INTENSIVE CARE HOTLINE

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

The 10 things you didn't know are happening BEHIND THE SCENES in Intensive Care that hold you back from having PEACE OF MIND, control, power and influence whilst your loved one is critically ill in Intensive Care

Ok, welcome to another Ebook in INTENSIVECAREHOTLINE.COM's Ebook series. And once again, congratulations for you taking action in getting informed and taking control!

Just by you getting informed, you stand out from the rest of the Families of critically ill Patients in Intensive Care and it will give you an edge when dealing with the challenges, difficulties and complexities in Intensive Care. Our Ebook series will help you to find **your voice and will show you how to have PEACE OF MIND, take control, be powerful, and influence decision making,** in the jungle of complexities surrounding Intensive Care and it will more importantly help you to have peace of mind, be in control, feel powerful and influence decision making.

In this Ebook you will discover the guide to

The 10 things you didn't know are happening BEHIND THE SCENES in Intensive Care that hold you back from having PEACE OF MIND, control, power and influence whilst your loved one is critically ill in Intensive Care

This is one of our most important Ebooks in our Ebook series, as Intensive Care tends to be such a complex, highly political, intriguing and volatile place with very different and difficult psychological dynamics at play, compared to other areas in a Hospital.

Therefore, in order to serve you, the Family members of critically ill Patients in Intensive Care, we give you the "**behind the scenes**" insight that will give you peace of mind, control, power and influence whilst your loved one is critically ill in Intensive Care, because the Intensive Care team has no interest whatsoever in giving you any insight into the moving parts of a busy Intensive Care Unit. And the Intensive Care team certainly has no interest in letting you know how they make crucial decisions and how they manage their resources.

After more than 15 years Intensive Care nursing in three different countries I have learned many valuable lessons in Intensive Care and I have always been wondering what would happen if Families of critically ill Patients would know what's really happening in Intensive Care. I have seen many dramatic situations and circumstances in Intensive Care, where Families of critically ill Patients have been without **PEACE OF MIND**, without control, without power and without influence. Those Families have always been suffering tremendous emotional pain, because there just wasn't enough support, advice and resources available to guide them through one of the biggest challenges in their life.

Whilst working in Intensive Care as a nurse in three different countries, I have also found that there are 10 distinct things happening **"BEHIND THE SCENES"** in Intensive Care that hold Families of critically ill Patients back from having PEACE OF MIND, control, power and influence, because the Intensive Care team is very adept at hiding their true motives from you, especially if your critically ill loved one is in difficult and critical situations such as

- very unstable and in a very critical condition
- in a life threatening situation
- in Intensive Care for long-term treatments and long-term stays
- approaching their end of life in Intensive Care

Those situations tend to be extremely challenging for all parties involved and those situations are often a massive dilemma for you, for your Family and for your critically ill loved one.

In those situations the Intensive Care team is usually positioning themselves and they also position your critically ill loved one's prognosis and diagnosis. The Intensive Care team's positioning, as well as the positioning of your critically ill loved one's prognosis and diagnosis often goes way beyond the clinical picture and often goes way beyond your loved one's disease or illness.

The fact of the matter is that Intensive Care is a very complex and sometimes complicated environment where many stakeholders compete for limited resources. They also compete for attention, they often lobby for interests and many powerful players in the Intensive Care environment, mainly senior doctors, try and drive their own agendas, which once again go way beyond your critically ill loved one's stay in Intensive Care.

Therefore you and your Family need to understand the dynamics, the politics, the psychology, the intrigue and the power play that's going on in Intensive Care if you want to have PEACE OF MIND, control, power and influence. The reality and the fact of the matter is that if you don't learn quickly what's happening "BEHIND THE SCENES" in Intensive Care, the Intensive Care team will keep you at *"arm's length"* so to speak and you will be like 99% of Families of critically ill Patients in Intensive Care who never have any PEACE OF MIND, control, power and influence.

But given that you are here and given that you are reading this right now, you have already shown that you are different and that you want to belong in that 1% bracket of Families of critically ill Patients who have PEACE OF MIND, control, power and influence, because you've learned what is important and you've learned that there's more to it than just "meet the eye".

Therefore let's look at "The 10 things you didn't know that are happening "BEHIND THE SCENES" in Intensive Care that hold you back from having PEACE OF MIND, control, power and influence, whilst your loved one is critically ill in Intensive Care!"

1) The Intensive Care team has already made up their mind about you, your Family and your critically ill loved one and depending on their perception about you and your Family they will position themselves and your critically ill loved one's diagnosis and prognosis accordingly...

The perception the Intensive Care team has about you and your Family has a lot to do how they position themselves and how they position your critically ill loved one's prognosis and diagnosis.

You see, many Families of critically ill Patients in Intensive Care have no idea what to expect. They have no idea what to do, they have no idea what questions they need to ask. In short, they are paralysed by fear. I have seen this over and over again in more than 15 years in working as an Intensive Care Nurse in three different countries. I can usually see it in their body language, I can hear it in their tone of voice and I can see their hesitancy by not doing anything at all, because they are afraid of making a mistake or they are afraid of looking stupid when they ask questions.

Listen, the Intensive Care team already knows that you are out of your comfort zone and the Intensive Care team can sense if you understand what's really going on or not. Look, if you have been quietly and silently suffering during the situation that you, your Family and your critically ill loved one are in and if you are feeling intimidated by the Intensive Care team, you must know that you are not alone and you must know that this is how most Families of critically ill Patients in Intensive Care feel.

But just because you are feeling stressed, vulnerable, overwhelmed, challenged, frustrated and totally out of your comfort zone doesn't mean that you need to carry on that way...

If your critically ill loved one is in a difficult and challenging situation, you need to start acting differently and if you don't start asking the right questions and as a byproduct change the perception that the Intensive Care team has about you and your Family from *"a Family who is not in control, who has no power and no influence"* to *"a Family who is in-control, who is powerful and influential"* the reality and the fact of the matter is that the treatment your critically ill loved one is receiving or not receiving very much depends on the perception that the Intensive Care team has about you and your Family.

Another very important factor that you and your Family need to consider is that the Intensive Care team's positioning of themselves and the positioning of your critically ill loved one's prognosis and diagnosis also heavily depends on the perception the Intensive Care team has about you and about your Family. If you are like 99% of Families of critically ill Patients in Intensive Care who don't have peace of mind, control, power and influence you will continue to be intimidated by the Intensive Care team and you will continue not questioning the Intensive Care team's positioning of your critically ill loved one's prognosis and diagnosis.

So your job is to change the perception the Intensive Care team has about you and about your Family by you asking the right questions, by you getting stronger mentally, by you getting out of your comfort zone, by you educating yourself and by you having a plan and a strategy in how to overcome this challenge.

Also, as a hint, I bet your body language has been really poor since you first went into ICU. You've got poor body posture, your arms are crossed, you avoid eye contact, you have a weak handshake, your shoulders are slumped down and your back is not straight. If you change all of that and if you have good body posture, if you make strong eye contact, if you uncross your arms, you put on a strong display and the Intensive Care team will notice. Try it out. Change your body language from a negative body language to a positive body language and the perception the Intensive Care team has about you and your Family has changed already. Mix that with starting to ask the right questions and I bet the dynamics start shifting in your favour!

The minute you change your body language from "I'm weak, I don't know what to do and I am intimidated by the Intensive Care team and my body language screams that I have no PEACE OF MIND, control, power and influence" to "I'm strong, I know what to do, I know what questions to ask, I'm not intimidated by the Intensive Care team and I have PEACE OF MIND, control, power and influence", that's the minute when dynamics start to change in your favour.

It is therefore entirely up to you to change the perception the Intensive Care team has about you and your Family, by learning the things you need to learn and by asking the questions you need to ask in order to have PEACE OF MIND, control, power and influence!

2) Many decisions about your critically ill loved one's prognosis, diagnosis and also the perceived outcomes have been made from the minute your loved one has arrived in ICU and before you have even met anyone

Intensive Care is a fascinating environment. That is if you work there and if your passion is in helping people in need. However, Intensive Care is also an environment that is so specialized and it took me years to learn the ropes and to learn the specific skills that are required to look after critically ill people and their Families.

However, it's also an area that is highly political, dynamic, volatile, where many stakeholders compete for attention and limited resources and that puts a very different spin on the dynamics in the environment that is Intensive Care.

What you as a Family member of a critically ill Patient don't know is that many trajectories of critically ill Patients in Intensive Care are already "mapped out"

when Patients first have been diagnosed. That is even more true when it comes to situations such as severe cardiac arrests and head injuries in particular.

And with anything that is life threatening and where the Intensive Care team thinks that a prolonged stay in Intensive Care might be necessary and with anything that is likely to take up plenty of resources, including the usage of an expensive and scarce Intensive Care bed, the Intensive Care team often presents a *"doom and gloom"* picture in order to

- Not give you any false hope
- To protect their professional reputation
- Keep the power for themselves because by painting a negative and *"doom and gloom"* picture it's easier for the Intensive Care team to "sell" you on a "withdrawal of treatment" and/or a "limitation of treatment" for your critically ill loved one
- On the other hand if the Intensive Care team thinks that your critically ill loved one might be a "good" and "interesting" case where they can get some new insights about treatments and therapies, they may be more positive and they may in fact try and "sell" you and your Family on false hopes and promises that only prolong the suffering of your critically ill loved one, where your loved one may in fact die, but the Intensive Care team thinks that it's a "good case" to do research and they only prolong the suffering of your critically ill loved one unnecessarily by continuing treatment. Of course the Intensive Care team wouldn't tell you or wouldn't be upfront about seeing your loved one's case that way...

That's why it's so important that you and your Family question everything that is happening, question everything that is being said and question everything that is not being said.

3) Many decisions about the treatment, the care, the diagnosis and the prognosis of your critically ill loved one are made in meetings where Intensive Care doctors and Senior Nurses are present and in those meetings they are allocating available, precious, expensive and scarce resources

Intensive Care is all about the allocation of precious, limited and expensive resources. And once again, if you as a Family member of a critically ill Patient don't

understand and quickly learn what's happening *"behind the scenes"* you, your Family and your critically ill loved one can quickly become a political case in the Intensive Care team's resource management plan and not so much a clinical case that needs to be cured.

Once again this is not so important if your critically ill loved one is a "straight forward" case and is leaving Intensive Care soon, however if your critically ill loved one is in one of the following situations such as

- very unstable and in a very critical condition
- in a life threatening situation
- in Intensive Care for long-term treatments and long-term stays
- approaching their end of life in Intensive Care

then the chances that your critically ill loved one is becoming a political case are tremendously increased and you need to know and understand that the Intensive Care team will be continuously looking at things such as

- the financial viability of your critically ill loved one's case, i.e. will the Intensive Care Unit and/or the Hospital make money or lose money?
- Does the Intensive Care team have other Patients waiting for an Intensive Care bed and do they think that those other cases and Patients are financially more viable?
- Do they need to "please" other stakeholders such as surgeons or other doctors to give some of their Patients preference?
- Does your critically ill loved one fall into a research category? I.e. is there some medical research that the Intensive Care team can conduct on your critically ill loved one that attracts 5, 6 or even 7 figure funding?
- If the answer is yes, then the Intensive Care team may actually continue treatment even to the point where they may give you false hope and the suffering of your critically ill loved one may be unnecessarily prolonged by the ongoing treatment
- If the answer is no, the Intensive Care team may suggest to *"withdraw"* or *"limit treatment"* because the Intensive Care team doesn't have an interest in putting more effort and resources in your critically ill loved one's treatment and they may suggest that it's *"in the best interest"* for your critically ill loved one, whereas it's *"in the best interest"* for the Intensive Care Unit to limit treatment

Another big factor that is highly underrated by Families of critically ill Patients is the fact that the Intensive Care team will always have a look at you and your Family and they will "seize you up" so to speak and they will always gauge how much they think you know and understand about the situation and about Intensive Care. Therefore, if you and your Family don't ask the right questions, if you take everything for "Face value" that the Intensive Care team is telling you, you and your Family might be perceived as "easy prey" by the Intensive Care team. You and your Family are also perceived as not having any control, power and influence. Therefore, it would be a lot easier for the Intensive Care team to drive their agenda if you are not asking the right questions, if you don't stand up for yourself and for your critically ill loved one

As I have said before, the minute you and your Family start asking the right questions, the minute you are questioning the Intensive Care team, the minute you don't take everything for "Face value", the minute you don't "suck up" to the Intensive Care team, the minute you become "difficult and demanding" and the minute you stop "sucking up" to the Intensive Care team, that's the minute when you will have PEACE OF MIND, you will have control, you will have power and you will have influence!

4) The Intensive Care team rarely assumes that Families of critically ill Patients have any kind of knowledge about Intensive Care and that's why they position themselves accordingly and therefore have a lot of perceived power. In their discussions they very rarely mention influence, power or control from Families, it's very rarely on the Intensive care team's radar

Unfortunately, even though we are living in the 21st century, the medical system is a very antiquated system with Doctors still thinking that they can pretty much get away with anything. You can call it **arrogance** and that's certainly part of the issue. But the other issue in this situation is that you and your Family, as well as society at large is still thinking that "doctors know best". And yes, Doctors and nurses in Intensive Care are specialists in their own rights and they have to go through special training, however Intensive Care nowadays is such a highly political, dynamic, volatile and intriguing place, where often the care and treatment of critically ill Patients is all but dependent on the politics, the power play and the things that are happening **"behind the scenes"**.

Therefore if you and your Family don't question the Intensive Care team's perceived power you, your Family and your critically ill loved one might be in big trouble!

You and your Family need to go against the grain and you and your Family need to stop doing what 99% of Families of critically ill Patients are doing, which is that they don't question and they continue to "suck up" to the Intensive Care team.

The Intensive Care team generally speaking assumes that you have no idea and insights about how decisions are being made and they consciously or unconsciously assume that you and your Family just go along with whatever they are suggesting, because that's how society has conditioned Doctors over centuries. But listen you and your Family are informed consumers nowadays, you can get all the information on the internet in this day and age and you can stop putting the Intensive Care team on a pedestal.

Therefore, because the Intensive Care team is so used to getting what they want and the Intensive Care team is so used to not being questioned that it's in fact a big weakness where you and your Family can leverage your level of control, power and influence, because the minute the Intensive Care team realizes that you and your Family have done your homework and the minute the Intensive Care team realizes that you and your Family question, that you and your Family assume control, power and influence that's the minute when the dynamics shift in your favour...

5) Continuation or limitation of treatment is heavily dependent on the individual's outlook and interests

Many challenging and frustrating situations in Intensive Care are often aggravated by some of the doctors and the nurses individual outlooks and interests in life.

What do I mean by that? By that I mean that many doctors and nurses have their own individual opinion about treatments in Intensive Care, about end of life situations in Intensive Care, they have their own opinions about long-term Patients in Intensive Care and they have their own opinion about *perceived "Quality of Life"*. Those personal opinions are far more powerful and influential than you think they are.

The reality and the fact of the matter is that many doctors and nurses in Intensive Care have been wrongly conditioned, if not ingrained that "you shouldn't treat a Patient in Intensive Care for more than 4 weeks" or "that we shouldn't pay too much attention to provide good end of life care" or "that we shouldn't pay too much attention to what Patients and Families want, because we are the professionals and we know what's best after all" and the list goes on. It's an unfortunate reality in Intensive Care that the Intensive Care team sometimes has this idea that they are *"infallible"* and therefore their behaviour is often quite frankly bordering on arrogance.

The reality is that they are not infallible and the reality is that you and your Family simply need to ask for what you want and you and your Family need to simply start asking the right questions, you need to start questioning the Intensive Care team's perceived authority and you need to make sure that your and your Family's individual outlooks and interests are heard, discussed and put into place.

It doesn't matter whether your critically ill loved one is in Intensive Care for a long-term stay, it doesn't matter whether your critically ill loved one is in a critical and uncertain situation and it doesn't matter whether your critically ill loved one is in and end of life situation. You and your Family have your own individual outlooks and interests.

What do you want? Where do you stand? What do you think can be improved in those situations? Keep asking for it, because if you don't ask for it, some powerful individuals within the Intensive Care team may get their way and you may find that it's absolutely not what you want for your critically ill loved one and your Family. Far too often in Intensive Care, the Intensive Care team is getting their way and Families of critically ill Patients feel *"pushed over"* only after it's too late and then Families feel remorse, guilt and they have a very bitter taste in their mouth about the situation.

Your job is to make sure that your interests, your beliefs, your values and your outlooks on life are heard and implemented into the care of your critically ill loved one. That's what this situation and challenge is all about, it's about you, your Family and your critically ill loved one and about nobody else! Don't let the Intensive Care team tell you differently, because most Intensive Care team's think it's about them, their expertise, their skills and "how smart they are". Nothing could be further from the truth. You and your Family are in a unique, special and often once in a lifetime situation. Once you and your Family have become clear that this is what it is, it's so much easier for you and for your Family to ask for what you want, by not holding back, go for what you want and as a direct result have PEACE OF MIND, control, power and influence!

6) End of life decisions are often hastened by the Intensive Care team because of bed pressures, financial viability and/or budget pressures and sometimes because of research interests

End of life situations in Intensive Care are a **privilege** if handled correctly, with compassion and with you, your Family and your critically ill loved one being at centre of the care delivered. Those situations can add tremendous value to the Family who is losing a loved one. Those situations can also add tremendous value to the Intensive Care team if they are open to make and end of life situations memorable, positive and compassionate.

Some Intensive Care Units are good at delivering outstanding end of life care and others are average. Some Intensive Care Units are shocking when it comes to delivering end of life care.

Those Units usually pay no or very little attention to a Family's wishes and their needs in an end of life situation, where they are faced with the challenge of losing a loved Family member.

If you think about it for a minute it's a massive, tragic and dramatic event in the life of a Family who is about to lose a loved one to critical illness. Often this massive challenge comes out of nowhere, where days or weeks before their loved one has been admitted to Intensive Care have gone by without Families anticipating that such a drama could unfold soon.

On the one hand end of life situations can be extremely challenging, frustrating, difficult and heartbreaking and once again they can be very satisfying, they can be a privilege and they can put people at ease.

On the other hand, many Intensive Care Units, because they have so many competing interests, they have so many *"moving parts behind the scenes"* that are hidden away from Families of critically ill Patients that Intensive Care Units hasten end of life situations and they all but look at your, your Families and your critically ill loved one's needs and wishes in such a challenging and difficult situation. After all, life is sacred and life is extremely precious. We must never take life for granted and we must never assume that we are invincible. The reality is that we are all going in the same direction one way or another.

In more than 15 years of Intensive Care Nursing in three different countries I have seen many poorly handled end of life situations, where the needs and wishes of Families of critically ill Patients have not been taken into consideration and the death of their loved one has been hastened just simply because the Intensive Care team had an interest in

- Freeing up the Intensive Care bed as quickly as possible to get the next Patient in
- Saving money and expenses on the care of a dying Patient
- Try and free up staff(doctors and nurses) in order to have them available to look after other Patients
- Trying to stay away from getting too emotionally involved in an end of life situation
- Trying to exercise their authority and power
- Making Families look stupid in the process- after all the Intensive Care team always thinks they know what's best

That has certainly always been frustrating, challenging and dissatisfying when dealing with such situations, especially since I am having an awareness that those situations could have been handled much, much better...

I have looked after some Intensive Care Patients in their own home at the end of their life, so for me those situations that have been handled poorly and without foresight in a clinical environment have always been a personal challenge as well...

However what's even been more frustrating in those situations is that Families who were about to lose their critically ill Family member had no idea what to do, they had no idea how to position themselves, they had no idea what to ask for, because they simply didn't have the tools available that enabled them to have PEACE OF MIND, control, power and influence!

So, the things you and your Family can and should ask for in an end of life situation are things like

- Comfort for you, for your Family and for your critically ill loved one-However this comfort looks like for you, simply ask for it and don't be afraid to ask for things that you feel are non-negotiable for you, such as having more time with your critically ill loved one because you want certain people to be here, you want certain rituals and you want certain religious and cultural needs met etc...
- Making sure that you, your Family and your critically ill loved one have privacy and dignity in an end of life situation- I have seen many

unfortunate end of life situations in Intensive Care where I have seen and looked after Patients who approached their end of life in Intensive Care over many months and many weeks in an open cubicle where they and their Family has been exposed to a busy and noisy, 24/7 Intensive Care environment with no natural daylight and with no shelter...

- Making sure that you and your Family know, understand and also support the Intensive Care team's conclusion why your critically ill loved one is dying- again, depending on what's happening *"behind the scenes"*, the Intensive Care team might suggest to you and your Family that death is the only option, whereas the hidden agenda of the Intensive Care team is to let your loved one die, because they need the bed, they don't see your critically ill loved one as a viable and profitable case and/or the Intensive Care team doesn't want to continue treatment because they can't do medical research on your critically ill loved one... it's absolutely critical that you have done your own independent research
- Last but not least. If your critically ill loved one is approaching their end of • life in Intensive Care, have you and your Family thought about taking your loved one home to **approach their end of life in their own home?** I have seen many Families in Intensive Care over the last 15 years who asked to take their loved one home, to have them pass away at home. Some surveys in western countries have revealed that 75% of people want to die at home, yet only 20% do so. That's a big shame and it's appalling that health services don't pay attention to the wishes of the people. Most Families that I have worked with over the years in Intensive Care in an end of life situation have been bitterly disappointed by the health system, because their wishes to have their loved one die at home remained unfulfilled and they often left with a bitter taste in their mouth. There is however light at the end of the tunnel. As I have mentioned earlier, I have personally looked after dying Intensive Care Patients at home and it's one of the most satisfying end of life situations for Patients, their Families and also for health professionals. Thankfully there are **INTENSIVE CARE AT HOME** services emerging in countries like Australia, Germany, Austria and Switzerland. For more information visit www.intensivecareathome.com.au
- Home care in end of life situations even for Intensive Care Patients are possible, irrespective of what the Intensive Care team is telling you. Remember, their agenda and interests often don't match your agenda and interests...

7) NFR(Not for resuscitation) and/or DNR(Do not resuscitate) orders issued without Family or Patient consent

This one is massive! And it's often well hidden from Families of critically ill Patients! And when I first found out about it, I was absolutely shocked that this could happen in any Intensive Care Unit, let alone in western societies.

Basically what it means is that if the Intensive Care team thinks or perceives that your critically ill loved is **not "worthy"** of resuscitation in case of an emergency, they will document that in the medical notes. They will do so, even though **it violates basic human rights**, it violates hospital policies, it often violates some of the staffs own values and beliefs and it certainly violates your beliefs and values, it's just plain wrong and it's often **illegal** and breaching the law.

It's happening all across the board in Intensive Care Units and again, there are some Intensive Care Units that are open and transparent and get Patients and Families involved in the decision making process and then there are many other Intensive Care Units who don't give a damn.

In the Intensive Care Units where the Intensive Care team documents "**NFR**" or "**DNR**" without your or your critically ill loved one's consent, once again the Intensive Care team is violating basic human rights, is violating hospital policies and your and your Family's job is to have an awareness that it might happen.

The unfortunate reality is that I have seen and questioned many of those situations and whenever I've seen it and questioned it, often the response was that a certain senior doctor **"wants it that way"** or that it's **"in the best interest"** of the Patient or that the Patient **"wouldn't have any quality of life anyway"** or even worse, the Intensive Care team **condescendingly** assumes that the Patient or the Family "don't understand". By that, **the Intensive Care team thinks that they are superior to you**, your Family and your critically ill loved one and that you and your Family "don't understand" what's happening in Intensive Care. Thank god that you've come to the right place...

Now, if you have read my **"INSTANT IMPACT"** report you would have seen me talking about Quality of Life. It makes me very angry and frustrated that some doctors and nurses think that they can make judgements about what's **"in the best interest"** of your critically ill loved one. It also makes me angry and frustrated that anyone can have opinions about other people's perceived Quality of life.

The bottom line, the reality and the fact of the matter is that whenever the Intensive Care team is issuing an "NFR" or "DNR" order it's serving their agenda and not yours. The Intensive Care team always has their bottom line in the back of their mind and not your or your critically ill loved one's well being.

They will tell you of course when you ask them, that it's **"in the best interest"** of your critically ill loved one.

Has anybody asked you and/or your critically ill loved one what you think is **in the best interest** for your critically ill loved one? If they haven't they certainly should. And as I have mentioned many times before, if you don't assert yourself, the Intensive Care team is walking all over you and your Family, because they are used to **Families being intimidated by their perceived power** and that's why they often get away with issuing "NFR" and "DNR" orders without consent that are illegal.

It's a bit like signing an execution order without telling anyone...

Your job is to question, ask the Intensive Care team for all the documentation and your job is to also make clear that you have done your own research and that you know and understand what's at stake here...

You see, for the Intensive Care team having issued an "NFR" or "DNR" order is like a shortcut to emptying Intensive Care beds. They can then say that they can send Patients with an "NFR" or "DNR" order to the ward and free up their beds. It all happens by **"selling"** to you and your Family what's **"in the best interest"** of your critically ill loved one or it happens by not telling you at all. And it will only get worse. An ageing population will put more and more pressure on Intensive Care beds and the only option of "managing" resources and the Intensive Care beds is by "making" vulnerable Patients "NFR" and/or "DNR"...

The grim reality is that Patients and Families in Intensive Care often don't know that the "NFR" or "DNR "order has been issued illegally without consent and it will just being mentioned when the doctors and the nurses hand

over and they hardly take notice of it, because that's how wrongfully ingrained this practice is in the culture of some Intensive Care Units.

8) Even if you and your Family are under the impression that your critically ill loved one is for "full treatment" and if you and your Family have been told that the Intensive Care team is going "full steam ahead" when treating your critically ill loved one, the Intensive Care team might view your critically ill loved one's case as a "hopeless case", a "difficult case" or a "research case" and the Intensive Care team therefore decides BEHIND CLOSED DOORS and without discussing with you and your Family that if your critically ill loved one deteriorates or if their heart would stop that the Intensive Care team "wouldn't rush things", which in the Intensive Care jargon means that they will let your critically ill loved one die. On the other hand if the Intensive Care team sees the opportunity to do some medical research, they might continue treating your loved one, giving you false hope and unnecessarily prolonging the suffering of your critically ill loved one. As a rule of thumb, always keep in mind that it's never what people say and it's always what they do.

Intensive Care is a strange place. Many good things happen in Intensive Care and many bad things happen as well. When things are good they are great and when things are bad in Intensive Care you always, always need to question!

You and your Family need to be **vigilant observers** of the Intensive Care team, because if you aren't, chances are that the Intensive Care team will drive their agenda forward without you even knowing that there is an agenda.

Like in number 7), where we've looked at "NFR" and "DNR", the Intensive Care team has often already made up their mind and they will **"twist and turn"** your critically ill loved one's case to their liking and according to their agenda.

What do I mean by that?

By that I mean, that the Intensive Care team will present your critically ill loved one's case to their liking and according to their agenda. It also means, that as I have mentioned before, the Intensive Care team will often make up their mind **behind closed doors** in how they present your critically ill loved one's case to you and to your Family. The Intensive Care team can often be very vague about outcomes, as they often want to protect their professional reputation by not giving you any false hope, in case things don't go well, so that they can say, "we weren't quite sure in the first place".

What I have also seen over and over again, is that the Intensive Care team often pretends that everything is done and that your loved one is getting the best treatment there is, only to find out that they are **withholding** certain drugs or **withholding** certain equipment that could potentially safe your critically ill loved one's life. For example, your critically ill loved one might be in **lung failure(ARDS)** and might be commenced on High frequency oscillation ventilation, however the best treatment nowadays is probably **ECMO**(acting as a bypass to the lungs), which is probably also more expensive. The bottom line is that if you don't question, you, your Family and your critically ill loved one are **at the mercy of the Intensive Care team** and you certainly don't want to be in such a situation.

If the Intensive Care team is doing that, they are deliberately withholding information from you and from your Family, let alone from your critically ill loved one. That's why it's so important that you and your Family know what questions you need to ask, that's why it's so important that you are watching the Intensive Care team very closely and that's why it's so important that you question everything.

For example, if your critically ill loved one has been admitted to Intensive Care with a **severe heart attack** or if your critically ill loved one had a **cardiac arrest**(cardiac arrest is when the heart stops and needs resuscitation), they may be very unstable and they may need inotropes(to sustain a blood pressure and the contractility of the heart), anti-arrhythmic drugs(to get the heart back into a normal rhythm), they may need an Intra-aortic balloon pump(a pump that improves blood flow and oxygenation to the heart) or they may even need ECMO(total temporary Bypass of the heart).

However, the Intensive Care team also knows that the **damage done to the heart is quite significant** and that if they commence aggressive treatment such as inotropes, anti- arrhythmic drugs and/or the balloon pump, that they may well rescue and save your critically ill loved one's life, however they also know that it might be a **lengthy and difficult** process, that it might take time and that it might take a fair amount of **expensive resources** to get your loved one out of Intensive Care **alive**. The Intensive Care team also knows that it's winter time and that the number of Patients needing an ICU bed for similar situations is at its peak. They therefore think twice before they go "full steam ahead" so to speak, because they know that there are other Patients awaiting similar treatment.

The Intensive Care team also knows that if the therapy is successful, that the next steps may well be to "bridge" your critically ill loved one to a Cardiac Assist device, that's taking over the function of the heart, at least for a while. Once again, that could be very expensive, **is using up an expensive ICU bed** and is time consuming and the Intensive Care team may weigh up their options, not only on the demand they anticipate will happen in the next few weeks or so, but they also weigh up other cases in the unit that may well use up a lot of expensive resources. At the end of the day, the Intensive care team has constraints, whether they are mindset constraints or whether they are resource constraints.

Having an awareness of what is happening is very important because if you don't have that awareness, then you are helpless without PEACE OF MIND, without power, without control and without influence.

On the other hand, if your critically ill loved one is in a situation where they had a **severe heart attack** and/or a **cardiac arrest** and the situation is dire and life threatening, where your loved one is **inevitably going to die**, the Intensive Care team, in some instances may have an interest in maximizing and continuing treatment, thereby **unnecessarily prolonging the suffering** of your critically ill loved one.

The Intensive Care team may do so, if they have an interest in keeping the bed occupied for longer, as they may currently have little demand on beds and/or your critically ill loved one may be a "good" case where the Intensive Care team can continue to do some **medical research**. Then the Intensive Care team will present your critically ill loved one's case in a light where they give you **false hope** so that they can continue treatment and usually in those situations your critically ill loved one's **suffering is unnecessarily prolonged**.

That's what I mean when I say that the Intensive Care team may **"twist and turn"** your critically ill loved one's case to their liking and according to their needs and according to their agenda.

9) The Intensive Care team's positioning of your critically ill loved one's prognosis and diagnosis is ALWAYS dependent on whether your critically ill loved one is viewed as a "good business case" or a "bad business case"

Yes, despite all the medical advancement in recent decades and despite the sometimes "heroic" things that can happen in Intensive Care, most Intensive Care Units are either there to make money or at least to adhere to an annual budget.

Therefore the Intensive Care team will use resources such as staff(mainly doctors and nurses), equipment such as beds, ventilators etc... as a means to an end, meaning that the first thing is to look at the Patients in the beds not only from a clinical perspective, they also view them as **"business cases"**. This is especially important for you to know, because lets say your 78 year old mother has been admitted to Intensive Care with a **heart attack** that resulted in a **cardiac arrest with cardiopulmonary resuscitation** and your 78 year old mother is now ventilated and in an induced coma.

Your 78 year old mother has previously been fit and healthy and she lived an independent life. The Intensive Care team is painting a pretty grim, doom and gloom picture of the situation and they mention from the very first time you have met them that a **"withdrawal of treatment"** and/or a **"limitation of treatment"** might be **"in the best interest"** of your critically ill mother.

The Intensive Care team hasn't mentioned that an Intra-aortic balloon pump or ECMO or and LVAD might save your mother's life and what the Intensive Care team also hasn't mentioned is the fact that in another section of the Intensive Care Unit they have two young Patients in Intensive Care after Motor vehicle accidents and both Patients have been occupying those beds for more than 2 weeks now, because they have both had severe head injuries and multiple other fractures.

Especially with severe head injuries, they can often take up time and resources and they can be very expensive to treat with uncertain outcomes. Even in those cases, where two very young Patients were battling for their lives, the Intensive Care team did suggest to the Families of those Patients to think about a **"withdrawal of treatment"** or a **"limitation of treatment"** as **"in the best interest"** for their critically ill loved ones. Again, just like with your mother, the Intensive Care team could foresee that those young Patients would be staying in Intensive Care for a potentially very long time, using up expensive resources that could potentially be used for other (more financially viable) Patients. A financially viable Patient, by the way, is usually a Patient who is not staying in Intensive Care for very long, usually up to 72 hours.

Getting back to our critically ill Patients, including your mother, thankfully the Families of the two young Patients with head injuries and multiple fractures didn't even consider or contemplate that a **"withdrawal of treatment"** or a **"limitation of treatment"** was an option for their loved one.

They also knew that the **Intensive Care team has other interests that go way beyond the prognosis and diagnosis** of a critically ill Patient. Those Families educated themselves, just like you do and they knew the right questions to ask and they also knew how to be *"difficult and demanding"* so that the Families had **PEACE OF MIND, control, power and influence**.

The same applies to you and your situation. You need to start talking to the Intensive Care team about your wishes, desires and your goals for your critically ill loved one, irrespective of what the Intensive Care team is telling you.

It's critically important that you are going to become **"difficult and demanding",** because if you are not, the Intensive Care team will have the upper hand and once again they may **"twist and turn"** your critically ill loved one's case to their liking and according to their agenda.

Never take "no" for an answer, because if you don't, you will find out the truth and you will find out whether the Intensive Care team has anything to hide or not.

10) Many Intensive Care Units are heavily involved in research activities and generally speaking a lot of money and funding- 5,6 or even 7 figure \$\$\$ funding- is going towards research activities. Therefore, if your critically ill loved one falls into one of the research categories, your critically ill loved one may get preferred treatment, at least for a while, however the outcome may still be uncertain. If, on the other hand, your critically ill loved one doesn't fall into a research category, the Intensive Care team may not be interested in giving your critically

ill loved one their fullest attention and they may suggest to "withdraw" or "limit treatment"

As I have mentioned in number 9), the way the Intensive Care team presents your critically ill loved one's case may go way beyond your critically ill loved one's prognosis and diagnosis. The way the Intensive Care team will present your critically ill loved one's case is always heavily dependent on the Intensive Care team's interests and agenda. **Part of that agenda is ALWAYS medical research!** Particularly in big metropolitan teaching hospitals that are affiliated with big universities!

Many big Intensive Care Units easily attract Millions of Dollars \$\$\$ per year in research grants and funding. The money needs to be spent on those Patients that fall into those research categories. In theory, every Patients who is enrolled into a research study, needs to give consent or if they are not able to give consent- and they often aren't because they are unconscious- the Next of Kin(NOK) and/or the Family needs to give consent!

The unfortunate reality and the fact of the matter is that many **Intensive Care Units don't tell the Families of critically ill Patients that they actually are enrolled into a research project or research study**, where the Intensive Care team is trialling a new drug or where the Intensive Care team is withholding blood transfusions, because they are trialling the outcomes of a certain disease without giving blood transfusions.

The bottom line is that the Intensive Care team is usually making those decisions right at the beginning of the admission to Intensive Care when Family members are not around.

The reality is that if the Intensive Care team would ask you and your Family or even your critically ill loved one whether you would want to "participate" in a medical research study, the answer would most likely be "no" and rightly so! **Medical research has its time and its place, but not when somebody is battling a critical illness in Intensive Care.**

I have seen many questionable research projects where neither the Patients nor the Patients Families had been informed.

More importantly, the Intensive Care team will use research as **a tool or even weapon** in the positioning of your critically ill loved one's situation.

What do I mean by that?

First of all, lets remind ourselves of the **Millions of Dollars \$\$\$ of research funding** that's going into Intensive Care Units every single year. That's massive and many Intensive Care Units simply couldn't survive without that money. That funding also helps to establish a certain reputation amongst other Intensive Care Units and Intensive Care Units like to be seen as research centres and they certainly want to publish research papers where the Hospital's name and the doctors names are published. Sometimes it can be nursing driven research as well.

With that in mind, lets just quickly go back to our examples in number 9) with your 78 year old mother who had a heart attack that led to a cardiac arrest and to cardiopulmonary resuscitation.

Lets just say that your mother's heart attack and the cardiac arrest have been so severe that a survival is unlikely and that any treatment would only unnecessarily prolong the suffering of your critically ill loved one's mother. But **the Intensive Care team is adamant** to continue treating your critically ill loved one's mother and they tell you and your Family that putting her on an Intra-aortic balloon pump(a pump that pumps blood and oxygen to the arteries surrounding the heart) might save your critically ill mother's life.

What they haven't told you is that they are currently doing a **medical research study about survival rates** after severe cardiac arrest with and without the Intraaortic balloon pump. The Intensive Care team therefore has a very high interest in continuing treatment on your critically ill mother, however in this example, the Intensive Care team only **unnecessarily prolongs treatment and therefore suffering of your mother**.

On the other hand, if the Intensive Care team knows that your 78 year old mother has a chance of survival, but also knows that enrolling her in a research study is not an option, because she doesn't fall into a research category and if the Intensive Care team also knows that two other Patients can be enrolled into a research study and they therefore need more resources for those two other Patients that are already enrolled into a medical research study, the Intensive Care team, once again might suggest that **"withdrawal of treatment"** and/or a **"limitation of treatment"** would be **"in the best interest"** of your mother!

In essence what I'm saying is that you and your Family need to be **vigilant, you need to question everything the Intensive Care team is telling you and not telling you** and you need to quickly get and understand why the Intensive Care team positions your critically ill loved one's prognosis and diagnosis in a certain light.

I hope that this Ebook has served you well and I hope that you have gained even more insight of how you can effectively deal with your fears, frustrations, your struggles, your vulnerability and how you can turn the situation around so that you feel powerful, in control, influential so that you are mentally well positioned and mentally strong to deal with adversity! Hopefully I was able to "elevate" your thinking and also to lift your spirits.

I also hope that I will see you in our other Ebooks so that you can find even more strength, more power, more energy, greater influence and also hope in your challenging journey through the Intensive Care landscape.

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 <u>"your questions answered"</u> section. Find the links here

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You can also send me an email to support@intensivecarehotline.com if you have more questions

Sincerely, your friend

Patrik Hutzel

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