

Integrating Dying into Living By Ivor Williams End Well Symposium, December 7, 2017

Start of Transcript

Hello! I have the unevoked privilege of being a British person and a Scottish person here so fine, reset the filter if this gets a bit too much. [Crowd Laughing]

So I'm gonna talk about a couple of things. I'm gonna start off by talking about poem control or get to something's a bit designed. And what I mean by that is we've been talking about this all morning but it's kind of obvious but in the context in we've described it, since the 19th century really, the healthcare professional, the doctor has been the expert in death. You know you've had all the power, you've had all the control. You've put us on some pathways and you diagnosed us and look at us with what Foucault called the "clinical gaze." You can see the reality of things, which is a really powerful thing as a non-clinician. And you gave us pain relief [00:01:00]. You know that's one of the most incredible that's happened since the 19th centuries that you can really make sure that when we die we so painlessly — but that's not always been the case.

Before the 19th century, the priest was the expert in death. They had all the power. They had all the control. They would sit over your bedside and they would guide you through to the next life. And that was something that was really a challenge then. They didn't quite have pain relief back then but he said, "Look, okay. It's really painful. You're gonna suffer but what's gonna happen next is all if it's worth it for you." And I guess my point is in the 21st century, it won't be the doctor or the priest that's gonna be in control and have all the power. But it's gonna be us. It's gonna be people. It's gonna be communities. Because the individual and the patient is the expert in their disease and, their illness. And in fact, the power that we can all have is the community to support each other through our end of life is incredibly [00:02:00] powerful. And that is the sort of... if I'm gonna throw it down, a bit of you know, a challenge today is that this is what we have to do in the 21st century. And I think design has a really important rule to play here... because death involves everyone from the patient to the doctor to the nurse to the healthcare system to the cleaner who comes and cleans the rooms, to the carer to the family to the neighbours that involves absolutely involves everyone! So as a designer we think, okay, so how can we do that? We have to design accordingly to make sure that we include everyone in there.

So when we start talking about patient-patient-centred care, I think BJ Miller even eluded to one where we think about is relationship-relationship-centred care. And that's what we do here at the Helix. The Helix centre is a design studio. It's embedded directly in St. Mary's Hospital in London. We're right next door to where Fleming discover penicillin by accident. And that's [00:03:00] spurt of innovation is really kind of key to what we do so we sit in this kind of weird glass and woodbox that often gets mistaken for their sonar or MRI scanner [Crowd Laughing] and then they find out the design studio and they're like "Oh, it's getting weirder."

[Crowd Laughing]

But we sit there and we work as a very unique team to try and tackle some of the biggest healthcare problems that we have in UK and internationally. And what's really unique about it is our team is made up of designers and technologists like me, but I sit next to oncologists and physios and surgeons. And we work directly with patients in the healthcare system. We work with public, we work with frontline staff. And that's like really fundamental to trying to tackle what our really most complex problems in healthcare and we do that in a number of ways. We have a whole bunch of projects that range from paediatric drug safety to stroke rehabilitation

and to burrow cancer screening but **[00:04:00]** one of the biggest areas that we've worked around is end-of-life care.

And when we started this end-of-life care a couple of years ago, we started in our own environment. We started in the hospital. And we kind of thought, "Okay, how is death handled in the hospital?" And it turns out pretty badly. There's lots of issues to it but one thing that really stood out for us, as we spoke to doctors and nurses and spoke to patients and families, was that there's a huge amount of people who have to die in the hospital, they done so through emergency admission. So they're getting carried in through an ambulance and as a result, they're drying through that experience. Now a lot of time, that's gonna be because you've had a car accident, it's been unavoidable admission but for a lot of old people, people that are frail, people with dementia, people at the end of their life, are coming through as an emergency and they end up dying in hospital.

And we thought about that. We tried to dig around and **[00:05:00]** using human-centred design principles, it means that we cannot spend time in spaces. I mean we really kind of dig around and we just observed and see how things work. And we found this thing, which in UK we called DNA CPR or Do Not Attempt CPR form. When I was writing this, I realised there's a very big distinctive difference between the UK and the US, and I'll explain but essentially if you're a clinical person, this is a form that says "if your lungs and your heart are gonna stop," and I'll be very non-clinical here to explain it so don't shun the reason of how it works but if your heart and lungs are gonna stop, there's a clinical decision that says, "We're not gonna try and resuscitate you." They do that because they got your best interest of heart by saying you probably wouldn't survive. If you do survive, you might have some brain damage. You won't recover very well. So this form is — it's a really important document to say that to do things to you, do more harm **[00:06:00]**. But the problem is is this is a form that sits at a medical document. It's signed by a clinician in the UK. A patient cannot demand any treatments. I think that's the difference in the UK and the US. In UK, you cannot demand CPR. The clinician will make a decision on your best interest and say, "This is not gonna be right for you." This leads to a lot of problems.

[Crowd Laughing]

Clinicians will fill in the form, could be 2 AM or could be 4 in the afternoon. They're filling the form, stick that in your medical records... they may or may not tell that person that they have that form. They may or may not tell the family that they have that form. And that has led some serious serious battles in the high courts in the UK. There's so many instances where families aren't told that their loved one will not be resuscitated if their heart or lungs stops. And this was the reason they constructed the 1960s to deal with cardiac arrest **[00:07:00]**. But it's been since expanded because we've medicalised death to include everyone who comes in and someone who's got a broken hip and you know, it's just a frail old person who has this form. So we thought, "Oh my god. We have to do something with this but how can we do it — what can design do to help this?" Thankfully there was a whole other, 40 other organisations in UK that have been doing a lot of research, building a lot of evidence about providing a solution. And this is the solution. There's another form, right? But get past that. [Crowd Laughing]

It's called ReSPECT. And it's fundamentally important and it is a form. It includes the CPR decision which sits around at the bottom. So what's on the rest? The rest is building a comprehensive picture on what you want in an emergency. And major contribution that we made and we really wanted to make sure we translate it the patient needs and the families needs, their wishes and desires, into a clinical document... it's this bit in the centre **[00:08:00]**.

So we understood the clinicians love to do things in order. Start at the top, go to the bottom. A clinician can't get past this section without actually having a conversation with the patient by saying, "What would you prefer? Would you prioritise license-end treatment? Or you would prioritise comfort treatments?" And the patient can then have a question, "What does that mean?" And there you go, you start having a conversation what comfort treatments are, what license-end treatments are. And the patient can then write on the form where they think they'd want things and that builds in the conversation about what would happen in an emergency. So before what was happening was that conversations were not happening, we designed in the conversations part of this emergency care planning treatment. [Crowd Clapping] Thanks! But what was really interesting was we designed this form but we realised we weren't just designing that. We're re-designing the relationship between the clinician and the patient and their family about what's so unwanted in an emergency [00:09:00] because we can't change the fact that the clinical matters might change but there's better ways that people can have conversations at the end of life, in the emergency acute setting at 2 AM. It's a really traumatising point for many many people so trying to build in the conversation and trying to build in the dialogue, finally a way for clinicians to have a conversation, coz they find it just as difficult as the patient to hear it. And that's what we're trying to do in Helix center. And that's one of the things we've been doing in our end-of-life projects.

Another thing that I've been working on, this is my confessional mission, is to realise that yeah, we're there's two unavoidable things in life, which is technology and death. And I want a mission to really see how we can use technology in a better way. To help us live with death and dying. And that's why the — my friend Alex and I, we set up a company called *Humane Engineering* a couple of years ago to really try and see how technology [00:10:00] could be used to tackle some really underserved and really important issues.

It all came about a couple of years ago. There was an interesting phenomenon happening where teenagers were taking selfies at funerals. And it was a really weird time because people were getting really upset and going, "Oh my god. These kids are so vain. They're so disrespectful. They don't know what they're doing." And I was like, this is awful! And I kept thinking, "It's totally normal. These kids are you know hold old, 14, 15. They take selfies every day, all day. What's more unusual is them going to a funeral for the first time. And this is just their way of possessing. This is just a way of saying, I'm here, I'm doing this. This is weird, like telling your friends getting some support. It made us think but the main thing was that is technology it's not built for this kind of stuff. It's not built for death and dying and grieving and grief. So we thought there's got to be a better way.

And it turns out this is like a silent crisis [00:11:00] along with death education, having the conversation about death with children is a massive problem, in fact, in the UK. In every classroom, there's one child who has lost a parent. There's millions and millions of children in UK who have lost a loved one. And from my own experience, coz I lost my friend when I was 17, that I knew that this was a huge problem. It can really have impacts in the rest of your life. There's huge implication for mental health, for truancy, for education for prime later on if have a bereavement when you're a young child. So we felt okay what can we do, what is the way in which we can support young people by using technology that they use every day? Which is why we create this thing called Cove.

Cove is a music therapy app. And basically you use music to express complex emotions and you can journal it, you can create a little journal for yourself that allows you to really do what we know is really difficult when you're going through a bereavement which is trying to get something out that you're feeling. Because we know [00:12:00] with the young people they find it really hard to talk to other people, find it very hard to actually just they have their feeling... but we really believe them. Music has this incredible potential — I think we're gonna hear a

little bit more later on about just how powerful music is when it comes to death and dying — that it's been so successful in supporting young people that we've actually been funded by the NHS, the Health Service in UK to roll this out even further. And I'm really excited because from next year, A GP family practice were billed to prescribe it to families, which I think if you imagine we're prescribing med — music as medicine. I just think it's fantastic.

So but what really makes the difference is when people come and write to us and tell us exactly how this music makes us help them process and go through their own grief and bereavement. Makes it all the way worth it for us. And I'm just gonna close with what seems **[00:13:00]** really obvious is that for most people the experience of dying is full of uncertainty and dread. It's really the most terrifying thing we've ever gone through and I think we have to kind of acknowledge it and there's no way to sort of design the way we had it, it's just gonna got to happen. I know it was a little too early. I'm really glad you didn't because I thought I was gonna steal my slide but this is Alice Moriandy. It's in the bitclip and this was a bit from the 1400s. It was the second book after the bible to be put into printable type, moveable type, which is in itself, design innovation. Okay?

So we've been doing this since the 1500s and this is the bit that allows you without a priest and a church to be able to guide you yourself through to have a good death, which is incredibly transformational and that is a good example of that shifting power and control. This really upset the church because they didn't have the power for death anymore. It was in the hands of the people. I think we have to kind of maintain that spirit as we move to 21st century. Because at the same time we have **[00:14:00]** issues like this. This is a syringe driver. And this is really interesting. This is introduced into a home of a dying person and the person might die a couple of days later. Families will be like, that did it! That killed my mom. Because people are so scared of all these machines that look after us, and in my opinion we need to have — stop having machines at the end of life. I'd love it for my loved one to be administering a pain relief, not a machine.

Because death is a four-dimensional experience, it's not just physical. It's spiritual, it's social, it's psychological, it's all these things together. So when I say that how are we gonna tackle death and end-of-life in 21st century, I have to say it's not your job anymore if you're a doctor. It's all our jobs. And I really think that design can do something about that. It's a really — it's a joint effort and I think design can help make death a social, human experience again. I think that we have to de-professionalize it. You know, we have to give this knowledge that all you guys **[00:15:00]** have to everyone, you have to de-medicalize it. I don't think it should be in the hands of a doctor to administer pain relief when someone can be trained to do it themselves. And to make sure that that person they're caring for gets the love and attention that they really deserve. And lastly just to say I think this is a huge conversation so let's just please keep this going and thanks a lot.

[Crowd Clapping]

End of Transcript