INTENSIVE CARE HOTLINE

Helping Families of critically ill Patients in Intensive Care improving their lives instantly so that they can exercise power, influence decision making and stay in control of their and their critically ill loved ones destiny

7 questions you need to ask the most senior doctor, most senior physician or most senior consultant in Intensive Care if your loved one is critically ill in Intensive Care.

You'll also get one bonus question at the end of the report.

Ok, welcome to another free report in INTENSIVECAREHOTLINE.COM's free report series. And once again, congratulations on taking action in getting informed and taking control!

Just by doing that you stand out from the rest of the Families in Intensive Care and it will give you an edge when dealing with the challenges, difficulties and complexities in Intensive Care. Our report/ video series will help you finding **your voice** in the jungle of complexities surrounding Intensive Care.

In this very important report, you'll learn quickly what 6 questions you need to ask your most senior doctor, most senior physician or most senior Consultant in the Intensive Care Unit so that you are able to

- Influence decision making and have power in the situation quickly
- Have more control and more negotiation power
- Position yourself well mentally
- let the doctor know that even though you are not a health professional, you have a good understanding of what is happening "behind the scenes" and that you speak the **secret** "Intensive Care language"

Try and stand out from the crowd

If you ask the questions outlined in this report, you'll immediately stand out from the "crowd" and you'll immediately distinguish yourself from the rest of the Families in Intensive Care. Just by asking the right questions, you'll find that you can shift dynamics immediately. You will find that doctors and nurses look at you differently than they do with other Families of critically ill people in Intensive Care. It puts you and your Family in a different light and you see immediate results.

The report is designed and structured for Families who deal with a very serious admission of their critically ill loved one to Intensive Care where your critically ill loved one is

- either very critically ill, very unstable and where the recovery and the future of your critically ill loved one is unknown
- expected to stay in Intensive Care for a long period of time with a long and slow recovery
- in an end of life situation and where you might have been told that your critically ill loved one is going to die or where the situation of your critically ill loved one is very dire and the survival and recovery of your critically ill loved one is uncertain
- The report might be less useful for Families who have a critically ill loved one in Intensive Care who is a "straight-forward admission" and therefore is expected to go to the ward in a short time span

ICU doctors are notoriously time poor, but you can have power, control and influence if you know what to do

You probably know that doctors are busy people and usually in a busy Intensive Care Unit doctors are notoriously time poor. Therefore you need to be prepared and you need to know succinct questions to ask in order to have the most influence, the most control and power in your, your Family's and in your critically ill loved ones challenging situation.

So, by now you have probably discovered that you are not in control of your destiny unless you learn techniques, strategies and get "behind the scenes"

insight that will ultimately leverage your level of control power and influence! You need to learn the **secret** "Intensive Care language", so to speak.

If you have read my previous **FREE "INSTANT IMPACT"** Report, you already have a good feel and good understanding about what is really happening in Intensive Care and how you can effectively deal with and influence the situation quickly- If you haven't read your **FREE "INSTANT IMPACT"** Report, I strongly recommend you read it as you'll gain a lot of insight that will further help you to manage your challenging situation effectively. You can get your **FREE "INSTANT IMPACT"** Report by downloading it from our website here www.INTENSIVECAREHOTLINE.COM

Let's get to the 'meat' of it all

I want to give you a couple of basic principles before we get to the "meat" of the report. As you have probably read and learned in your "**INSTANT IMPACT**" Report, it is critically important that you do not "suck up" to a doctor and that you do not put them on a "pedestal". As you remember, I suggest you treat them as your friend.

With this in mind, let's get to the "meat" of the report so that we can dive right into the questions you need to ask the most senior doctor, the most senior physician or the most senior consultant in Intensive Care, if your loved one is critically ill in Intensive Care.

I have to warn you, some of these questions you might think are confrontational, but you need to ask them anyway. If you don't ask the right questions, other people will continue driving the bus and you don't know in which direction they will be driving the bus. Because you want to be and you need to be in control of your, your Families and of your critically ill loved ones destiny, you need to ask those questions, period!

1. **How does the Intensive Care Units budget impact on my critically ill loved ones stay in Intensive Care?**

As you might know by now, every Intensive Care Unit is generally allocated an annual budget. In public hospitals, it's usually a set figure for a financial or for a

calendar year, whereas in a private hospital it's more like a revenue target, as the funding is more like a "reverse" funding model, where money comes in through activity. The annual budget depends on a number of things, including expected number of admissions, acuity of admissions, staffing, research activities and so forth.

On average you can expect an ICU bed to cost $ 4,000- $ 5,000 per day. This number varies slightly in different countries, but certainly holds true in countries such as the USA, Canada and Australia as of 2013.

Applying those numbers to your critically ill loved ones situation

In order to apply those numbers to your and to your critically ill loved ones situation, you need to know another thing before we come to the "meat" of this question. You must know that Intensive Care beds tend to be scarce resources and they tend to be in high demand. I have rarely seen beds empty in Intensive Care. There is usually a high turnover of Patients, even more so during winter times, but even in summer there is a high demand on ICU beds, with lots of outside activities happening, causing accidents (biking, cycling, swimming etc…). We are also living in times where we have a growing ageing population and more and more old people get admitted to Intensive Care.

This is the "bigger picture" overview and in order to apply this question that you need to ask the most senior doctor in the Intensive Care Unit to your and your critically ill loved ones situation, I'll give you a quick real world example so that you understand the connection, between the ICU budget and your critically ill loved ones admission to Intensive Care.

Does my critically ill loved ones treatment eat into the ICU's budget?

Let's say your critically ill loved one is 76 years of age and just had an "out of hospital cardiac arrest" after a severe heart attack. Your loved one has been admitted to Intensive Care and is now at the point where he or she is on full life support including mechanical ventilation. The doctors and the nurses have

been telling you that your critically ill loved one has a poor prognosis and that he or she may well die. The Intensive Care team is telling you and your Family that they could escalate treatment and that the outcome would be uncertain and they think that if your critically ill loved one survives that he or she wouldn't have any "Quality of life" anyway.

Now, Patients in Intensive Care are different and even people who have similar clinical pictures (diagnosis), react and respond differently to treatment and if you have read through my previous free reports you will have found that unexpected things happen in Intensive Care, as Intensive care tends to be a highly volatile environment. These unexpected things can be good or bad.

Now, in our example, your critically ill loved ones recovery may take quite some time(many days to many weeks) and therefore it would eat into the Intensive Care Units budget. If the Intensive Care team decided to escalate treatment, it could mean to use an Intra-aortic balloon pump or it could mean to use expensive drugs such as Levosimendan to improve heart failure. Without going into too much detail, all I want you to understand at this point in time is that prolonging treatment with an uncertain outcome is going to impact on the ICU's budget and resources.

Let's also say that in another bed space in Intensive Care is another 22 year old Patient, who after a severe car accident has had multiple fractured bones and he also had a severe head injury. He also has developed lung failure and he is now on special ventilation for lung failure. The Intensive Care stay for this young man currently costs $ 7,000 per day as treatment is more advanced and therefore more expensive.

Is asking the right questions helping my critically ill loved one?

The prognosis for this young Patient is poor as well, but given the Patients young age and also given the determination of the Patient's family "to do whatever it takes", the Intensive Care team has continued to carry on treatment. The Intensive Care team has also realised that the 22 year old Patient's Family has good insight about what is happening in Intensive Care

and the Family has certainly asked all the right questions in regards to their loved one's prognosis, expected future Quality of Life and they have also asked about how the costs for their critically ill loved one's treatment might impact on the Intensive Care team's decisions about life sustaining treatments. The Intensive Care team by now is well aware that the young Patient's Family would not accept a decision, to limit or withdraw treatment on their critically ill loved one, period.

Without going into further detail, both of those scenarios are occurring right across most Intensive Care Units most of the time in one way or another. The scenarios are interchangeable and therefore to add even more controversy, it could well mean that the 76 year old would be continued to be treated and the 22 year old would have treatment limitations.

In order for you and for your Family to have maximum power, control and influence in those challenging and difficult situations you need to have a heightened awareness of any surrounding issues or complexities that are occurring in Intensive Care all the time!

The Intensive Care team is often facing challenging and difficult moral and ethical decisions

It also means that therefore the Intensive Care team always faces huge and massive ethical and moral challenges and decisions. Therefore, it is absolutely crucial that you have a heightened awareness of these details so that, besides the clinical diagnosis, the clinical prognosis and therefore the clinical realities surrounding your loved one's admission and critical illness, you also need to understand the movements, the politics, the power dynamics, the intrigue and the Psychology around you and around your critically ill loved one so that you can ask the right questions that are addressing the issues behind your loved one's clinical picture and prognosis.

What if my critically ill loved one is in ICU at the end of a budget/ financial year?

Going back to our example, imagine your loved ones admission is at the end of a budget/ financial year and the Intensive Care Unit knows that an extended and lengthy Intensive Car stay of your critically ill loved one might well eat up the budget with the outlook of an uncertain outcome.

Do you think that the Intensive Care team might rationalise their decisions in one way or another? Do you think they might rationalise that your critically ill loved one's age and his or her prognosis might contribute to the decision making process?

Do you think that if you knew what other Patients are currently being treated in the Intensive Care Unit, you would get a better understanding why the Intensive Care team might "feel a certain way" about your critically ill loved one and their prognosis?

Do you think the Intensive Care team will continue treating the 22 year old or the 76 year old Patient? Do you think the situation could be reversed if the Family of the 76 year old was more influential and kept asking the right questions? Do you think the 76 year old would continued to be treated if the Family didn't take "no" for an answer and if they kept firing the right questions to the Intensive Care team?

Health care is about fairness, not about money and also about the level of influence you and your Family have

Now, I don't want to open up more flood gates here, but I certainly do know that these scenarios are happening all the time and I want to raise awareness and since I consider myself a strong Patient and Family advocate, I do also want fairness for all Patients in Intensive Care. Health care should never be a monetary issue and it should always be a human issue first, period!

I am not suggesting that Intensive Care Units should treat "hopeless" cases, but in order to strengthen my point and my argument, I am definitely suggesting that all due consideration needs to be given to the Families and to

the Patients treatments first and no quick decision should be made, especially when it comes to limitations of treatment or withdrawal of life support. Intensive Care Units and certain senior doctors, physicians or consultants can sometimes be quick in deciding to withdraw or limit treatment in light of financial and other reasons.

I have seen more than once that one senior doctor, physician or consultant suggests a limitation of treatment and as soon as the next senior doctor, physician or consultant walks in, that he or she turns it all around and decides to go "full steam ahead". I have seen it the other way round too. I could continue and carry on here, but I am conscious of your time because I know you want to learn the things that are essential quickly.

2. **How do differing views and differing outlooks between the Intensive Care Unit's medical team and the "parent medical team" impact on my critically ill loved ones prognosis and recovery?** (the "parent medical team" is the team that covers your critically ill loved one from a non-Intensive Care point of view, i.e. the trauma team, the surgical team, the neurosurgical team, the general medical team, the oncology team etc… you can also find more information on the "parent medical team in our report "**10 things doctors and nurses are talking about if your loved one is critically ill in Intensive Care when you are not present at the bedside"**, number 4 "controversial and contradicting views between the ICU medical team and the parent medical team"

What you need to know

So here is what you need to know. Most Intensive Care Units are run by senior doctors, senior physicians or senior consultants who have special training in Intensive Care and they are called "Intensivists". In some countries they might be Anaesthetists running Intensive Care Units. It doesn't really matter whether the senior doctors in charge of Intensive Care are Intensivists or Anaesthetists, but what you do need to know is that there are usually two different teams involved that are

a) The Intensive Care team and

b) The parent medical team

Who are the 'parent medical' teams?

You have probably met the Intensive Care team by now and you may have met the "parent medical team" as well. If you haven't met the parent medical team, I'll quickly explain who they are and what they do. Then I'll explain some possible dynamics to you that might impact on your critically ill loved one's care.

The parent medical team is the team that first took care of your loved one when he or she got admitted to hospital.

- If your critically ill loved one got admitted with a heart attack, chest pain, angina, heart failure or Cardiomyopathy it would be the Cardiology team
- If your critically ill loved one got admitted for open heart surgery or a lung resection it would be the Cardiac surgery or the Cardiothoracic team
- If your critically ill loved one has been admitted with head injuries, skull fractures or a brain tumour it is usually the neurosurgical team
- If your critically ill loved one got admitted with Pneumonia, Asthma, COPD it would be the respiratory team
- If your critically ill loved one got admitted for a bowel resection, gall bladder removal it is usually the general surgical team
- If your critically ill loved one got admitted with a stroke it is usually the neurology team
- If your critically ill loved one got admitted with cancer it is usually the oncology or haematology team

Who is responsible and who is making decisions?

I am sure you get the gist and you now understand that most Patients in Intensive Care have two medical teams looking after them. The main

distinction really is that the Intensive Care team is looking after your critically ill loved one during their stay in Intensive Care and the parent team "manages" your loved one's care before and after Intensive Care. Before Intensive Care, meaning operating room or theatre, on the hospital ward, in the emergency room etc…

Generally speaking, the Intensive Care team is responsible for your critically ill loved one's stay and treatment in Intensive Care, keeps the parent team informed, but as a rule of thumb, doesn't want the parent team to get too heavily involved in your loved one's care, while in Intensive Care. There is of course always the exception to the rule…

An example from the real world

I, once again, give you a vivid example so that you understand how differing views and differing outlooks about your critically ill loved one might impact on his or her care and what you need to know about it and more importantly what you can do about it.

In the example that I want to give you, imagine your 64 year old father has been admitted to Intensive Care after the resection of a brain tumour. The neurosurgical team operated on him and they send him to Intensive Care as a precaution. Your 64 year old father has been diagnosed with a brain tumour 2 years ago and he already had the first tumour removed 12 months ago and now the tumour has come back, despite him having had chemotherapy and radiotherapy.

Your father has come back to Intensive Care and he still requires mechanical ventilation, sedation and is therefore in an induced coma. The Intensive Care team and the neurosurgical team are very optimistic that your father will be off the ventilator quickly and that he can leave Intensive Care in the next couple of days. After the Intensive Care team has decided to 'wake up' your father, get him out of the induced coma and take him off the ventilator, he doesn't show any signs of improvement and he doesn't seem to wake up, despite all the sedation and pain medication being taken away.

Your father isn't waking up, but…

After your Father has been taken off the sedation, he hasn't woken up and it is therefore not safe to take him off the ventilator. The Intensive Care team informs the neurosurgical team and they decide to take your father for an urgent CT(x-ray) of his brain to find out what is happening.

After your father had the CT of his brain, the doctors tell you that they couldn't find any clues in the CT as to why your father has not woken up. The neurosurgical team has told you that they believe that they have removed the whole tumour and they did not have to cut into any other brain tissue that could have potentially damaged your father's brain.

Anything related to the brain and to the head from my experience can turn out to be a waiting game, as the brain is the only organ mankind is still unable to control. Despite modern technology and CT's and MRI's, the brain still remains a mystery.

Does the Intensive Care team want to limit treatment?

Your 64 your old father is now completely off sedation and he is still not waking up. No sign of him opening his eyes, moving his arms or feet, the only thing he is doing his breathing with the assistance of the ventilator. After about another week of your father staying in Intensive Care, he still isn't waking up, even though he is now moving his arms and legs gently, but they are not purposeful movements. The Intensive Care team gets impatient and is thinking, what they need to do as next steps? They can't take him off the ventilator as they are unable to assess whether his cough would be strong enough to maintain a safe airway. If he continues to be ventilated, they would have to perform a Tracheostomy and the Intensive Care team questions whether that would be the right approach if your father isn't going to wake up. The Intensive Care team is therefore thinking about limiting or withdrawing treatment.

The neurosurgical team wants something else…

The neurosurgical team has a totally different point of view. They think and they know that sometimes Patients after brain surgery simply just don't wake up and they are taking their own time. It is similar with head injuries and/or skull fractures. Those injuries take time and Patients wake up in their own time, if given the time. Some Intensive Care Units from my perspective are prematurely withdrawing or limiting treatments on Patients with head injuries or brain tumours. They simply don't want to invest the time, energy and resources a Patient needs to recover.

Going back to our example, the Intensive Care team wants to discuss further treatment options of your 64 year old father with the neurosurgical team, as the Intensive Care team thinks that since your father hasn't woken up as yet and is not showing any signs of improvement that a limitation of treatment and a withdrawal of treatment would be the way to go. They also mention that further treatment would be "futile".

Differing views and what to do about it

In contrast to the Intensive Care team's point of view, is the neurosurgical team's point of view who wants to wait, wants to give your father more time and they want the Intensive Care team to perform a Tracheostomy so that your father is given enough time and a fair chance to recover. The Intensive Care team thinks that given that there are no signs of real progress a Tracheostomy would not be warranted and would be a 'waste'.

Both teams have decided to speak to you and your family independently and you would then need to make your views heard and clearly state what you want and what you believe is in the best interest of your father. It is often that the Intensive Care team has more decision making power compared to the parent medical team in those situations, but of course it depends. It is also extremely important that you and your Family know what you want for your critically ill loved one in this situation. What would your father want in this particular situation?

If you feel like you and your Family are getting pushed towards a 'withdrawal' or limitation of treatment don't take 'no' for an answer and don't let people get you to sign any paperwork if you don't think it's the right course of action. You can also read two blog posts if you need more information on these areas.

"Follow this proven 5 step process on how to be in control and influential if your loved one is a long term Patient in Intensive Care or is facing treatment limitations"
http://intensivecarehotline.com/follow-proven-5-step-process-control-influential-loved-one-long-term-patient-intensive-care-facing-treatment-limitations-intensive-care/

"the 5 questions you need to ask the Intensive Care team is talking about "Futility of treatment", "withdrawal of life support" or about "withdrawal of treatment"

http://intensivecarehotline.com/5-questions-need-ask-intensive-care-team-talking-futility-treatment-withdrawal-life-support-withdrawal-trea/

The example I have just given to you should give you an understanding of what might be going on behind the scenes and how it might impact on your critically ill loved one's care.

Differing views in other specialities, too

It could be a different and yet similar scenario if your loved one gets admitted to Intensive Care after heart surgery and things are not going well and there have been issues and complications and a prolonged stay in Intensive Care maybe looming for your loved one with an uncertain outcome. There may be differing views of the Intensive Care and the cardiothoracic team.

In any situation where you think that there may be differing views and/or maybe competing interests of the different medical teams involved, just speak to the teams independently and try and get an understanding of where they stand and what you need to do, to get your voice heard. If you feel like your and your Family's voice are not heard, you need to speak up and you mustn't take "no" for an answer. Believe it or not, but making some "noise" is actually a pretty good strategy and it generally works well!

3. **How do you know or how do you expect to know how my critically ill loved one's Quality of Life is going to be after their stay in Intensive Care?**

This is a tricky question and you need to ask this question to the most senior doctor in Intensive Care anyway, because people have different views about Quality of Life. The reality also is that ICU doctors and nurses are extremely poor at judging what a Patient's perceived Quality of Life is going to be once they leave Intensive Care.

Intensive Care doctors are like fish in water and very good in ICU, but…

Why do I say this? I say this because Intensive Care health professionals are like fish in water and they live and breathe Intensive Care and they are usually very good at what they do in Intensive Care. Take them out of ICU and they are lost. They wouldn't have a clue. Intensive Care units are designed to treat critically ill people and they are very good at it. What they are not good at is to say, "Ok, your mother has been admitted to Intensive Care with multiple injuries, therefore we think and believe that in 6 months time she will have no Quality of Life or this Quality of life." It's a perception and I think it's just a whole lot of rubbish.

Intensive Care Units deal with high acuity Patients with the main goal of survival and stabilisation. As soon as a Patient leaves Intensive Care, the ICU team generally has no idea what is happening from there.

The number of people dying in Intensive Care is relatively low

Now, given that hospital mortality is around 10%(meaning 10 out of 100 hospital admissions are actually dying) and the Intensive Care mortality is around 6%(meaning 6 out of 100 ICU admissions are dying), we have no idea in Intensive Care about what is happening to Patients after they have left Intensive Care. Therefore, the Intensive Care doctors and nurses should not make too many predictions and judgements about a Patient's future "Quality of Life" and their perception of it.

Are the perceptions about the future correct?

Judgements and perceptions of Quality of Life after Intensive Care are often based on the realities in Intensive Care and because of the nature of the Intensive Care environment those views can be distorted. Furthermore, because of the lack of Quality of Life for Patients in Intensive Care, doctors and nurses often think that the severity of the critical illness might lead to a future lack of Quality of life for Patients and their Families. I have seen this over and over again. The judgement about future Quality of Life and perceived Quality of Life from an Intensive Care doctor and nursing point of view is just that. It is a perceived future. I also believe it's a very premature judgement. Whether that's true and real or not is unclear and once again, Intensive Care health

professionals tend to have no clue as to what is happening outside of Intensive Care and given that the majority of Patients who leave Intensive Care do not come back, it means that they can't do all that bad, can they?

Your view and your perceptions about the future are just as important

So you need to ask this question not only to the most senior consultant in Intensive Care, but also ask the nurses and most importantly, ask yourself, ask your Family and if your critically ill loved one in Intensive Care is conscious and can make his or her own decisions, ask him or her. Don't presume that health professionals in Intensive Care know everything or even "know what is best". They know pretty much everything in Intensive Care, but we all have blind spots and theirs is what's happening outside of Intensive Care.

What's really important for you and for your Family to know in the discussions around "perceived Quality of Life" is that often a "withdrawal of treatment", a "limitation of treatment" or a "not for resuscitation" order may be justified by the medical staff in Intensive Care, with a perceived outlook of poor Quality of Life. This from my perspective is a very limiting mindset and I personally don't think that it's good to have a limiting mindset.

Would a more abundant mindset help in such discussions about perceived Quality of Life?

How stress in Intensive Care might impact on perceptions and decision making

Intensive Care is a very challenging, volatile and often highly charged environment and therefore people working in the environment, doctors and nurses in particular, can be stressed and they can be overwhelmed by complexity, by dealing with death and by dealing with critical illness. It comes with the territory.

I do therefore think that sometimes decision making is dependent on those complexities, and just like you and your Family, health professionals in Intensive Care can be frustrated at times as well. They may have had a bad run with several deaths in the last few days. They may have had people calling in sick today, putting more pressure and a higher workload on the remaining

people. Once again, as I mentioned before, it's not all black and white in Intensive Care and your job is to always read between the lines.

Also, read our other free resources on our blog(http://intensivecarehotline.com/category/blog/), to give you a better understanding how "Quality of Life" and also perceived "Quality of life" and the discussions and the 'justifications' around it may impact on your thinking and on your judgement.

As a side note to "Quality of Life" and "perceived Quality of Life". In some countries, mainly in the USA, Canada, Australia and in some European countries like Germany, Austria and Switzerland some thoughtful Intensive Care professionals have taken the "Quality of Life" issue for long-term ventilated Adults& Children with Tracheostomy to another level and they have started to look outside of the box, by offering Intensive Home Care services for those Patients, by providing those Patients and their Families with a much better Quality of life, despite their limitations. Those models of Intensive Home Care are massively successful and provide a genuine alternative to a long-term stay in Intensive Care. Find more information at WWW.INTENSIVECAREATHOME.COM.AU

Some of our resources in particular might help you to clarify any misconceptions you may have about Quality of Life inside and outside of Intensive Care.

- **Follow this proven system to avoid the 3 most dangerous mistakes that you are making but you are unaware of, if your loved one is a critically ill Patient in Intensive Care. Avoid these mistakes and you can exercise more control and gain influence fast, in an environment where other people are in control. Get this one wrong and you'll lose control fast, during a time where your critically ill loved one and your Family need you the most!(it is hard to ask the right questions, without the 'behind the scenes' insights)**

- **Follow this proven system to avoid the 3 most dangerous mistakes you are making but you are unaware of, if your loved one is a long-**

term ventilated Patient with Tracheostomy in Intensive Care. Avoid these mistakes and you can exercise more control and gain influence fast, in an environment where other people are in control. Get this one wrong and you'll lose control fast, during a time where your critically ill loved one and your Family needs you most!(it is hard to ask the right questions, without the 'behind the scenes' insights)

- **10 things doctors and nurses are talking about if your loved one is critically ill in Intensive Care when you are not present at the bedside**

4. **How does other Patients awaiting admission to Intensive Care impact on my critically ill loved ones prognosis?**

This is an interesting question. And one you need to definitely ask your most senior doctor, most senior physician or most senior consultant in Intensive Care.

This particular question, as well as question number one "**How does the Intensive Care Units budget impact on my critically ill loved ones stay in Intensive Care?"** connect with each other.

Intensive Care Units have a high demand on beds

Intensive Care Units usually have one thing in common. They usually have a high demand on their beds and therefore a high demand on their resources. I have rarely seen that beds in Intensive Care stay empty for longer than 24-48 hours, meaning one Patient goes out and one Patient comes in. Some Intensive Care Units even have to defer admissions and direct them to other hospitals, due to a lack of resources, which may mean lack of beds or sometimes lack of staff or sometimes lack of both.

Many first world countries, including the United Kingdom and Australia have waiting lists in hospitals for elective surgery, due to a lack of resources. Some Patients on those waiting lists would require an Intensive Care bed after their surgery, which is one of the reasons why they are on a waiting list.

There is a fine line between what can be done and what is done in reality

I have touched on issues in Intensive Care regarding end- of- life, regarding Quality of life, regarding "withdrawal" or "limitation of treatment", amongst other significant ethical and moral issues and dilemmas in Intensive Care. There is often a fine line between what can be done and what is done in reality. **This fine line is very often invisible for Families of critically ill Patients in Intensive Care and is only visible to insiders and to people who know and understand Intensive Care inside out.**

One of those fine lines regarding decision making and perceptions about your critically ill loved one's prognosis, perceived future Quality of Life etc… often play out in the dynamics in Intensive Care. It might actually happen right in front of the doorstep of ICU, often in the operating theatre, in the emergency room or emergency department or even out on the road with paramedics and ambulances picking up Patients.

What if your critically ill loved one has a relatively poor prognosis and is 84 years of age? What if at the same time there are two more admissions waiting to come to Intensive Care? Could there be pressure on beds?

Pressure on ICU beds, but…

What if the Intensive Care team knows that in the next few days the pressure on beds is going to be high, due to a predicted high activity in the operating theatre or operating room?

What if the Intensive Care team knows that some of the admissions coming to Intensive Care are significantly younger than your 84 year old critically ill loved one?

You also know that your 84 year old critically ill loved one wants to live and wouldn't give up lightly…

With your previous knowledge about what you have discovered about Intensive care and the realities about it thus far, you now know and understand the implications of limited resources. With that knowledge in mind, I can't stress enough that Intensive care Units have finite resources and the allocation of those finite resources is what matters.

Clinical or hospital realities and prognosis do matter, but your knowledge, your input and your level of control matter just as much, if you are positioning yourself correctly and if you keep asking the right questions.

In order for you to have maximum input, maximum control and maximum influence in those decisions you need to have a heightened awareness what the realities are in Intensive Care and how 'decision makers' think and on what 'realities' they base their thinking and ultimately their decision making, besides the clinical realities and besides your critically loved ones prognosis.

So here is the next question you need to ask the most senior doctor in Intensive Care

5. **Is it possible that you are giving me and my Family a poor or negative prognosis for my critically ill loved one, in case things don't go well so that you can protect your professional reputation?**

Maybe you have figured this one out already. If not, or if you are unsure, let me shed more light on it.

Let's say that your critically ill loved one is 80 years of age and has just had a car accident with multiple rib fractures and multiple bone fractures, including their pelvis, but thank god, your critically ill loved one has no head injuries. Your critically ill loved one's situation is, well, very critical. Given your critically ill loved one's age and the nature of their injuries, they appear to be very frail and very slow on their way to recovery. However, given that your critically ill loved one has no head injury and no heart problems, your loved ones recovery will be slow, but he or she will recover.

Will complications and setbacks impact on the medical staffs reputation?

This doesn't necessarily mean that the Intensive Care doctor(s) will tell you so. Of course there is always a risk of complications and setbacks in Intensive Care and generally. However, there is a tendency that the Intensive Care medical team will paint a rather negative picture towards the recovery of your critically ill loved one. Some of the reasons why some of the Intensive Care doctors may have a more negative outlook I have touched on in questions #1 and questions #4. But there is of course also their professional reputation at stake, if they promise you that your critically ill loved one is going to fully recover and then isn't, you might actually hold them accountable and you might question their professional judgment, to the point where you may consider suing them.

If things go much better as predicted, even better and you might see them in a more favourable light.

Here is a quick tip. Try and ask the nurses. They are usually more than happy to give you their genuine opinion about your critically ill loved one's prognosis, for a number of reasons, including that they are probably less worried about their professional reputation and more about honesty.

6. **If my critically ill loved one is going to approach his or her end of life, in what time frame do you expect this to happen? Can we ensure that he or she has a dignified death and can he or she have a private room and a peaceful death with Family and friends around?**

So, if you and your Family are in the situation where your critically ill loved one in Intensive Care is approaching their end of life and you and your Family have accepted that this is the way it is and it is sad, but you are also certain that the Intensive Care team has done the best they could possibly do in order to save your critically ill loved one's life, your next question might be about the timing of the end of life situation for your loved one.

Negotiate the timing of your loved one's death

Depending on your critically ill loved one's circumstances and depending on how much life support he or she is getting, you should be able to negotiate the timing of the end of life situation with the Intensive Care team. The goal in those negotiations should be your and your Families/ Friends comfort and wishes, as well as your loved one's comfort and wishes, so that you had the chance to say goodbye and you also might want to ensure that certain cultural, religious or spiritual needs that are appropriate for you and for your loved one have been addressed and fulfilled before you and your Family are ready to let your loved one go.

One of the main reasons why I want to bring this to your attention, is that I have seen very unfortunate and very inconsiderate circumstances more than once, where Intensive Care Patients have approached their end of life, in less than optimal circumstances, where Families were pushed to let their loved one die at a specific time, before some important Family members or friends had arrived or before certain cultural, religious or spiritual needs had been addressed. It leaves a very bad taste for everybody involved, including the doctors and the nurses. It's almost like a cloud hanging over the Intensive Care Unit. Everybody can feel it, including other Patients and their Families.

The reasons for "pushing" Families to let their loved one die earlier than they wanted to? You guessed it. Limited resources. The Intensive Care team wanted the bed for the next Patient. Don't let the Intensive Care team push you. It's your loved one and not theirs. Do things on your terms and you are on your way to learn to do it your way!

Ask for a private room for your loved one

There are very few hard and fast rules and guidelines about end of life situations in Intensive Care, however I believe that certain issues and wishes need to be addressed in an end of life situation and if they are not openly discussed and addressed(and the reality is that they are often not openly discussed), prior to your loved one dying, you and your Family might have bad memories for the rest of your life.

You also might want to think about asking for a private room in the ICU, depending on the layout and depending on open or closed bed spaces in the Intensive Care Unit. I do strongly believe and I also know from experience that a private room tends to be better for everyone involved in the end of life situation. Imagine your loved is dying in the middle of an open unit, with very little privacy and very little dignity?

Some Intensive Care Units think ahead and offer your loved one a private room, however sometimes you need to ask for it. Don't be shy to ask. If you don't ask you don't get.

I have said this in other reports of our report series, I have been involved in many end of life situations in Intensive Care and I do strongly believe that dealing with an end of life situation is a privilege, if the situation is handled well and due consideration has been given to the Family and their loved one's needs.

If the situation is handled poorly, it leaves a bad taste in everybody's mouth. Some Intensive Care Units are very good at dealing with end of life situations, but others aren't. Therefore, it's your job to control what you can control and ask for what you think you need in your circumstances.

There are some very unfortunate circumstances where you can't "time" or plan end of life situation, but if you can, you need to do so, period.

It's in the best interest for everyone. It's bad enough that you are losing your critically ill loved one in Intensive Care and if you need to let your loved one go, make sure you remember it as a "good" death and make sure you do it on your terms as much as you can!

7. **If you and the Intensive Care team want to or suggest to "limit treatment", "withdraw treatment" or "withdraw life support" on my critically ill loved one, are there any conflicting interests that you as a senior Consultant/ Physician and/or the Intensive Care team has, because you are doing research on some Patients that meet certain criteria and you don't want to continue treatment on my critically ill**

loved one, because my critically ill loved one doesn't meet those criteria for your research paper/ research thesis?

That's an extremely powerful question to ask, because if you do ask that question, your level of power, your level of control and your level of influence will immediately skyrocket and go through the roof!

Now, the Intensive Care team and the most senior doctor or most senior consultant in Intensive Care has no interest whatsoever to let you look into the interests, the dynamics and the research that is constantly going on in a busy Intensive Care Unit.

And you must also know that Millions of Dollars go into clinical research in Intensive Care!

I have seen research that would blow your mind and yet, Universities, even Government funded Departments of Health throw money at some ICU's and Intensive Care Consultant to publish a research paper, where they conduct research at a time where your critically ill loved one is most vulnerable!

It's of massive interest for an Intensive Care Unit and for a senior Consultant/ Physician to have their name published on a research paper, because that will open other doors, including money for more research. Another benefit senior Consultants/ Physicians get is benefits from Pharmaceutical companies, because a lot of research is done with drugs and medications.

Often research will be commenced from the minute your critically ill loved one has entered Intensive Care and when you first meet the Intensive Care team, they might throw in comment along the lines of "oh, by the way, we've enrolled your critically ill loved one into this study about blood transfusions, or about ventilation or about this new drug that we are trialling", and the list could go on!

Because generally speaking you and your Family are so overwhelmed, so freaked out, stressed, challenged and out of your comfort zone that you hardly pay any attention to these sort of things. All that generally matters

to you and your Family is the well being of your critically ill loved one and somebody mentioning research hardly enters your mind.

I'll give you a couple of examples so that you know what's going on in the name of medicine and how it could impact on your critically ill loved one.

One of the research studies that I have seen that nearly blew my mind was that a Patient was ready to be taken off the ventilator and was out of the induced coma and the Family of this Patient was asked by the Intensive Care team to put their loved one back in an induced coma and then wake him up again and take him off the ventilator then. The Family was gobsmacked and they said to the Intensive Care team that they will think about it and get back to them. I was the nurse looking after this Patient and the Family asked me what I thought and I told them not to agree to putting their loved one back to an induced coma. The longer a Patient is on a ventilator, the higher the risk that they won't get off the ventilator!

Another situation I witnessed was a particularly cruel one , where a young man with a head injury was enrolled in a study for "cooling" or "hypothermia" for head injuries as the theory was that "cooling" the body and also the brain after head injuries suggested better long term outcomes.

The young man was cooled and hypothermic for about three days and on his third day, he ended up having deranged clotting of his blood. The blood was getting too thin and caused another bleed in his head, which was basically his ultimate fate and caused him to die.

Now, don't get me wrong, head injuries are challenging at the best of times, however doing research on extremely vulnerable people is from my perspective just plain wrong. The reality however is that there is a million dollar industry attached to it.

The young man's prognosis was very poor from the start, however doing research on such vulnerable people is ethically and morally extremely questionable, as far as I'm concerned.

To bring it back to the initial question that you must ask the most senior Doctor/ Consultant or Physician in Intensive Care about conflicting interests

regarding their research and a possible withdrawal or limitation of life support, know this:

If a critically ill Patient fits a certain criteria to do research on them and even though their prognosis might be poor, the Intensive Care team will most likely continue treating that Patient, allocate resources towards this Patient for the sake of the research paper and research thesis.

On the other hand, if your critically ill loved one doesn't fit the criteria for research that the Intensive Care team or the most senior Doctor/ Consultant or Physician is doing, the Intensive Care team may tell you that a "withdrawal of treatment", a "limitation of treatment" or a "withdrawal of life support" might be in the "best interest" of your critically ill loved one.

Often nothing could be further from the truth and that's why it's so important to ask the right questions that get you on the path to control, power and influence!

8. ***Bonus question*:**
   If my loved one is going to die, is there a possibility that he or she can die at home?

I do think and I do strongly believe that this is a big one. It's highly underrated. That's why I included it as a bonus question for you to consider.

In over more than 13 years Intensive Care Nursing, I have seen many critically ill Patients and nursed them at the end of their lives and once again, in most instances, it was a tremendous privilege. There aren't many 'jobs' or professions in this world who have the privilege to look after people and their Families at the end of their life. As I have said in previous free reports, I am a big believer that death is part of life and that the sooner we accept it as a fact, the better off we are as a community of people.

People want to die at home, if given a real choice

If we would be more accepting of the fact that death is part of life, we might also be more accepting of the fact that a lot of people do actually want to approach their end of life at home if given a choice, according to some recent surveys.

Now, as a Nurse in Intensive Care I have also seen numerous Families asking the doctors and the nurses in Intensive Care, whether their loved one could die at home. And in fact, one thing most of them have in common is the statement of “how much nicer would it be if our loved one could die at home?” or another common statement that I hear over and over again is just plain and simple “can’t we take our loved one home?”

Unfortunately, most Intensive Care Units do not think that this even an option as yet. Health professionals do not think outside of their clinical realms as yet. Very few Intensive Care Units actually have an extension of their services outside of Intensive Care and they also do not want to “upset” the status quo for a number of reasons. Some, but very few ICU’s that I know of, happen to offer to take Patients out of Intensive Care to their Home and let them approach their end of life in their own homes. There is no doubt about it that this can be done. People need to have the right skill set but it’s far more important that they have the right mindset.

Home equals peace of mind

Also, keeping in mind that not even 100 years ago, there were 3-4 generations all living under one roof, with baby’s being born and people dying under the same roof. It was just natural.

So if you feel like you and your Family would have more peace of mind, more control, more influence and also the wish to let your loved one die at home, why not ask? You never know. Maybe the hospital can arrange something.

Besides my work in Intensive Care, I have also worked in the community, providing specialised home Intensive Care Nursing for long-term ventilated Adults& Children with Tracheostomy and I have been involved in looking after

ventilated Adults and Children who approached their end of life at home as well. It was a good experience and I have found that Families who have a loved one approaching their end of life at home, tend to have a lot more piece of mind and control of course.

If you happen to live in Australia, there is one designated Intensive Home Care Nursing service, specialised in taking long-term ventilated Adults& Children with Tracheostomy out of Intensive Care and they also specialise on Quality of-end-of life services for ventilated Adults& Children out of Intensive Care. You can find more information on www.intensivecareathome.com.au

For more information on a variety of topics, within Intensive Care, check out more of our reports and Ebooks and also read our "**blog"** for more tips and strategies and the **"your questions answered"** section. Find the links here

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Sincerely, your friend

Patrik