32. Intensive Care At Home – Patrik Hutzel

Intensive Care Support

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Stroke Podcast Episode 32 – Many people who experience a stroke may need to spend some time in the intensive care unit. Is your loved one currently in hospital in the ICU (Intensive Care Unit)?

Patrik Hutzel is an Intensive Care nurse who provides support services for families who's loved ones are in a serious health crisis in hospital and the doctors are asking family members to switch off life support.

In this episode you will learn that life support can now be arranged for your loved one at home.

ICU at home can have many benefits for families.

- Travelling to and from hospital can cease
- Costly accomodation expenses can be avoided
- Time off work can be minimised and
- Routine can be restored

I pray that no one ever ends up in this situation but in the event that they do its important to know that now hospitals are seeing the benefits of offering ICU at home as a way to make beds available for other patients.

Withdrawing life support.

Many families have been faced with this situation and it is never easy.

While removing life support may be inevitable at some stage you do not need to feel rushed into agreeing to the request. You can now negotiate with the hospital to extend life support until you or the family have all had enough time to come to terms with a difficult situation, but most importantly you can ask for life support to be provided at home.

Whilst not everyone will be able to negotiate life support at home for their loved one, this episode of the podcast will shed some light on what your rights are as next of kin in the event that your loved one ends up in intensive care.

Visit Patrik's website at here.

Highlights:

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Transcript:

Intro 0:05
The transit lounge podcast moving you through life's transit lounge and helping you go from where you are to where you'd rather be.

Bill 0:15
Good day, everyone. Thanks for joining me for another episode of the transit lounge podcast. My guest today is Patrik Hutzel. And Patrik is an intensive care nurse. And in his years of practicing intensive care, he found that there was a gap in the service and found that very difficult to comply with a lot of the decisions that doctors and hospitals were making about people that were receiving the life support services and were on life support systems.

Bill 0:44
So he's set up a service that allows people to actually have an intensive care

service at their home for their loved one. And in this episode, he explains the process that he had to go through to have that type of service approved in Australia, and have that type of service available to people that were supporting their loved ones in intensive care.

Bill 1:10
So that when the doctors and hospitals required the bed for another patient, they were able to come up with a solution, and to provide extra time for families to make those serious and difficult decisions about their loved one, and now he provides information via his website, intensivecare@home.com. Now, this is a challenging conversation for people to have with their hospitals.

Bill 1:39
And hopefully what you'll get out of this episode is you'll get some tools and feel a little bit empowered about how to go about managing and dealing with hospitals and doctors who are interested in taking your loved ones off life support. I hope you enjoyed this episode and if you do enjoy this episode in you feel that it's been worthwhile listening to it, please do give us a thumbs up on YouTube.

Bill 2:05
Share this on your favorite social media and tell other people about it. Especially somebody that you know, that may be finding it difficult to deal with doctors in a hospital, especially during those moments when, you know, emotions get the better of us. And we don't want to hear or listen to doctors tell us to do the worst case scenario which is to switch off a machine.

Bill 2:33
Good day Patrik, welcome to the show.

Patrik 2:36
Hi Bill, thank you for inviting me.

Bill 2:38
You are so welcome. I am so excited to have you on the show. After chatting with you briefly some days ago and getting to know a little bit about what you do. This particular topic is really, really important and people that have loved ones that are experiencing difficulty in life with regards to their health really need to have the opportunity to hear what it is that you're going to share with us today.

Bill 3:06
And the topic is intensive care. And before we get stuck into the topic and have a real deeper talk about what it is that happens in intensive care, can you give us a little bit of information about how it is that you got involved in intensive care and what it is that you did prior to going into this point?

Patrik 3:28
Yeah. So again, thanks for inviting me to your show. I really appreciate it. So as you've said, I'm an intensive care nurse by background and I did my nurse training starting starting in 1996. I was a car mechanic prior to that. And, you know, and I wasn't, you know, it was only like 19 at the time and I wasn't thought What do I want to be in become mechanic for the rest of my life? And the answer was no.

Patrik 3:52
So I was looking for other options. And I ended up doing a little bit of work in a psychiatric hospital. And you know, I really enjoyed that. And I thought, I think I really want to work with people in the future and I want to help them and that's how I decided to become a nurse. So I did my nurse training. And after I finished my nurse training, I, you know, thought, What do I want to do now with nurse training, and I decided I wanted to go into intense two stints in ICU during my nurse training, and I really enjoyed working with really critically ill patients and their families.

Patrik 4:26
And I also enjoyed the technology side of things. You know, there's a lot of machinery in ICU and all of that. So, you know, I enjoyed both worked a couple of years in ICU in a big teaching hospital in Munich in Germany, which is where I'm from originally and where I did my nurse training, and then working in Austria for a couple of years. And then I joined a startup health care company in Germany called, you know, like a home ventilation service, also known as intensive care at home.

Patrik 4:55
We were basically the first service provider in Germany, looking after patients on lifestyle bored at home, right? And that was pretty crazy at the time people thought it was crazy. But you know, we were doing it anyway. And you know, after a couple of years I then went overseas work in the UK as an intensive care

nurse if my critical care training there. And then in realized in the UK, there is no intensive care at home services for patients on life support, they stuck in ICU or they die.

Patrik 5:24
There were no services offered in the community. I came to Australia in 2005. Again, I work as an intensive care nurse in a number of hospitals. And I realized again, there are no intensive care at home services in Australia for patients on life support. And, you know, I was working in many hospitals. I worked as a nurse unit manager for five years in intensive care. And, you know, I eventually decided, well, something's got to be done about intensive care at home because it was a growing industry in Germany.

Patrik 5:55
And people were leaving intensive care and could go home on life support. I just thought, well, there is absolutely no reason why it can't happen here. And that's when I eventually in 2012 started my own company intensive care at home only to find that nobody was interested in. And people thought it was crazy to provide intensive care at home, they didn't really understand what was happening in other countries. So there was a lot of frustration initially, when I started my company realizing, oh, people have no idea what this means and how it can improve people's lives.

Bill 6:27
What kind of person does unfortunately have to end up or fortunately, end up in intensive care? Because if it didn't exist, well, maybe they wouldn't have the opportunity to be alive.

Patrik 6:38
Yeah, absolutely. is it's a good question. And, you know, you you saying, you know, it's fortunately or unfortunately, whichever way you want to look at it. But the reality is intensive care is actually a really new specialty. You know, we only started out I believe, in the late 1950s, early 1960s. If you think about it, that's not a long time. That's 50 years. Right? Not a very long time. So it's a really a new specialty, if you will in the medical field.

Patrik 7:05
So who ends up in intensive care most intensive care units or big intensive care

units have a number of specialty with in the intensive care, and that usually starts with trauma. So anybody involved in CBM, motor vehicle accidents, people falling off rules, bike accidents, ski accidents, whatever, you know, sport injuries, head trauma, you know, those are people who end up in a trauma intensive care.

Patrik 7:32
Then you have the general section where people go, you know, after stroke with and I'm sure we talk about that in more depth later. You know, people come to generally intensive care, maybe with burns, maybe with a pneumonia, maybe after abdominal surgery, after Arctic aneurysms, you name it, that the the, the other specialty in intensive care is cardiac, basically anything related to the heart.

Patrik 8:00
Okay, so people come they after open heart surgery, they come there after they sustain a heart attack cardiac arrest, cardiomyopathy, you know, you name it. other specialties are pediatric intensive care children, and another sort of, yeah, absolutely. And I can talk about that too. I've worked in pediatric intensive care to and we're doing a number of pediatric work with our intensive care at home as well.

Patrik 8:30
So we have a number of pediatric clients, excuse me. other specialties are neuro trauma that's only specializing on head trauma. And and other specialties are like transplant, heart transplant, liver transplant, kidney transplant, lung transplant. So that's it in a nutshell, those are people who go into intensive care, but the commonalities they all have whether they go into trauma ICU, generalize ICU, colleague ICU, the commonalities they all have. They are critically ill They need life support most of the time intermittently, and their life is in danger.

Patrik 9:08
Right, those are the commonalities.

Bill 9:10
So the machine is designed to keep them alive

Patrik 9:16
Very much. So it's not only machines, it's also medications that are classified as life support. So you have the machinery like mechanical ventilation, or like a dialysis machine for kidney failure. But you also have medications, for example,

like iron and drugs. And again, I don't want to get too technical here that maintain a physiological blood pressure because many people who are critically ill can't maintain a blood pressure that's keeping them alive.

Patrik 9:43
So there's medications that can keep people's blood pressure above physiological level and keep them alive. So there's a number of life support mechanisms and that includes machinery, as well as medications.

Bill 10:00
Well, that's a surprise, it's something I never would have realized. I mean, you hear about intensive care. And most of the things that we see on TV well, we have to switch the machine off now. And that's kind of how people in the non medical world associate intensive care to a machine that's circulating the blood or keeping the heart pumping or keeping the lungs inflated.

Patrik 10:24
And that's part of it too, you know, there's now the latest sort of developments in intensive care, if you will, is ECMO. And again, I don't want to get too technical here. But ECMO is basically a bypass machine in the US in intensive care for heart failure and for lung failure. Basically, an ECMO machine can replace the function of the heart or the lung for a period of time until other solutions might come up. Right and heart transplant or lung transplant, or it could just be the recovery of those organs. Right. So there's a number of options In some intensive care units,

Bill 11:02
So is intensive care is something that I get to decide about as a loved one of somebody in intensive care or is it something that the hospital just decides is going to happen? So somebody comes in, there's a trauma, how do people end up in intensive care? They have all these challenges. But is everyone eligible? does all the injuries make it possible for people to be in intensive care or not?

Patrik 11:24
Yeah, so that's a good question. Let's just run through an example right? To illustrate that. Let's just say somebody is in a motor vehicle accident and you know, somebody witnesses an accident and they call the paramedics they call the ambulance and the ambulance arrives and the patient they find is unconscious.

Patrik 11:47
When they see the patient is unconscious and potentially doesn't breathe, can't open their eyes. There's a very good chance they start life support at the scene, okay, that automatically gets a patient in intensive care if they need to start life support with a ventilator at the scene if they need to put in a breathing tube, there is no other way but this patient will go into intensive care.

Patrik 12:15
The same applies for example, if somebody has open heart surgery even though it might be scheduled, okay? A patient after how open heart surgery can't come off life support straight away because of the the complexity of such surgery. Okay, so they know that the patient can't after an open heart surgery can't come off life support straightaway.

Patrik 12:40
So that qualifies for them to go into intensive care, there's no other place for them to go. So, you know, but you are right that some patients might present to the emergency department or emergency room. And somebody you know, when the doctors and the nurses assess a patient, they might say does this patient need to go into intensive care or not? There's always a gray area would look at criteria like, you know, what are a patient's vital signs? What are their results? What are What does their chest X ray look like? What does the CT scan show? You know, what interventions Do we need down the line? Do they need a central line? Do they need arterial lign? Again, I don't want to get too technical here. But there are a number of interventions that can only be done and then also monitored in intensive care.

Bill 13:31
Okay, so the work that you do at the moment, you're not making these types of decisions. You're dealing with people who are already in intensive care. Is that right?

Patrik 13:41
Yeah. So I do a couple of things at the moment. Just to illustrate that to our listeners. So as I said, I started my own nursing service intensive care at home In 2012. only to realize I'm not getting any traction, couldn't get any funding through hospitals. They all thought it was crazy and that I was out of my mind and all of that. So then I thought to myself, what else do I need to do to educate

people around this and that's when I came up with another business idea.

Patrik 14:10
And I thought, let's start a resource and, support website for families in intensive care. And that's when I started another business and the name is intensive care hotline, right? So we help families in intensive care to deal with the stress to educate them, to help them asking the right questions to make sense out of what is a quote unquote crazy situations for families in intensive care?

Bill 14:38
So somebody has a loved one in intensive care. And for some reason something happens and they decide that they're not dealing with or they're not understanding or that they don't have any information. How did they come across? How do they move from out of the hospital to that? Because the way I see it is, if I was involved, thank God, I have never been involved with some of my loved ones in intensive care.

Bill 15:37
I would seek all the information that I needed from the hospital because I see them as being the place where it's being supplied and provided. But also, I would expect that that's where the expertise is. So how, what happens when somebody says, I can't, I'm not getting what I want, and I need to go somewhere else. I gotta understand.

Patrik 15:58
Fantastic question, and it comes. And that's really the crux of the question. And you know, I will give you the answer. So, when I was nursing at the bedside in intensive care, right, I really enjoyed my time in intensive care had a great time, I, you know, made a lot of differences to people's lives and all of that. But there has also been as time went on, there has also been an increasing frustration on my behalf.

Patrik 16:27
Because, you know, as you work in intensive care for nearly 20 years, you also know all the bullshit that's happening, excuse my language, but, you know, you learn all the bullshit as well. And, and you know, what families get told, but you also know, what is true and what is not true of what they're getting told. Okay? And I understand, you know, families need to be managed in intensive care,

patients need to be managed, and I get all of that, you know, and sometimes they simply don't understand what's really happening, but that's besides the point.

Patrik 17:00
I do believe that as intensive care professionals, whether doctors or nurses, we have a duty to educate people to the best of our abilities. But to illustrate this further, there have been many situations in intensive care, especially when I was nursing at the bedside, but also as a nurse manager in intensive care where I felt compromised in my ethics, even in my duty to report to the nurses board, right, because I don't mind my first, my first report is always to the nursing board and not to a hospital to an employer, if you will.

Patrik 17:38
I'm a registered nurse, I report to the authorities really about my practice. To give you an example, I come on to a nightshift it one day and I look after a 62 year old man who fell off the roof of his house, okay, and he fell on his head. And, you know, he was probably dying, but we weren't quite sure yet. You know, his head injuries were really significantly at high brain pressures and whatnot. So we knew it was pretty critical. And, you know, we weren't sure what he survived the next 24 48, 70 to 96 hours.

Patrik 18:16
So at a very unstable night on that nightshift, you know, we managed to get the patient through the night, and I was on again, the next night, so I was the two nights in a row. And you know, look after the same patient, so when I come on the next night, you know, the doctors were just in the room and they said, oh, by 10 o'clock tonight, you're going to remove life support. Right? And because I looked after the patient the night before I knew the family, you know, and my first response to the doctor if you want to remove life support, you can do it yourself because I won't.

Patrik 18:50
And he says to me, Oh, are you refusing my orders and I said that's exactly what I'm doing. So and I said to him again, if you want to remove life support at 10 o'clock, you can do that, but I'm not doing it. And if you think that's the right thing to do, that's fine. But I'm either going home or I went to the nurse in charge and said. Look, I'm either going home or you reallocate me to another patient, because he's basically asking me to kill a patient. I feel like I'm executing a

patient here. And having worked in intensive care at that stage for 15 years, they needed the bed.

Bill 19:25
Let's go back for a second. That's a pretty big deal, right? Somebody has asked you to remove life support from somebody that is ultimately going to end that life now I understand what you're saying that makes you feel like you're going to execute that particular patient because of the difference in opinion as to where you believe the patient is at and where the doctor believes and what the doctors priorities are, as opposed to what your priorities are. So what are your priorities as a nurse and what are the doctors priorities?

Patrik 19:59
Yeah, So I don't think it's so much the doctors priority or the nurses priority. I think in that instance in particular, I tell you what it was, it was a really senior doctor, and he was managing the unit. He needed it. Right, he needed to free up that bed for the next patient. My duty as a nurse is looking at it from a holistic perspective and the holistic perspective to me is the family is the patient. And I'm the advocate. And there was no question in my mind that this patient would die but the family wasn't ready for that.

Patrik 20:37
And that's not how you orchestrate palliative care. Right? End of Life is fine. I have no problem with people dying in intensive care. I've seen it hundreds of times I have no problem around that. I know it's happening, but there are ways to do it. And that includes giving people an option to intensive care at home for example right, so not giving people options and saying, Oh, yeah, we're going to remove life support by 10 o'clock.

Patrik 21:06
And we told the family already, yes, they have told the family but the family said no, you're not. So there was a huge conflict. And as I said, in the end, the patient passed away. But number one, not on my shift. Number two, the family was given more time because they were waiting for people to come in from overseas brothers and sisters and whatnot. You know, as I said, from from a nursing perspective, or even from anybody's perspective, it's about a holistic picture. And the holistic picture is the family as well.

Bill 21:38
So it's a holistic approach that we're talking about here. So I really appreciate what you said, you what you're interested in is not necessarily when the patient is going to pass or survive, but obviously we want the patient to survive if it's possible, but if it's not possible, what we want to do is provide enough time for loved ones, enough time for the family to be able to gather and make the decision in their own way. Now, the challenge with that, though, Patrick is a doctor. And I'm not a doctor, but maybe the doctors thinking. But if we don't make a bed available, there's another person that can't come into intensive care. And as a result, that person may not make it.

Patrik 22:25
That is correct. And, look, I'm well aware of the pressures in intensive care. I have managed two intensive care units when I worked in hospitals, so I was responsible for ICU beds. For the staff. I'm well aware of the pressures, right. But that was also one of the reasons why I didn't want to work as a manager anymore, because I just felt this is not why I went into nursing. I went into nursing to provide care to a patient and to a family.

Patrik 22:58
And that to me includes you know, providing end of life care that includes the family in decision making. And it includes, you know, the cultural, the spiritual. The you know, the history of a patient. It includes so much. And, that's where I believe, yes, I'm well aware of the pressures and but at the end of the day, this is a life. And on the end, what's also playing into that, as well as there are a number of patients in intensive care, not the example that I've given you.

Patrik 23:40
But there are patients in intensive care where life support gets stopped or withdrawn prematurely. And I argue, well, if you continue to treat this patient, maybe they would have survived. To illustrate that with some numbers. More than 90% of intensive care patients leave intensive care alive okay, so the vast majority of patients in intensive care survive. So, again, I have been exposed and been part of hundreds of end of life situations. I'm not disputing the fact that patients are dying, not at all. But there are ways how to provide end of life care. And we are providing palliative care at home with intensive care at home for people on life support. And, again, that's not for everyone, but people need to be given an option.

Bill 24:25
Yeah. Okay. Let's talk about that. Tell me how does somebody transition from intensive care in the hospital to intensive care at home? How does that process happen? And now is it readily available in Australia?

Patrik 24:40
Yeah. So let's just quickly talk about what's the category if you will, you know, so I talked earlier about trauma ICU, I talked about general ICU I talked about cardiac ICU, pediatrics. I almost believe we are carving out the fifth option with intensive care at home. Right? Who can go home? It's patients who need life support, but who are medically stable. Okay, what does that mean? It means they have medical issues that need to be managed with life support mainly ventilation.

Patrik 25:19
But other things like (inaudible) drops for example, they have a stable blood pressure most of the time. Okay. And it, it doesn't really some pages that go home and life support our conscious, some are unconscious, but most of them would be conscious. And how do they transition and Is it readily available? Look, when I first started out with intensive care at home, which was basically myself going into a person's home on life support. That's how I started and as the demand grew I hired staff.

Bill 25:51
Going into the home of a person who's on life support. How did they come out of the hospital who made the decision to send them home on life support. And yeah, and when I'm thinking of life support, are we talking to that patient? Is a patient responding or are they just going down?

Patrik 26:08
Yeah, very good question. It really depends. You know, take this example, you know, the very first client that we work with in the home where I started with doing some shifts there was a guy in his mid 30s. He was his quadriplegic, his C1 spinal injury. And that happened at his age of six, he was in an accident, okay. And that was in the early 1980s. Now, this guy in particular can talk, you know, is fully compos mentis.

Patrik 26:39
And the stories he's telling me are not dissimilar to my stories that I experienced

in intensive care in intensive care if it hadn't been for his parents, they would have stopped life support. Right. So it was the parents at the time who said, No, you're not going to stop life support. We want our child to live. And they took their own responsibility then. To take him home services, right? But you know, the reality is, there is a market for intensive care at home.

Patrik 27:12
And that market would even be bigger if people in intensive care thought there is a perceived alternative for somebody on life support that they think is not getting any better. Right? Again, I'm not disputing that some patients don't want to go home on life support that's fine, but people need to be given a choice.

Bill 27:28
Yeah. Okay. So now we have the option where, you know, hospital, if the hospital makes a decision, like, we're going to stop life support. Is it something that a patient, family carers, etc, can request not to stop it and transfer to life support at home?

Patrik 27:46
Yeah, that's a very good question. That's one thing we're trying to achieve with intensive care hotline as well as intensive care at home. We're trying to educate people constantly on their rights. Okay, so we're both in Melbourne and Victoria, you know, and states differ with their laws and regulation. And with my intensity hotline I do (inaudible) is all over the world.

Patrik 28:10
So I have a very good idea especially what's happening in the US in the UK as well as Australia in terms of you know, people's rights and so forth. And in Victoria, for example, because we're both in Melbourne, the law at the moment it's not crystal clear, but at the moment, it's slightly in favor for hospital or doctor that they can make a decision. However, the law is changing as early as March next year, March 2018.

Patrik 28:36
The law in Victoria is changing and life support cannot be removed without consent of either a patient or their medical power of attorney. Okay, so this will be huge. And the medical profession I know already, they won't like that, because that's how they manage their ICU beds, quite frankly, or how they manage some

of the ICU bed whereas I see it, you know, from my perspective, I see it as a huge step, people will have more choice.

Patrik 29:09
And people will also demand will be more demanding about having options like intensive care at home. And we're doing that already, you know, with intensive hotline (inaudible) put pressure on the system, right. And we have clients here in Melbourne that say that hire us for consulting in intensive care. And they go back to the ICU and they say to the doctors, hey, if my mom or my dad can't come off the ventilator, we want intensive care at home.

Bill 29:37
Okay, so that does achieve the job of freeing up a bit. That allows the hospital to have the bed free for another patient coming in, great. And that allows that person to be cared for at home so that people don't have to travel to hospital, pay for parking. Do all the stuff that's associated with being in a hospital which is really difficult for people and, when that person is at home, who is funding that person?

Patrik 30:06
Yeah, very good question, Bill. We have a variety of funding sources. And I don't want to really publicly disclose that. But you know, we get funding through, let's just call it insurance companies. We also get government funding and we get funding through hospitals directly. Okay. But it took a long time. Right. It went from this guy's crazy to we're now getting funding and we're providing intensive care at home and we've done enough work to prove the concept.

Bill 30:41
Yeah. So the concept was up and running in other countries, though, wasn't it?

Patrik 30:47
That's right. That's right. But as you know, some people might feel you know, if I haven't invented it sort of, it doesn't exist, right. And I had even people you know, when I first went out to hospitals, And tried to market the service I had some people tell me don't waste your time you're not in Europe. Right? And I just went like okay, well that's what you think but just because you you think I should be giving up? I'm not

Bill 31:17

So tell me from the perspective of your fellow nurses How are they talking about this service walking? How do they sort of respond to this type of service?

Patrik 31:31
Yeah, look my when I you know, when I started this, I was still working in ICU because I needed an income. Right? So I was still working ICU full time trying to get this off the ground. And you know, I'm sort of most people thought it was crazy and this guy's crazy just thinks, you know, he can do something that nobody has done before. And you know, just yeah, this guy is just a bit nuts and you know, just doesn't really matter what other people thought.

Patrik 31:59
Obviously now that we are operating, I hire ICU nurses. And I do believe that I attract a certain kind of ICU nurse that is really passionate about this area of work. And I can describe that ICU nurse to you. Because I'm telling my best ICU nurses that I have now in my business are an ICU nurse was working in ICU for more than 20 years.

Patrik 32:24
They are frustrated by the system. They have been bullied. And they don't feel appreciated in a public or in a private hospital. And they want to use their skills that they've learned over decades to make a difference to a patient to a family in a much more friendly environment. They are my best performers. They get it and they don't want to go back into hospital they know we have to make it work.

Bill 32:49
So what are some of the feedback that you're getting from carers families, friends.

Patrik 32:59
Families you know, they say good things about us because we get referrals through families. Okay, that's, you know, word of mouth.

Bill 33:09
How's it changing their minds. How's it making their lives better?

Patrik 33:12
Yeah. So I give you an example. Okay? So if you have somebody at home and life support, and you have no one to look after your child, your spouse, whoever the

person might be, and basically, their life stops completely, they often can't produce an income. Right? They are awake at night.

Patrik 33:35
Because they care for a loved one on life support, right or, in another instance, they're still in ICU. Night in ICU pay for parking travel, depending on where they are. Right. So the impact is huge. But you also mentioned earlier and I want to hone in on that very briefly too you mentioned earlier, it's freeing up the ICU bed it's not only doing that it's costing half of the money. So an ICU bed is, five to $6,000 per bed day. 24 hours in ICU costs around five to $6,000. So we do intensive care at home for less than 50% of the cost. So it's a win win.

Bill 34:27
Wow, so all of the equipment that's necessary to sustain life keeps somebody going all the things that you do in a hospital, is it just the same equipment? Is it just as good at home as it is?

Patrik 34:38
Look, it might be some people might think, Oh, it's not quite as fancy as in the hospital, but it's definitely doing the job. It's definitely keeping people alive. You know, and I refer to this to our very first patient, you know, that we had for intensive care at home, on life support for 30 plus years.

Bill 35:00
Wow. That's amazing.

Patrik 35:04
So it is amazing. So technology is one side of things. And it's important but people's mindset. People's will to leave people making arrangements to make it happen is way more important or it's 50% of the equation, if you will.

Bill 35:18
Yeah. Well, that's pretty amazing. So, is there a 24 hour seven day a week nurse in shifts attending that person with intensive care at home?

Patrik 35:29
Yeah, we have provided 24 hour care. I'll tell you, I'll give you a real case study at the moment. We were looking after a toddler at home on life support and 20 month old toddler, and we're dealing with the authorities and the authorities

threaten us as a service provider to take funding away for you know, they think it's too expensive, blah, blah, blah.

Patrik 35:53
And, you know, we were almost fighting daily battles to maintain the funding and basically an end at the end, keep the toddler alive. Right. So there are many people out there in this world who would like to see us go out of business rather sooner than later. I know that. And that's including some government authorities, you know, because we are I believe we are revolutionising the space, we are challenging the space. And, you know, we move heaven and earth to advocate for our patients and for our families.

Bill 36:25
Yeah, it sounds like for the first time, maybe a long time, the people that caring, or and the families have got somebody on their side really doing a task that somebody is going to do, but often the carriers and the families don't know to do it and don't know how to do it. Right. Is it possible is it It sounds like it's possible for people to come off of life support too soon, but is it possible to leave people on my support too long?

Patrik 36:57
At definitely, yes, definitely. Yes. I have seen that too, right? where people were suffering because they were on life support too long. And nowhere probably life support should have switched off. But you see, one of the biggest problems that I can see is even though intensive care professionals are exposed to death and dying on a day by day basis, I do believe they are very poor communicators when it comes to it.

Patrik 37:26
Okay, one part of my business especially with intensive care hotline, I do a lot of bereavement counseling. Okay, I do believe I have the skill to help people in end of life situations to come to terms with it, if it's inevitable, right, because I've seen it many times. So yes, the answer to your question, definitely, yes, there are patients who are on life support for too long, especially if they're suffering and end of life is inevitable. Okay, that that's definitely happening too. But I do believe the number of people that where life support is stopped prematurely is higher.

Bill 38:04

Fair enough. Well, in my community in a stroke community, I imagine a lot of people that are listening, who knows somebody who's had a stroke or they've experienced a stroke, or who are caring for somebody who experienced a stroke, that their loved one would have gone. Very likely a lot of people experiencing stroke would have gone through an intensive care period of time in intensive care.

Bill 38:29
What can we advise people to do to make sure that they're getting the best result for the patient, their loved one, their family member? While they are in intensive care process? What can we advise them to do how do they go about managing their process?

Patrik 38:49
Yeah, fantastic question. So when patients get admitted to intensive care, and they're really critically ill You know, I'm not talking About an overnight stay, you know, some patients go into intensive care just for a night for monitoring, they're not on life support. It's just maybe you know, what might be referred to as a medical emergency.

Patrik 39:09
I'm not talking about those patients, I'm really talking about a critically ill patient that's fighting for their lives. That's the example that I'm trying to illustrate. And let's take a stroke patient, because I know you're a stroke survivor and your community of listeners will be very interested in this topic. But coming into intensive care with a stroke, they come into intensive care, they stop breathing during the stroke, they need mechanical ventilation, they have had a CAT scan, right, a CT scan, they might have had an MRI scan, you know, it shows some brain damage, you know, and patients now alive support. And it's not, quote unquote, wakin up.

Patrik 39:58
And if you're listeners either have been in intensive care or have a family member in intensive care that with our intensive care hotline and the number one question we get is how long does it take to wake up after induced coma? That's the number one question we get. Okay, the answer to that question is it depends and it can take weeks. Okay, so now you're coming into intensive care with a stroke. So you have some neurological damage, and you are induced into a coma.

Patrik 40:31
And people ask, Well, how long does it take to wake up after a stroke? And the answer is, it depends. Okay, so after three or four days in intensive care, the ICU is getting nervous, you know, patient with stroke is not waking up unstable. The worst case scenario for an intensive care unit is to look after a patient indefinitely with an uncertain outcome. That's the worst case scenario for an intensive care unit.

Patrik 40:57
Okay, so after three or four days treatment, nothing's happening, you know, not moving forward not moving backwards, maybe the patient's getting infection now because of ventilation. So the families off, then get pulled into what's called a family meeting and they get told look, your mom's not waking up, your dad's not waking up, they had a severe stroke. MRI looks pretty bad CT scan is looking pretty bad.

Patrik 41:20
We think it's, quote unquote, in the best interest to stop life support because your family member won't have any quality of life in the future. You know, and that's after three or four days, the ICU was under pressure, they need the bed. They don't want to look after patients indefinitely with an uncertain outcome. So my advice to families in such a situation is communicate to the intensive care team what they want, and not back off from that because otherwise they will walk all over them. I know I'm speaking harsh words here, but that's just what I've seen.

Bill 41:52
Okay, so as a patient carer a family member, loved one, we've got the right to say this is what I want. You have to comply to what I want. And under those conditions, can the hospital make the alternative decision? After three or four days? Can I say, Well, sorry we don't agree with you, we're going to switch it off. Can they do that?

Patrik 42:16
They could, in theory, but it happens rarely, especially if families are doing their own research. And, you know, they, are prepared to move heaven and earth to not let it happen and more families are heading that way that you know, they are getting more assertive. They're doing their own research, you know, so, yes, the law in Victoria is still in slight favor of the of the hospitals, but at the end of the

day, the last thing a hospital wants is to get sued or get into the papers, you know, and as you know, Bill, everything in life is negotiable.

Patrik 42:50
I'm a big believer in that. So, and what I also refer to, I have a blog post on my website. That's know a lot of people read and the title is something like Is your last one in intensive care in a real or in a perceived end of life situation right a real end of life situation is nothing can stop your loved one from from dying in intensive care there's no life saving device no surgery no drug that can save your loved one from dying real end of life situation.

Patrik 43:26
A perceived end of life situation is where the ICU team says to you as a family member or to a patient even if they're awake. Look, we think it's quote unquote in your best interest to let you die. Okay, that is a perceived in the flesh situation. Right? It's it's a perception of a doctor maybe where we think you don't have any quality of life and therefore you should die. What's the quality? What is quality of life is it's a subjective experience. Anybody to judge?

Bill 43:54
Yeah, I see what you're saying. So there are different opportunities for a doctor to make a decision. Because there's no other alternative outcome, that's it, a patient's going to pass. There's no other outcome, we can even ask for a little bit of time to be with their patient for a little bit longer, just to make us feel a little bit better so we can get the family around, we can do all that stuff.

Bill 44:15
We can accept it in our own way. And we can enable the process to take place to occur, right. But in a situation where you feel like it's just a difference of opinion. Sure, it's an opinion of a doctor, a well educated doctor, somebody who knows a lot of things about the challenges that the patient might be dealing with. Still, we have the opportunity to say hang on a second. Now we want to question with all due respect, your opinion, we have a different opinion and we want more time and we will also want to take up the opportunity or consider the possibility of doing an at home Intensive Care Program.

Patrik 44:55
Correct. It's really all about giving people choice.

Bill 44:59
So this is topic that this interview has been a little bit heavy. I feel like it's been a little bit heavy because we're talking about a serious situation. Yeah.

Patrik 45:08
Yeah. Yeah. You see, it's interesting for you, it's heavy for me, it's bread and butter. Yeah. You know, it desensitize to a degree. You know, but not desensitized to not care. You know, it's just, I, how can I How can I, you know, people say you asked earlier how friends respond, you know, a family or whatever. And, you know, a fish efficient water doesn't know what water is, right? And I feel like when I go into intensive care, it's like, well, it's what I do. Yeah, I get it. You know, I have my own opinion about it. And if some people might think, Oh, it's a really strong opinion about it, but I could ever imagine doing something different I could never imagine I'm drawn to this like a flight to the to the light, you know,

Bill 45:52
that's really great that you're doing and it's really great that you have a different opinion and then you've had the courage to share that and to make a difference. Because without somebody taking a different approach, nothing will ever be invented without somebody bucking the trend or, you know, challenging people, nothing would ever happen. So I'm glad that you've done it. And I think you've done any one of the best parts of the medical system that you could possibly do that which is at that moment where a loved one's about to lose a loved one. There was somebody is about to lose a loved one. I mean, that's really important that somebody has an advocate somebody by their side and is able to support them with loved ones and people that are going through a tough time of people that are suffering hospital, probably not in the right frame of mind to make decisions correctly here.

Patrik 46:42
They're not they're running high on emotions, the you know, they don't know what they don't know. They don't know what to look for. Right. And you know, they're not in the right frame of mind to make a rational decision. And how could you How could you, no matter How prepared you are, you aren't.

Bill 47:04
You wouldn't want anyone to be prepared for something like that. That means that gone through it too many times.

Patrik 47:09
That's right. That's exactly right. You know? And the other thing Yes. Now Now I've now I remember what I want you to say, which I think is really important for for our listeners. So I mentioned to you earlier 90% of patients in intensive care survive intensive care, okay. And especially when it comes to end of life situations, discussions around withdrawal of treatment, stopping life support, and all of that, right.

Patrik 47:33
One thing that I one thing where I believe intensive care professionals are falling short, including myself, is we don't know what a patient's life looks like when they leave intensive care. We don't know what their life looks like in six months time, in 12 months time in five years time. We have no idea and a lot of doctors in particular claim while this patient won't have any quality of life, how do you know how do you know what a patients in a coma would want as quality of life, you can't even ask them.

Bill 48:04
That's a big assumption that they make. I know that something similar happens in rehabilitation, right? So in rehab when people go in and they are 75 years old, often they get the bare minimum amount of rehabilitation because they're considered too old and considered them to be at the end of their life. And it's a resource that maybe we should allocate to somebody who is more likely to be useful to the community. Which is just crazy. It's crazy. If it was your loved one, and you're making a decision on them. You wouldn't take away rehabilitation or any service, you would offer them every possibility so that you could spend time with your loved one or they could get better and be whoever they need to be. or pass away with the dignity that the family chooses.

Patrik 48:54
Correct? Correct. And also talking about dignity about end of life. There is another big aspect of surveys in Australia as well as in other first world countries have shown that 75% of people would want to die at home if given the option. And yet, less than 15% actually do die at home. That's one, five. So I believe it's about 50% of the population currently dies in hospitals, you know, and I know from nearly working in hospitals for 20 years, they use the one size fits all approach. Right? And again, I believe this just individuality is needed at the end of life as well.

Bill 49:34
I think so, too. Let's end this on a positive note. Tell me about an amazing story of somebody that came into intensive care, and just walked out of the hospital jumping up and down and being amazing.

Patrik 49:46
Yeah, I tell you a story. So it was in my early days in intensive care. We looked after a young man he would have been late 20s. He was a carpenter. And you know, Odyssey VX and again, he fell off a roof or fell off a scaffolding or Condren, I fell off something hit his head head really badly. Had a massive head injury and you know, he was going to multi organ failure.

Patrik 50:14
Remember, we were really fighting for his life for weeks. He was on kidney dialysis, his kidneys were failing. And, you know, after many weeks of intensive care, and he he left intensive care, right. And, you know, went out of ICU but probably wasn't conscious at that stage. And then about six months later, you know, he comes back to ICU as a visitor and says, Hey, I'm such and such. I don't remember anything. But I do want to thank you for saving my life. And you never forget that. You never, never, never.

Bill 50:52
Yeah, beautiful story, man. That's a great way to end the podcast. Before we go. Where can somebody find you if they need to get In Touch if they?

Patrik 51:01
Yeah, so take out. Yeah, thank you check out the intensive care@home.com or check out intensive care hotline.com. And you can always send an email to support at intensive care. hotline.com.

Bill 51:15
Excellent. Patrick, I am so grateful that we got the opportunity to meet each other and have an opportunity to chat. I'm sure we'll have a lot of discussions in the future. And I also have a feeling that unfortunately, I'll probably be ringing you to say, look, I had somebody who needs some advice in this situation.

Patrik 51:36
Probably not. Me. Yeah,

Bill 51:38
hopefully not. But I'm glad that you're there if that ever happens for anyone in my community. Thanks so much. Again, I really look forward to just keeping in touch and just I really support you. I hope that everything that you're aspiring to achieve with the service and the you know, and the way that you want to go about people having options and carrying out that comes to fruition and occurs in exactly the way that you envisage. I think it's a great vision.

Patrik 52:05
Thank you so much, Bill.

Bill 52:07
Well, I hope you enjoyed the episode. Thanks again for listening, and was another very interesting topic. I think the more information we can give to people about what's really, you know, how we can go about supporting our loved ones who experienced a stroke, I think the better the outcome will be, regardless of how serious somebody has a stroke. In the event that you meet somebody or come across somebody that is facing a serious challenge.

Bill 52:36
With regards to intensive care and removal of life support systems by a hospital or by a team of doctors. Well, then I think that could be a very important episode for them to listen to. So they can get a better understanding of how how much authority they have and how much of an influence they can have in the outcome. Their loved one. I really like the fact that now, in a lot of countries, especially in Australia, and in Europe, it's possible to have my, you know, to have intensive care at home. And it's a matter of requesting that from your doctors, and it's a matter of requesting it from the hospital.

Bill 53:19
But also, isn't it really great to know that it's potentially something you can speak to your insurance company about now, so that you can be covered for events such as Intensive Care Services at home on your policy, just in case the worst happens. Now, I'm all for empowering people, as I said earlier, and hopefully what this episode does is empower people to feel comfortable about making some really serious decisions in their life about people that they love.

Bill 53:50

Now, if you or someone you care about has experienced a stroke and has started the recovery, you'll know what a scary and confusing time it can be. There are all these questions Probably going through your mind, like how long will it take for me to recover? Will I actually recover? What things should I avoid in case I make matters worse, my doctors and therapists were always helpful in explaining things. But obviously, because I've never had a stroke before, I didn't know what questions to ask. And so I worried a lot and missed out on doing things that could have sped up my recovery.

Bill 54:23
So if you're finding yourself in that situation, stop worrying, and head to the transatlantic podcast calm, where you can download a guide that will help you. It's called seven questions to ask your doctor after a stroke. These seven questions are the ones I wish I had asked when I experienced my stroke because they not only helped me better understand my condition. They also helped me take a more active role in my recovery, rather than just waiting to be told what to do at my next appointment. So head over to the website now. The transit lounge podcast.com and download the guide. It's free. Thanks once again for listening to another episode of the podcast or Wish you a speedy recovery.

Intro 55:13
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