

Talking Improvement

The Improvement Cymru Podcast

Episode: Sepsis: raising awareness

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Guest(s): Terence Canning

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Introduction

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Martine Price: Hello and welcome to Talking Improvement. I'm Martine Price, I'm the lead nurse with Improvement Cymru.

Today, I'm really delighted to be joined by Terence Canning, who's the Welsh Executive Director for UK Sepsis Trust. And this is particularly relevant as actually we're launching this podcast on the 13 September, which is World Sepsis Day.

Terrence, thank you so much for joining us on Talking Improvement. To start us off really, it would be great if you could tell us a little bit about you and how you came to be in the role as the Welsh Executive Director of UK Sepsis Trust, thank you.

[01:56]

Terence Canning: Thank you Martine, and thanks for inviting me on to the podcast. I'm always very happy to raise awareness, particularly on World Sepsis Day. And the reason for that is the reason I came into this, really, and that was because just over ten years ago, I'd never heard of sepsis.

Until my brother was taken suddenly unwell, he was unwell in the community. He then went through into hospital setting. Unfortunately, he was one of the unfortunate ones, one of the 48,000 per year.

And sadly he passed away and the first time I saw the word sepsis was on his death certificate. I consider myself to be quite a well-educated man, quite a well-travelled man, but I had never heard of it. And when I did look into what it was, I was quite astounded that it was just somebody's reaction to infection. I didn't know why I didn't know what that was. And so that's why I became involved with Sepsis Trust and raising awareness of sepsis.

Because the more I looked into what happened to my brother, the more I realised that, you know, with maybe better education, communication and awareness and slightly different behaviours from people, maybe, it may not have changed my brother's outcome, you know, but by getting involved with UK Sepsis Trust, it could certainly perhaps drive a bit of change.

It could result in more positive outcomes for others in the same situation. So that's why I'm involved in UK Sepsis Trust and sepsis awareness.

[03:25]

Martine Price: Terrence, thank you. Thank you for sharing that. And I think, we hear, don't we? The stark facts around sepsis and the devastating impact it can have. And very often we do talk about numbers don't we, in relation to sepsis.

And you know, five people die with sepsis every hour in the UK. And the figure that you just gave us as well. But to actually really think that every one of those numbers is a person. And every person - how it affects them as individuals and how it affects their families as well.

And I think it's so important that we really think about that and in improvement work, obviously, we focus very much on measurement and data is fundamental to that in terms of knowing that a change has made a difference.

But actually, it comes down to people. So I think it's very, very important to highlight that. And I know in the work that the Sepsis Trust does, that you do work closely with families and people who have had sepsis and recovering from sepsis.

And you also take patients' stories as well. I don't know if you can tell us a bit more about that and how you use those stories to raise awareness?

[05:03]

Terence Canning: Sure. I mean, as I referred to in the introduction that, you know, my brother was one of those stories. And using that story in health care setting is such a power and impact. I never would have realised that until I did it one of the first times. But what we would say with sepsis is, it's so indiscriminate, it affects everybody. So we need to collect these patients' stories just to highlight the fact that, you know, it's not dependent on age or ethnicity or... it can be absolutely anybody.

So we have a whole range of stories from the very young to the very old. And I think, you know, this needs to form a part of our messaging within, you know, communities and health care so people realise actually that it's not just the very old or the very young or the already very sick that die. That's important. But the other thing I think from an awareness messaging perspective is you need to be able to see yourself in those stories. So if it was just me telling my story that may resonate with a 41 year old man.

It may not resonate with the mother of a very young child. So we need to collect these stories so we can use them to really improve awareness. And the sad thing is there are so many of them. There are so many of these stories. So we never have a shortage of stories to share with people and that they can provide such a big part of collaborative education and learning, and especially in the awareness space.

[06:35]

Martine Price: Yeah. No, I absolutely agree with that. And I would encourage anyone to have a look on your website as well. And there are a number of stories that people can have a look at. And thinking about that, and as you say, in terms of raising awareness and for health care organisations, I guess then, you know, do you have any advice for them about how they might raise awareness using some of those lived experiences?

[07:08]

Terence Canning: Absolutely. My first piece of advice would be absolutely do it. If you're thinking about using a real life story as an organisation, who wants to raise awareness around sepsis, I've experienced it first hand, the benefit and the impact of complementing formal training with a relevant patient story.

It just adds a name and a face and a real context to teaching. I think sometimes there's a bit of a perception that, you know, these experiences are private or personal and people don't want to share them. Or if somebody has had a bad experience with health care, they'll become an antagonist. But in reality, I know a lot of the people that we deal with, I can say for myself as well, that's very often not the case and people want to be involved in change and it's partly to sometimes process understanding, what is the experience you've been through yourself, but also to use this negative experience often to achieve a more positive outcome.

You know, I was never motivated or driven by blame, because blame doesn't change anything, even though there are a lot of things in my brother's timeline where things could have perhaps been done differently, but blame doesn't change anything.

And I think people are very keen to use their experience for a positive outcome. I think it is a privilege in a way to be brought into your world or the world of health care from the outside, because we often come in, come out, but there's no relationship beyond that.

There's no sharing of stuff beyond that, really. So I think that we've been able to bring those two worlds together, the experts, the medical experts and the people who've been affected by it. You just get a broader sort of, I think, grasp of the situation.

So I think, you know, certainly if you're thinking about bringing the public community world into the health care setting. Absolutely. Do it. And, you know, in terms of sepsis, we will always be very happy to work with Improvement Cymru and NHS Wales, you know, to facilitate that.

[09:12]

Martine Price: Thank you, Terence. That's really good to hear. And when we talk about, as you say, improvement work, actually you know, we should be doing that in partnership with people who are receiving those services.

So I was going to use the word patient there and, you know, our patients, but just thinking of wider health and social care, but actually meaningful involvement of the people who are experiencing or receiving that care can give huge insights into our improvement work and actually make that much more meaningful.

And in terms of improving efficiency and reliable care as well, when you truly understand the perspectives of those people who we are delivering care to, then actually how we design and deliver care can be completely changed and be much more reliable.

And if you think about sepsis, you know, that's absolutely key, isn't it? Getting it right and getting it right every time when you think about the steps around detecting sepsis promptly. So, moving on then and thinking about that and the work that you do, I'm just interested in when we talk about reducing the number of people that, you know, suffer with sepsis and preventing sepsis, what do you see as the most important factors through the work that the trust has taken forward.

[10:58]

Terence Canning: I think one of the, well there are a number of things really I mean, the first thing to realise is, sepsis is everybody's problem. You know, it's a problem, you know, for us to recognise in the community, for us to present to health care on time and then for health professionals to recognise it and then treat it.

So I guess one of the things I've learned is that, you know, it's everybody's problem, but everybody has a huge part to play in the solution. And that's what we do as a charity, work collaboratively but personally as well.

When I first became involved, because of the reasons I got involved, I thought, you know, this is an awareness raising project. I could do this on my own. I can make plenty of noise, which I did, but that will only get you so far. So, you know, collaboration is the key. Working with each other and not against each other is really, really important. As I was saying earlier about, you know, the perception about this blame and antagonism between the public and health care, actually, in this sort of situation moving forward, often, you know, we can work together very well. And knowledge is everything, I guess would be my second point, 80% of sepsis is community acquired. So everybody really needs to know enough about sepsis to do the right thing at the right time.

So, you know, often I'd say that the first person you see is the most important one when it comes to sepsis, because that's the person who can recognise something, raise the alarm, speed something up, that doesn't have to be health professional.

That could be, you know, a friend and neighbour, a parent or whatever, somebody who recognises sepsis and acts. And that's where the knowledge is key, you know, because once you have this knowledge in place, you can then look at things like behaviours.

And one of the things I learned from the journey of my brothers and myself is that, we're not trying to reinvent the wheel or change the universe here. We're just trying to get people to act a bit differently. So, for example, in the community where my brother was, perhaps if he had been safety netted by the GP and said don't go home, wait to get better. If you get worse, do this, you know, ring us back, go somewhere else.

So that safety netting thing I think is really, really key to the reduction of sepsis because people often, especially to a demographic like my brother, the 40 year old, will wait to get better. But really a little nod to say, you know, if you get worse, do something else.

So there's that safety netting sort of behaviour thing around it. And then with knowledge as well, you know, if I had the knowledge then that I have now, my behaviour would have been different in the health care setting.

When I was with my brother in A&E and in triage, had I known what I know now, I could have asked very different questions. It really could have helped the health care professional come to their diagnosis. And I'll give you an example of that.

I'd seen my brother the night before. He was seriously unwell and he was absolutely fine. He was coherent. He was as normal as you'd expect him to be. What I saw the next time at the hospital, he was very, very different.

He was confused. He was hot. His breath was quite rapid. I didn't know what the significance of that was. Had I known prior to being there, I perhaps could have asked the question of the health professional. You know, my brother was fine yesterday.

Can you explain what's happening to him? Because he's very, very different. He's very confused. And could that be linked to an infection? And then could that perhaps be sepsis? Because my brother arrived with a swollen tummy and a bad belly.

And that's what the focus was. They didn't know my brother, you know, the expert on my brother at that time on him, not clinically but in every other respect, was myself. So I guess the other thing, the fourth thing I guess I would mention then is, you know, it'd be great to develop a culture of listening as well where, you know, patient advocates have a voice where they can say to the health professional, you know, I'm not trying to interfere here, etc., but, you know, my mother, I always use my mother as an example.

You know, she's normally fine, she's very different. She doesn't access health care very often. Is this significant? Oh and she hasn't been to the toilet for quite a while, she's told me that. So I think, you know, there's almost an opportunity to come to a decision together by the member of the public providing enough information. So I think, you know, so it's everybody's problem, everybody's part of the solution. That awareness and knowledge is everything because it gives the community and the health professional more of a chance to work out what's going on and you can play a lot more part in the diagnosis.

I mean, people, we have to take responsibility for our own health, but you need knowledge to do that. So I think they would be my top four things if that answers your question.

[15:52]

Martine Price: No. Absolutely, it does Terence, I think there are some really key fundamental points that you've raised that can make all the difference, be that whether you're, you know, a patient and a relative or a health care professional as well, in terms of that awareness.

And really listening, I think is absolutely fundamental. And looking at the whole person, I think, you know, you can very often go to, you know, like you say in terms of acute abdomen or whatever it is, but really, really looking out for those key signs of, could this be sepsis?

So just thinking then and obviously with the pandemic and, you know, the challenges that has brought. I'm just interested in any perspectives you may have from the pandemic and maybe, how that may have influenced the work of the trust going forward or any learning that's come from that?

[17:00]

Terence Canning: Well, one of the main things, you know, was we weren't able to operate in the way we previously were doing because we'd always done a lot of face to face meetings, education and teaching. So we had to really look at the way we can get our health messaging out to people.

And how we can support them better and in different ways. So one of the ways we've done that was to move a lot of our education, our support materials, even our support groups online. So although we were very restricted by the pandemic in terms of being able to get out there, we were actually able to improve our reach in some ways by refocusing how we delivered our messaging. So now, for example, where we'd have to have one face to face support group per month maybe in the whole of the UK, we're having three or four a week online.

So we are actually able to have a very positive reaction to the way we actually approach our community. One of the issues I guess we have though is that people I think are a bit more afraid to access health care now.

So while we can solve or help people post sepsis, what we really need to do is actually realise and understand that, you know, sepsis is still a medical emergency. And even though, you know, we know the NHS is massively under pressure and

COVID I think scared people into staying away from the health care setting. It's still very, very important that if you are unwell that you do present to health care because with something like sepsis, that hasn't changed. It's still a very, very time sensitive condition and it still needs very, very, early treatment. So one of the key challenges, from it is that. The positive is that people now are a lot more receptive to health care messaging because they're so used to seeing and hearing it now from all avenues, you know, it's been everywhere. So I think people are a bit more interested in health care now as well.

So there's an opportunity there as well to just re-engage with the public on the importance of health care and what to do when you're unwell.

[19:26]

Martine Price: Yeah. No, no, absolutely. And I think obviously, you know, the health care system remains under huge, huge challenges as we go forward now and certainly when I think of our work in Improvement Cymru, you know, post pandemic we launched our strategy, of how we want to go forward obviously in taking learning from the pandemic and have launched a Safe Care Partnership with all health boards and trusts in Wales. And I think the point that you make about working in collaboration is absolutely key.

And I know from the diagnostic work that we're doing and when you look at the information that's out there that, you know, acute deterioration and sepsis, you know, it needs that focus and will remain a safety priority to go forward.

So how we work together in collaboration with that is absolutely fundamental. And it would be good to hear your thoughts on that, about how you want to work in collaboration with organisations to help support them.

And a little bit about, I know you have a wealth of resources as well that are available.

[20:53]

Terence Canning: Sure, and your absolutely, right Martine. You know, the health service even prior to the pandemic was stressed, even more so since I think, you know, because of that, it's so important that health care and health services work with partners and third sector organisations such as UK Sepsis Trust.

So we all want to do the best for patients, don't we? I mean that's what we want to do is give patients a really good service. And I think, you know, if one group of people is trying to do that it's very difficult.

But when you collaborate on that, we can really help each other out. So, you know, for example, we've put in place a couple of things during the pandemic, which is an education program called Sepsis Savvy, which is a very nice, simple kind of introduction to sepsis education for the community and business, really. But if they're educated then when people are coming to you, maybe they'll be at an earlier stage. So we've worked with that. We're working with Sepsis Savvy in schools, Sepsis Savvy for schools. So that's also another area we developed during the pandemic.

We have an education program for schools. So we're really trying to work hard in the community. And obviously working with health care would be if you could help us signpost to those things or to distribute our recovery materials, etc., so we can help pick up, you know, often where you guys don't have the capacity. The other thing we were able to do recently was to update all our clinical tools. So for the healthcare setting itself, all of our clinical tools for example, I won't name them all, but we have them for acute hospital settings, community settings, general practice, out-of-hours, etc. All of those have been rewritten with the Royal Colleges guidance in mind and with a view to minimise the impact of AMR [Antimicrobial Resistance], which is that which is also a huge thing at the moment, as you will know, a lot more than me because I'm not medical.

But I think everybody's aware of the conversation around AMR [Antimicrobial Resistance], which is particularly difficult with sepsis, because obviously the treatment is antibiotics, but all of our clinical tools are freely available and downloadable on our website. So I guess for us then in that sense it's about visibility of us and what we do.

So how can we best help you? I think that conversation together would be really useful. You know, these guys exist, this is what they do and you know what? They might really be able to help us here.

So that's one of the things we do. Also though, we provide an awful lot of post discharge sepsis support. So again, we can really work with health care on that. I mean if people know we are here. We've got a support team of three full time ITU [Intensive Therapy Unit] trained support nurses, people can call them, they can email them, they can request a call back if they want to or if they need to. You also have a whole suite again of free downloadable resources, recovery advice, wellbeing, recovery diaries, advice to patients and relatives as well bereavement advice.

So we have a whole suite of resources that I think would be of huge use to the health care and especially in Improvement Cymru and NHS Wales. And I think you know, we would love to have a sit down with you guys to think 'what's the best way of people knowing that we can work so well together on this?' I think we both do things really well separately, but how much more effective could it be for the patients if we could work more closely together? We often find that people find us eventually.

But I think what would really, really benefit a patient, just after discharge from hospital with sepsis, we're not entirely sure what's happened to them, would be to access us really quickly and we can really help with that.

Those initial few weeks of recovery and possibly, you know, stop a visit to the GP, there's not quite maybe required because people go back to the GP or the hospital for that information where they can probably get that from us.

So that takes a bit of strain off the system in that respect. So I think it's about conversation, collaboration, signposting and see what we both do that works well together. And not everything will do, but some things will complement each other really, really well.

So I think there's a real opportunity now post pandemic for the third sector and health care and other parts of society as well to re-engage and do things together. I do think one of the positives of the pandemic really was that people realised how quickly they were on their own and the need for collaboration then became so important. We worked together with partners through the pandemic that we had never worked with before. I mean, this is like, you know, big corporations and industry.

So there were so many people willing to help. It's just how you harness that and turn it into something that can be effective.

[26:25]

Martine Price: Yeah. No, I absolutely agree, Terrence. And I think in terms of, you know, some of those things that we did during the pandemic and that learning we absolutely have to take forward. And, you know, the challenge feels even greater now.

So we have to work collaboratively, we have to work together. And I've just, you know, just hearing all those resources that you've shared with us there and what's available. And I just think what a difference that can make because it is, you know, preventing sepsis is such a priority and can make a huge difference in terms of harm to the people that we care for. So we have to get it right and we have to work together to try to achieve that.

[27:17]

Terence Canning: I agree. I think one of the main things of it is we do work in both of those spheres in a way, where we have a strong awareness campaign, with the intention of keeping people informed and aware enough to not require intensive treatment for sepsis.

But there will be people that still require that. And that's where our second body of work would kick in with our recovery and support, etc. So in an ideal world, there'd be a really straight line where somebody in the community becomes ill and there's some aware of sepsis because they've seen all the messaging that they access health care early, they're diagnosed quickly and treated quickly. They leave and everything is fine. And there are situations I want to highlight as well actually, you know, it's not all negative. That does happen. And when it works, it works really, really well.

We just don't hear about it quite so much because we tend to hear all about the bad stuff that happens rather than the good. So I am confident from the feedback that I've had that many times that system works really, really well, but we have to be prepared for every eventuality.

So our aim would be to make people very, very aware, to reduce the numbers. But people will still become sick and we're there to help them when that happens. So that for me would be the best way.

[28:34]

Martine Price: But yeah, absolutely that that sums it up beautifully. Terence, thank you so much. I think it's been really great talking to you today, and I would certainly encourage people to access your website. So the UK Sepsis Trust website and I'm sure we will make that available to you as well alongside the Improvement Cymru website. And I think in terms of, you know, it absolutely complements, you know we're all trying to make it better, aren't we? For people that receive health and social care and so, once again, huge thank you to you, Terence, for your time in joining us today and it's been great talking to you. See you soon. Thank you very much.

[29:37]

Outro

[Audio ends]