but they don't necessarily get around to doing it or they don't know what to say or all sorts. There's all sorts of little humps in the way of actually taking action here.

So, when somebody, in your experience, when somebody just will not talk about this, maybe their doctors brought it up, but they will not talk about it, what can you do? Is there anything that you can do?

**Kathryn**

Well, I guess, first thing to say is it's their right to not talk about it, isn't it?

**Jane:**

Exactly.

**Kathryn:**

So, it's absolutely fine. Maybe we've got to start from there. So, "Mum, if you don't want to talk to me about this, I would understand." Also, one of the ways that really does help people to talk about it is actually most of the time, if we want to talk about something that's a little bit difficult, what happens is it goes around and around in your head, doesn't it? You can feel your chest getting tighter, and you've got a knot in your tummy. Eventually, you go, "I need to talk to you about this thing," and it all falls out of your mouth, and it's all just a terrible mess.

So, actually, why don't we decide to not have the conversation today, but to have a conversation about having the conversation today?

"Mum, I've been looking all of this stuff in the news about COVID and doctors trying to decide what to do with people who are really sick. I know you've been listening to it as well. So, some time in the next couple of weeks, do you think we could just sit down and I'll tell you what I would want to happen if I got really sick, and could you tell me what you would want to happen if you got really sick?"

So, it's an invitation now, and that would you give that person some control. If they don't want to talk about happens to them, that's fine. They might still be willing to hear what we would like to happen to us, and they might even express opinions about that which will help us when the boot is on the other foot and it is about them and they never really told us, but, "Oh, when I was talking about those things with Mum, and I suggested I would like that, she said, 'Oh, I definitely wouldn't want that.'" Well, at least I know that now.

**Jane:**

Exactly. Exactly. So, that was really beautifully put over there, Kathryn, because I always talk about planting seeds. You can plant the seeds, and you can maybe keep watering them, and you don't know whether they're going to grow or not, and that's really what you've given us as an example there. So, that's really lovely. Thank you.

Okay. I'm aware of the time going on. Obviously you and I could talk about this for a long time, but we have a few other questions. Joelle said, "I would like your advice on the best way to deal with when somebody decides that they no longer want to take in any form of food or drink." So, obviously, this is because they're coming towards the end of their life. So, what would you say to her?

**Kathryn:**

That's a really important question. Thanks, Joelle. I guess there are two different sets of circumstances we could talk about here. One is that towards the end of dying, normal dying, people reach a phase of just not being hungry and not actually feeling thirsty anymore, which is really interesting because in Britain, we show people we love them by feeding them. So, it's really hard for us when we can't feed them, but what we do know is that just tiny taste of lovely things can be really, really just refreshing and light.

So, that's a useful thing to think about, and then just being very, very careful that you look after somebody's mouth, so, very often, too, again, as the person get more exhausted, muscles start to relax in our face. People very often will be breathing through their mouth, and that makes your mouth really, really dry inside.

So, having the proper source of kit with safe dispensers to be able to wet somebody's mouth inside, and not to forget about the surface of the teeth or where the teeth touch against the inside of the gum. There's nothing worse than your teeth sticking to your gums. You know how you feel when you come out of the dentist. Yeah. That means it's all dry and gummy and horrible.

So, one of those important conversations is, "What are you favorite tastes? What do you want in your mouth tray?" because they put some minty disinfectant stuff in the tray, and some people would have smelled it. I don't want that anywhere near my mouth. Thank you very much. So, I looked after a lady who had sherry and lemonade in her mouth tray.

**Jane**

Lovely.

**Kathryn:**

That worked really well for her.

**Jane:**

Wonderful.

**Kathryn:**

In fact, a really nice little tip is if you freeze things that are fizzy, tonic water or lemonade or anything like that, the bubbles make the ice more crackly and softer, so they become chewable.

**Jane:**

Oh, that's interesting.

**Kathryn Mannix:**

Okay. So, not really chewy, but they'll crumble easily in the mouth. So, you can make little ice cube makers of fizzy drinks and just put a little bit on somebody's tongue and they can chew it. It's not a big lump of ice that will slide to the back of their throat and choke them. As long as you don't put a lot of alcohol in, a little bit of alcohol won't be an anti-freeze. So, you can have gin and tonic ice cubes or lemonade ice cubes or whatever you like.

**Jane:**

Lovely.

**Kathryn:**

So, that's the first thing, which is towards the end of life, it's normal not to be drinking, but we do need to make sure that somebody's mouth isn't uncomfortable. I wondered whether this was a question about somebody who's decided that actually, "I want to turn my face to the wall now. I want to stop eating. I want to stop drinking." That's a much, much more difficult situation because people do feel hungry, people do feel thirsty, and sometimes the sense of thirst makes it more difficult for them to stick to the decision that they've made.

Palliative care teams would really welcome people and their beloveds discussing that situation with them. They won't try to persuade them, not to make that decision. That's their decision to make, but they will talk to them about how to help to reduce the sense of hunger, how to help to reduce the sense of thirst because, of course, if you give anything that's got liquid in it to reduce the thirst, it's a little bit of fluid, and it makes the dying that they're trying to bring forward take a little bit longer.

So, that's a really difficult situation, but, again, just knowing that you can have these micro-tastes, those little moments of pleasure, and just refresh your mouth can be part of a much more comprehensive packet of really good palliative care to help somebody to be comfortable, if that's the decision they've decided to make.

**Jane:**

That's great. That's really useful information. Okay. Thank you. So, Matt said he was interested on how we view the future of funeral provision. What have we learned from this challenging time, and what wisdom can it offer us for the future in relationship to funerals? So, we'll have to be a little bit

concise on this, Kathryn, because I said it was only going to be on for an hour. We've only got 10 minutes or something like that.

### **Kathryn**

Okay. Okay. Right. Well, Matt, it has been an interesting time. So, really difficult to not be able to gather, to not be able to touch each other, to not be able to accompany our dying people to their deaths, and not be able to be companions with them afterwards for viewing at the hospital, in the undertakers. It's been devastating for people.

I think people got very creative about funerals and online funerals. My parents have been to several online funerals during COVID, not all of which were COVID-related deaths, but, of course, there are no funerals for anybody at the moment.

So, one of the things that I've heard people reporting about that were helpful were, first of all, that somebody has created and held a space. If you can't get in to a physical space together, then at least you can get into a grieving virtual space together. That sometimes means those of us who are technically able going around to help our friends and family who are less savvy about the tech.

I think what it's made us do is realize how much we belong to each other, and I suspect when you look in newspaper announcements about deaths, there are lots and lots of announcements that say "a memorial event will take place once we can gather again". So, I guess that makes us then start to ask ourselves what are the events about, and there has been a tendency for funerals to become more about celebrations of a life than talking about the devastation of a loss.

Both of those things are true. It sometimes turns out that because the majority of people at a funeral are less closely bereaved, what they want, what they need, is a celebration of a life. They want something uplifting. They want to say what a great person this was, and all the wonderful things they did.

Some families find that actually that's not meeting their immediate need, which is for lamentation and mourning and huge distress. They feel that they're not allowed to be distressed.

So, one of the things that we might be able to find out from this, because celebrants and funeral directors have been very, very careful in the way they've managed families, and it has been really admirable the things that I've been reading and hearing about this, is that the immediate family will have been able to organize a funeral that matches what it is that they feel they need because they can't have the big service way, family saying proudly, "You couldn't get another person in the room. It's just us."

I'm going to be interested to see what the balance is of early, very grief-focused therapy at ceremonies compared with early life-celebration ceremonies. My hunch is that families will be less celebratory when it's just themselves, than they are when they're going to include the wider public.

So, maybe one of the things we might learn from this is what do we need to do to enable families to mark their moment of grieving in the very early parts of their mourning, and what do we need to allow them to do rather than saying, "Oh, we need to have fun and a marvelous time." What's the appropriate time after that where we can do that other important thing, and where families won't feel disloyal if they come along and celebrate with us despite the fact that their hearts are still broken?

**Jane:**

So, yes, it has been really interesting. I would agree with all of the things that you're saying there. I also think that it's highlighted the importance of ritual, the ritual ending of a life, the acknowledgement of that. We have rituals in all sorts of things that we do, even in, most people have a ritual as a way of getting up in the morning, for example, but we don't think of it like that.

When it comes to saying goodbye to somebody, understanding the importance of aspects that go to make a good ritual, which is what a funeral is, (is important), but unless we break it down (into the relevant aspects, it doesn't work so well). I think that's been highlighted because the whole thing has broken apart. We haven't been able to do it in the way that you've been talking about.

So, for example, in my training, we go in to that in detail in terms of what makes a good ritual because a ritual can be anything that you want it to be. So, when we can't have it the way that we got used to it or when we even maybe choose not to have it that way, it's important to know what actually constitutes something that really works for us, so we can include those things when we want to say goodbye to somebody. So, yeah, I think it's been a really interesting time.

**Kathryn:**

I would agree. Something that I've noticed on social media is the number of social media memorial shrines that have started during COVID that I've seen it once or twice before, but now, to have a photograph of the person who's died, to have cans or to have some keepsakes around it, to have letters and mementos written by them and also from other people to them or to you in your mourning, and they're popping up on Instagram, they're popping on Facebook.

That's almost like a virtual shrine, and people are leaving messages underneath. Again, that's a really interesting way of gathering as a community when we can in the same space, but not necessarily at the same time. So, I think we can start to be very creative and empathic with it. I think we maybe won't go back to doing things the way we used to.

**Jane:**

No, no. Exactly. Yeah. Gosh! We could talk all about that as well, couldn't we?

**Kathryn:**

We could.

**Jane**

Okay. So, if you were to go in to a hospice or hospital for end of life, what will you make sure was in place for a good death? What are the maximum top tips ?

**Kathryn:**

That's a great question, isn't it? I should really just have a list, shouldn't I? If I was properly prepared, I'd have it. I think the first thing to say is that I've never met a team of people looking after a person who's dying who haven't been trying to do their best.

So, wherever I go, I will go with complete confidence that my best comfort and consolation and the comfort and consolation of the people who are dear to me around that bed will be their intention. I have that confidence from working many, many years in the health service, as well as in independent hospices.



I think a sense of confidence is a really important part of the comfort there. I would like to be treated as a person. I would like to be a person who has opinions. I would like to be consulted about the way I'm cared about, and I'd like you to notice when I'm just too tired to have that conversation and then you just make it up and do it for me. Okay. I think that's a really, really important thing.

I'd like to be consulted about the environment. So, I want the temperature right for me. If it's freezing, to get a jacket put on, but I don't like being hot in bed. Don't play your teeny pop music at me. I'm a talk radio person and, actually, I really go for silence, but I do have some audio tracks that I do quite like and there's a list of those, not for my funeral, for my comfort and peace of mind when I'm lying in bed and I want to listen to something nice.

I would like time to think, time to reflect, time to compose myself, as well as time to see my nearest and dearest. One of the really important things that professional carers can do is the gate-keeping. That allows people to have some peace and quiet without having to say no to visitors themselves because that's so hard to do.

Families can do this at home - have times when they stick a notice on the door and say, "Just don't knock between 2:00 and 5:00 in the afternoon. This is family time. Any other time you can come." So, just protecting people.

I'm confident that the symptom management will be good. I know that symptom management is very much better now than it was when I first embarked into the world of palliative care. I'd like things that I find really tasty to be available in tiny amounts. That may or may not include frozen gin and tonic! That's quite possible, but something for people to bear in mind is that when you're really sick (and if you've ever had a vomiting or if you ever had the flu, you might have noticed this,) your sense of taste changes. So, you can't make assumptions about this.

Same thing happens to some people in pregnancy where you just lose the taste for those things that you always loved. So, one of the things that I really love is at hospices in the tasting sessions where people discover what have we got in the kitchen that you really like, so we can make sure you've got that.

So, rhubarb fool, something like that, that's my thing. So, it's thinking about the senses, isn't it? What you want to smell, what you want to taste, what you want to hear, whose voice is really important to you, what do you want to feel. Some people like big, woolly, snuggly blankets, and I probably just want nice plain cotton. Don't want it to be too hot. So, it's just about creating an environment in which somebody can just relax and feel safe.

**Jane:**

That's lovely. That's really lovely. Actually, that's really quite a lovely way to end, I think, our conversation. Clearly, we could carry on for a long time, and maybe we'll end up having another conversation!

**Kathryn**

That would be nice.

**Jane**

I'm sure there's more questions out there that need to be asked. So, all those things that you've just described, in order to be able to voice them, you have to have thought it through beforehand, don't



you? That's a really private thing sometimes, but it really helps as we've discovered on this call, and it's part of your work and part of my work, is that it's really important to talk about this stuff.

So, I would encourage you if you are listening to this or watching it to get a copy of Kathryn's book if you're intrigued by reading a bit more about what she's talking about, because I can highly recommend it. If you want to know more about taking action on any of these things, then you can visit <https://www.beforeigosolutions.com> , and you can sign up for a copy of the free PDF, The 8 Essentials for Creating a Good End of Life Plan, which covers quite a lot of what we've talked about, and quite a lot of other things.

It just gives you a little starter to the sort of things, that we've been talking about today. You can get it at <http://www.beforeigosolutions.com/8-essentials>

You'll be on my mailing list, and then you'll get to hear about all these other things that we might be doing or other useful things, and if you don't want to be on the mailing list, you can just subscribe, get the PDF, and then come off it.

So, I just want to say thank you so much for listening in. I hope you've learnt a whole lot, I certainly have, and I probably do have more questions myself. For now, thank you very much, and take care.