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 5 things you need to know if the medical team in Intensive Care wants to "LIMIT TREATMENT", wants to "WITHDRAW TREATMENT" or "WITHDRAW LIFE SUPPORT" or wants to issue a "DNR" (Do not resuscitate) or an "NFR" (not for resuscitation) order for your critically ill loved one in Intensive Care

Ok, welcome to another Ebook in INTENSIVECAREHOTLINE.COM's Ebook series. And once again, congratulations for 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 Ebook series will help you finding **your voice, will help you taking control, power and influence decision making** in the jungle of complexities surrounding the critical illness of your loved one in Intensive Care.

In this very important Ebook, you'll learn **the 5 things you need to know if the medical teams in Intensive Care want to limit treatment, withdraw treatment or wants to issue and NFR(not for resuscitation order) for your critically ill loved one in Intensive Care**.

In the report you will discover how to

- Influence decision making and have power in the situation quickly
- Have more control and more negotiation power
- Position yourself well mentally
- Use your gut feeling to determine the right course of action
- Ask for the Intensive Care Unit's policies, procedures and guidelines that may guide or even determine the decisions about ***"treatment limitations"***, ***"withdrawal of treatment"*** and ***"NFR"*** for your critically ill loved one

- let the Intensive Care team know that even though you are not a health professional, you have a good understanding of what is happening "behind the scenes" in Intensive Care and that you speak the **secret** "Intensive Care language"

A highly emotionally charged topic outside of the public eye

Ok, this is another very hot topic and a topic that is not very often discussed in the public arena- for a number of reasons. It is a highly charged, a highly sensitive and a highly emotional topic and you want to know what is really happening if your critically ill loved one is in this situation that a ***"withdrawal of treatment"*** or ***"treatment limitation"*** is something that the Intensive Care team is considering. It is also a topic that comes with massive moral, ethical and sometimes legal implications as well.

Private, transparent and open discussion with no "hidden agendas"

One of the reasons is that of course, if your critically ill loved one in Intensive Care is in a critical condition and ***"treatment limitations"***, ***"withdrawal of treatment"*** and/or ***"Not for resuscitation"(NFR)*** is something the Intensive Care team considers or suggests, you and the Intensive Care team would want to have a private and open discussion and not a public discussion about the issues at hand. There are more often than not conflicting views about ***"treatment limitation orders"***, ***"withdrawal of treatment"*** and ***"NFR"***. And so there should. People have different values and beliefs, different cultural, different religious and different spiritual beliefs. So there must be different views and it's good and healthy to have different views and to have a healthy debate!

First off, be aware that there is very little standardised literature or standardised approaches about the ***"limitation of treatment"***, ***"withdrawal of treatment"*** and ***"NFR"*** (not for resuscitation). Very few hospitals and Intensive Care Units have their policies, procedures and guidelines about end of life issues such as ***"treatment limitation"***, ***"withdrawal of treatment"*** and ***"NFR"*** in the public domain. Hospitals and Intensive Care Units tend to be very secretive about their policies and procedures in these very important and also highly sensitive areas. It is very often up to you and your Family to find out these policies, procedures and guidelines surrounding these massive ethical, moral, highly emotionally charged and very often grey issues.

One of the reasons why Intensive Care Units and Hospitals don't want to have their policies and procedures and general information about and regarding

"limitation of treatment", ***"withdrawal of treatment"*** and ***"NFR"*** (not for resuscitation) is crystal clear to somebody who has worked in the system for a long time, but is often hidden for Families of critically ill Patients.

It's crystal clear that the Intensive Care team wants to make the ultimate decision and it's therefore that Hospitals and Intensive Care Units don't want to get you involved in those decisions. It is therefore that they don't want you to look at those policies and procedures and it's easier for the Intensive Care team to tell you and also "sell" you what is ***"in the best interest"*** for your critically ill loved one. After all, most of those polices and procedures regarding decision making around ***"limitation of treatment"***, ***"withdrawal of treatment"*** and ***"NFR"*** (not for resuscitation) clearly state that all parties involved would have to agree. But that's not what the Intensive Care team wants to have happen. They want you to stay out of the decision making process, because that would give you and your Family far too much power, control and influence!

Let's therefore quickly look at the definitions of the three main terms that we are talking about in this Ebook. Because of the lack of standardisation, ***"treatment limitations", "withdrawal of treatment"*** and ***"NFR"*** orders are very much dependent on individual Intensive Care Units policies and procedures.

In more than 15 years Intensive Care Nursing in three different countries I have also found that different Intensive Care Units have different cultures, different people have different views and that therefore "it all depends".

It's usually never black and white and there are a lot of grey areas. That's why it's so important that you educate and inform yourself about these sensitive, often highly charged and highly emotional topics.

Please also keep in mind that I am specifically talking about and giving out information about Intensive Care. Different rules and different perceptions are being used outside of Intensive Care.

- ***Treatment limitation*** **(in Intensive Care)**
  A ***"treatment limitation"*** or a ***"treatment limitation order"*** (plan) that is documented is an order, usually issued by the most senior Intensive Care consultant, doctor or physician in Intensive Care. The treatment limitation order is normally based on the grounds that your critically ill loved one is very critically ill and not curable and therefore a full continuation and a

maximisation of treatment and therapies would not be achieving a desired health outcome.
If anything, it would be likely that a prolonged suffering for your loved one would take place, if treatment was maximised and it wouldn't be in the ***"best interest"*** for your critically ill loved one.
Usually, a ***"limitation of treatment"*** means that "*life- sustaining medical technology and techniques, such as cardiopulmonary resuscitation, ventilation, nutrition and hydration, dialysis, blood transfusions and antibiotics are to be limited.*
A treatment limitation should only be documented after open discussions with the critically ill Patient's Family have taken place. Furthermore, all parties involved need to understand and agree on the implications of such (a) treatment limitation(s). The treatment limitation plan should only be put in place after ***mutual agreement between the Intensive Care team and the Patient's family has been achieved****."*

- **<u>"Withdrawal of treatment"(in Intensive Care)</u>**
  In Intensive Care a ***"withdrawal of treatment"*** is usually the ***"withdrawal of a life sustaining treatment"*** that has already been started. This means in practice that life sustaining treatment such as mechanical ventilation, medication therapy, dialysis, blood transfusions and antibiotics are to be taken away and they are not to be recommenced from the point of decision to withdraw, going in the future.
  The rationalisation or driver behind the ***"withdrawal of treatment"*** is usually that life sustaining treatment would not be ***"in the best interest"*** of a critically ill Patient and would only prolong unnecessary suffering of a critically ill Patient in Intensive Care. It is often rationalised with "***Futility of treatment"***. *Futility of treatment is often referred to as "Treatment to a Patient when there is no reasonable hope of cure or benefit. This may in form of a surgeon operating on a terminal cancer patient or doctors or nurses keeping a brain dead person on life support machines other than to harvest their organs."*

  It is a highly sensitive and highly emotionally charged area that often causes conflicts between Intensive Care health professionals and Patients and their Families, who expect everything possible to be done for their critically ill loved one in Intensive Care.
  I am not further evaluating on *"Futility of treatment"*, as it is a term not used as often as ***"withdrawal of treatment"*** or **"limitation of treatment"**, but it's

good that you now know what it means anyway and it ties right in with the information that you want to know more about.

A ***"withdrawal of treatment"*** should only be documented after open discussions with the critically ill Patients Family have taken place.

Furthermore, all parties involved need to understand and agree on the implications of such a ***"withdrawal of treatment".*** This should only be agreed upon once mutual agreement between the Intensive Care team and the Patient and/or the Patient's Family has been achieved.

- ***"NFR"*****(not for resuscitation in Intensive Care)**
  An ***"NFR"*** or ***"not for resuscitation"*** order(in some Hospitals DNR= Do not resuscitate) is a specific order on a specific document that states "that in the event that a Patient's heart stops beating or in the event that a Patient stops breathing, that no life saving measures such as CPR(cardiopulmonary resuscitation) and no mechanical ventilation should be initiated. It is usually a sub-group of the ***"treatment limitation"*** order and once a ***"treatment limitation"*** order has been agreed upon, an ***"NFR"*** order might be the logical consequence.

  This is usually a response to a critically ill Patient's maximisation of treatment in Intensive Care, with the expectation that an extension or a prolonging of a Patient's life would only prolong the Patient's suffering and that a minimisation or a palliative approach of treatment might be ***"in the best interest"*** of the critically ill Patient.
  This should be documented by the ICU medical team on the ***"NFR"*** form and written consent needs to be given by the critically ill Patient's Family.

Warning: You should always check and also make sure that none of the above mentioned- ***"treatment limitation"***, ***"withdrawal of treatment"*** and/or ***"NFR"*** have been documented in your critically ill loved one's medical notes without you and/or your Family knowing about such orders and/or knowing about that such a documentation exists without you, your critically ill loved one and/or your Family giving consent.

Unfortunately, in more than 13 years Intensive Care nursing experience in three different countries, I have witnessed in some Intensive Care Units that ***"treatment limitation"***, ***"withdrawal of treatment"*** and/or ***"NFR"*** have been documented, even though Families of critically ill Patients and/or Patients themselves(if conscious) did not know that these documents existed. This is illegal and if found out Doctors who issued such documents could be sued as their practice is basically denying basic human rights!

Let's now look at the five specific things that you and your Family need to know about *"limitation of treatment"*, *"withdrawal of treatment"* and *"NFR"*.

1. **Transparency, openness, consideration and due diligence in the decision making process are paramount**

You might think that this should be a "no- brainer". And I totally agree. It is a "no-brainer". Transparency, openness, consideration and due diligence are paramount in this hot topic.

Some Intensive Care Units are very good and very open about end of life and "treatment limitation issues and others simply aren't. It also might vary within an ICU, where some of the medical and nursing staff are open, transparent and considerate, whereas other medical and nursing staff have differing views and they might also be less open to differing views.

But what exactly do I mean by "transparency, openness, consideration and due diligence" in the decision making process?

Is there a distorted reality?

Well, a lot of the issues that I have informed you about in INTENSIVECAREHOTLINE.COM's Ebooks and blogs are issues that I have encountered over and over again in more than 15 years Intensive Care Nursing and there is often a real power struggle for Families of critically ill Patients.

Unfortunately there are a lot of moving parts behind the scenes in Intensive Care that you are unaware of and therefore what you actually see and what you get told is often not "what you get" and you might be dealing with a "distorted" or "twisted" reality. The Intensive Care team generally speaking is trying to hide away

from you what's happening "behind the scenes" so to speak, because what's happening "behind the scenes, often has a dramatic impact on the Intensive Care team's positioning and it generally impacts one way or another on your critically ill loved one's treatment.

Let's give you an example

Your 55 year old husband has been admitted to Intensive Care. Your 55 year old husband has been suffering from Leukaemia for the last three years and he has already been through hell and he has had multiple Chemotherapies, as well as having a bone marrow transplant about two years ago. Your husband has been feeling up and down during the last three years, since first diagnosed with Leukaemia. So has your Family. It has been an extremely difficult time and an emotional roller coaster for you, for your husband and for your five children.

Your husband has a strong will to live

Your husband has never given up and he has a very strong will to live and you are thinking to yourself that everybody else would have probably thrown in the towel by now. He has also managed to stay out of Intensive Care thus far, despite many setbacks and disappointments in his treatment.

Your 55 year old husband has been admitted to hospital about 2 weeks ago as he has developed Pneumonia from his recent Chemotherapy. He struggled on the ward, required increasing amounts of oxygen and he finally had to be admitted to Intensive Care, as the ward staff were unable to manage his deteriorating condition any longer.

Once in Intensive Care, your husband was put on Non-Invasive or BIPAP mask ventilation, a form of ventilation that doesn't require sedation, but it does require for your husband to be able to tolerate a tight face mask, oxygen and a lot of pressure filling his lungs, in order to treat the Pneumonia.

You can see that your husband is struggling and you can also see that the BIPAP ventilation is helping him, but you can also see that it is very tiring and exhausting for your critically ill loved one. You also know that your husband wants to live. He still has this zest for live!

Now it's the Intensive Care team's turn

You are at your 55 year old husband's bedside and the Intensive Care team approaches the bedspace to examine him. They do want you to leave the room

while they examine him and they will get you back in to have a chat once they have finished their examination.

After about 30 minutes the bedside nurse Sarah comes to collect you at the ICU reception and you go back into the unit. The Intensive Care medical team is waiting for you and they suggest a meeting with you in a few hours, preferably with some of your children around as well. They do want to have a ***"discussion"*** about managing your husband's further stay in Intensive Care and his prognosis.

You're already thinking that if they want your children to be present it might be bad news. Given that only two of your children are living locally you'll ring them and you ask them to be in ICU by 5pm, which they agree to. In the meantime you can see your critically ill loved one struggling on the BIPAP ventilation more and more and you wonder what might be next. You can see that he is not coping and you are very concerned. You ask the bedside nurse Sarah, what the next steps might be if your husband does not improve on the BIPAP ventilation. The bedside nurse says that the next step would be mechanical ventilation with an Endotracheal breathing tube, but she is unsure whether that is something the Intensive Care team wants to initiate and that it is something they want to discuss with you and your Family later today.

Is this meeting about life or death?

At 5pm, you and two of your children are greeting the Intensive Care consultant/physician, one of his senior registrars and the bedside nurse Sarah. The six of you enter the ICU meeting room and the senior ICU consultant/physician opens the meeting.

He explains that your 55 year old husband has been admitted to Intensive Care for his deteriorating Pneumonia, which they believe to be a direct result of his recent Chemotherapy. The consultant says that unfortunately many Chemotherapy Patients with Leukaemia end up in Intensive Care with Pneumonia as the Chemotherapy weakens the general immune system and therefore infections such as Pneumonia develop. Furthermore, the ICU consultant says that your husband's white cell count(white blood cells are cells of the immune system, defending the body against infections) is minimal, suggesting that his body might be in a weak position to defend and fight the infection.

Your husband has also been commenced on Antibiotics for the Pneumonia.

The ICU consultant/ physician continues by saying that given the overall clinical picture, with your husband's requirement for increasing oxygen demand and his struggles on the BIPAP ventilation that he would require intubation and mechanical ventilation. He would therefore require to be in an induced coma.

The purely clinical view, the options presented and what you need to do

The senior ICU consultant/physician also says that given the clinical picture with your 55 year old husband's ongoing Leukaemia, ongoing Chemotherapy and probably limited life expectancy, he has concerns that if the Intensive Care team was going to put him on a ventilator with an endotracheal tube, that he would not be able to come off the ventilator quickly, and that he might be too weak to breathe by himself without ventilator support.

He therefore suggests two ways to manage the situation

a) Leave your husband off the ventilator, support with BIPAP ventilation, making sure your husband is comfortable and let nature take its course and in that course your critically ill husband could potentially die
b) Put your husband on a ventilator with an endotracheal tube and induce him in a coma. The ICU consultant/physician has concerns that your critically ill loved one will not manage to come off the ventilator once on mechanical ventilation. He therefore fears a prolonging of your loved one's suffering and he can't guarantee that mechanical ventilation will cure the Pneumonia.
   He furthermore suggests that if they did ventilate and intubate your critically ill loved one that a "one way extubation" would be the best course of action. You ask what a "one way extubation" means and the consultant explains that once your husband comes off the ventilator, he wouldn't be for another intubation and mechanical ventilation.

One of your children asks whether this would be a "sink or swim" approach. The ICU consultant/physician confirms that this would be a "sink or swim" approach.

He then asks whether you or your children have any questions thus far. You and your children deny having any questions thus far.

The Intensive Care consultant/physician continues saying that they would need to make a decision very soon, because if the medical and nursing team were going to mechanically ventilate your critically ill loved one they would need to do that soon, as there are more staff around before 10pm, as there are less staff on night duty.

You are crystal clear about what you want

You and your children look at each other and for you and your children it's not even something you even have considered that you would let your husband and father die, without even trying.

You and your children are crystal clear about the wishes for your husband and father and you explain what a strong will to live he generally has.

The Intensive Care consultant/physician continues to have a grim look on his face and says that they would want to put your 55 year old husband on the ventilator if you would want that, but he also suggests that the Intensive Care team has come to the conclusion that if your husband was going to be mechanically ventilated and in an induced coma that he would want to issue and document specific ***"treatment limitations",*** including ***"NFR"***(not for resuscitation), in case your loved one's heart stops and that if your husband should go into kidney(renal) failure that he should not go on a kidney machine(Dialysis).

The Intensive Care consultant explains that he doesn't think that CPR(Cardiopulmonary resuscitation) and Dialysis would be in the ***"best interest"*** of your critically ill loved one.

You and your children look at each other in disbelief. You always knew that your husband was very sick with Leukaemia but you didn't expect him to "crash" to the point that extensive treatment wouldn't carry him further on his journey through life.

The Intensive Care consultant is adept at reading your and your children's body language and there is an awkward silence in the room for a minute or two.

You could feel tears coming up ten minutes ago and your were able to hold them back then, but now you let them roll and you *grab* one of the tissues on the table. Now you are sobbing uncontrollably.

One of your children puts their arm around you and you are looking for words. Finally one of your children gets crystal clear and says that you and your Family don't want any ***"treatment limitations"*** at this point in time and that you and your Family want everything done for your husband and father.

Differing views and what to do about them

We leave this "fictional" meeting now and we zoom out and I hope that this example shows you where the issues and challenges are. Without putting any judgement on what either, the Intensive care team's view is and what your views are, those or similar situations occur in Intensive Care Units at all times and those situations tend to be very challenging, difficult and very rarely are those challenges and issues black and white.

You also need to know and understand that the positioning of the Intensive Care team was clear from the start and that the team had talked amongst themselves before the meeting, regardless of your views and opinions. That's why it is so critically important that you are mentally well positioned, mentally well prepared and that you have as much "insider" information as possible in those situations.

On the one hand there are you, your family and the love and concern for your husband, who wants to live. On the other hand there is the Intensive Care team who knows and understands the clinical implications of your 55 year old husband's diagnosis and prognosis.

There are a number of challenges that the Intensive Care team is dealing with in the background that you are unaware of and I won't go into detail here(for more information tap into our other Ebook and read "**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"** and read our Ebook on "**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"**).

What other questions do I need to ask?

What is important for you to know is that you have made your wishes and views clear from the start and so has the Intensive Care team. As you can find from the discussions in the meeting, the Intensive Care team has already made up their mind to where things go from here. You need to be very mindful what is getting documented though. In many instances that I have seen over the years and in many similar instances, I have witnessed that the exact things that the ICU consultant/physician mentioned about ***"treatment limitation"*** and ***"NFR"*** would be documented without you knowing that it has been documented already. This is illegal and it's breaching many policies, procedures and even laws.

It would mean that the Intensive Care team knows what has been said in the meeting, because it is usually documented. The crux however is that you would

have to agree to a ***"limitation of treatment"*** and ***"NFR"***, which you clearly haven't.(like in our fictional meeting)

There are also formal processes in forms of policies and procedures regarding ***"treatment limitations"***, ***"NFR"*** etc… those formal processes would have to be adhered to and it usually includes your consent to the management plan for your critically ill loved one. The reality often is however that those policies are ignored. You as a Family member or Next of Kin of a critically ill Patient in Intensive Care are unaware that such policies and procedures even exist.

You therefore need to ask for

a) If the management plan for your husband adheres to and complies with the Intensive Care Unit's policies, procedures and guidelines regarding ***"limitation of treatment"*** and ***"NFR"***?
b) The documentation about the meeting in your husband's medical notes and
c) the formal policies and procedures regarding ***"treatment limitations"*** and ***"NFR"***

Just by asking for those documents you will be viewed differently and you will have more control, more power and more influence straight away. You will show that you are not giving up lightly. You will also find that by asking succinct questions that the dynamics will shift. You might also think that you and your children want more time with your husband, even if it's only a few more days or weeks.

These are exactly the points where most Families of critically ill Patients in Intensive Care fall short and this is exactly why they are not influential and this is why the Intensive Care team has all the power. Families of critically ill Patients in Intensive Care lack the ***"insider knowledge"*** that leads them to asking succinct and important questions. Just by doing that you will see the dynamics shift and you will see that you have control, power and you have an ability to influence decision making.

Furthermore, listen to your gut. If your gut tells you that your husband would want to continue treatment then you should stand up for that. If you feel like your husband had enough, well then maybe it is time to let him go. Always ask lots of questions. Do not worry what the Intensive Care team thinks about you asking lots of questions. It's none of your business what they think.

Intensive care is a busy, stressful and challenging environment and for you, for your Family and for your critically ill loved one it is often a ***"once in a lifetime"*** experience and you don't want to get it wrong.

2. **There are massive moral and ethical implications and challenges involved in *"treatment limitations"*, *"withdrawal of treatment"* and *"NFR"* and those situations are rarely "clear cut" nor are they "black and white"**

As I have mentioned before in this report, as well as in other reports of INTENSIVECAREHOTLINE.COM's Ebook series, Intensive Care is very rarely black and white and there are a lot of grey areas. And there are lots of people with different views and different opinions.

The important thing is that everybody's views and opinions need to be considered and people need to compromise and make mutually agreeable decisions that are in the ***"best interest"*** for a critically ill Patient.

But what exactly are decisions that are in the ***"best interest"*** for a critically ill Patient in Intensive Care? What exactly are those massive moral and ethical implications and challenges that I am talking about? More importantly, what **do you** need to know when it comes to issues such as ***"treatment limitations"***, ***"withdrawal of treatment"*** and ***"NFR"***?

I'll give you more real world examples again, so that you understand and you also get perspective

- A previously fit and healthy 90 year old gentleman gets admitted to Intensive Care after Open heart surgery. The gentleman was a planned admission and he had been in Intensive Care for only 2 days before discharge to the ward. Everything went smoothly and he got out of bed on day one after surgery and he is now going to the ward

- A 60 year old man had a tragic accident with severe head injuries and he is now dying. The Intensive Care team wants to ***"withdraw treatment"*** in a few hours and let the Patient pass away. The Family wants to wait another 24-48 hours as they are waiting for the Patient's brother to come from overseas and they want to make sure that he is not going to pass away without his brother being there

- An 85 year old lady has had a severe heart attack with the consequences of acute kidney failure. If the Intensive Care team isn't commencing Haemodialysis(kidney machine), the 85 year old lady is likely to accumulate toxins in her body that will eventually kill her. The lady was dependent on other people before the heart attack but had a reasonable Quality of life. The 85 year old lady required ventilation and the Intensive Care team suggests to the Family to take her off the ventilator, but is not planning to put her back on a ventilator should she deteriorate, which would be very likely without haemodialysis(kidney machine). The Intensive Care team therefore wants to clearly document ***"treatment limitations"*** and ***"NFR"*** and let nature take its course. The Family does want to continue treatment including ventilation and Haemodialysis(kidney machine). They are optimistic and don't want to let their mother deteriorate. The Family believes that their mother will recover and that their mother was happy with her limited Quality of life before ICU admission

- A young 22 year old cyclist has been admitted to Intensive Care after a car crashed into him. He sustained life threatening head injuries, multiple severe rib fractures and a pelvis fracture. After many weeks in Intensive Care with maximisation of treatment, the fractures have been fixed and he is not waking up due to his severe head injuries. He is stable otherwise. The Intensive Care team wants to transfer him to the ward as he doesn't require Intensive care anymore. The Intensive Care team also wants to document a ***"one way discharge"***, meaning that a transfer back to Intensive Care, should he deteriorate, is excluded. The Intensive Care team further suggests to have a documented ***"NFR"*** form, as the Intensive Care team thinks he will not have any Quality of Life. The Intensive Care team thinks that therefore ***"NFR"*** and not coming back to Intensive Care is in the Patient's ***"best interest"***. The family of the young man is appalled by the Intensive Care team's approach and does not agree to a ***"one way discharge"*** nor do they agree to ***"NFR"***

What are the commonalities in these examples, despite the differences?

You might see that some of the examples I have given you don't seem to have much in common at first. The thing they do have in common however is that

people could argue about the allocation of resources. You can also see that things are not "black and white" and that there are many "grey" areas if anything

- Why would a 90 year old man need open heart surgery?
- Who in their right mind would not wait for Family to come to a dying Family member?
- Why is the Intensive Care team so adamant in ***"withdrawing treatment"*** on an 85 year old lady?
- And last but not least, why would you want to limit treatment on a 22year old with a head injury, when everybody knows that head injuries take a long time to recover?

I am not trying to put too much judgement on each individual case, however I see and I have seen those or similar cases over and over again and with the knowledge and the insights of the moving parts in the background in Intensive Care, I also know and I understand where Intensive Care Units stand.

Your insights, negotiation skills, positioning and knowing what you want is critical

But this is where your and your Families negotiation skills, strategies and tactics come in. Your job is to estimate the situation from your perspective, whereas the Intensive Care team will argue from a standpoint of "evidence based practice" or "best practice", whereas you will more likely argue from an emotional and gut standpoint. Of course, some of the Intensive Care staff are emotional too, but they might be more detached.

Do also not underestimate your ability to use your judgement and your discrimination in the situation, of what is really in the ***"best interest"*** for your critically ill loved one. Your judgement might be more based on your gut feelings and on knowing your critically loved one well enough, to understand his or her strengths and weaknesses and therefore understand how he or she deals with adversity.

As I have said in #1, and I can't emphasize this enough that every Intensive Care Unit has documented policies, procedures and guidelines regarding ***"limitation of treatment"***, ***"withdrawal of treatment"*** and ***"NFR"*** that they have an obligation to follow and adhere to.

If you ask for those documents and don't be shy to do so, you will find that there is always documentation that the Family needs to agree and give written consent to ***"limitation of treatment"***, ***"withdrawal of treatment"*** and ***"NFR"***.

They are massive steps to take and you certainly don't want to have your 22 year old son or daughter leave Intensive Care with a ***"treatment limitation"*** order.

Just by taking a stand and asking the right questions you automatically exercise more influence

And once again, just like I said before, you will stand out from other Families in Intensive Care, just by you asking the right questions and having an awareness of the moving parts in the background that most other Families in Intensive Care are totally unaware of. Most Families in Intensive Care are just suffering silently without taking any initiative, because they are overwhelmed and often paralysed by stress. Be different and keep asking lots of questions, keep asking the right questions and you'll do yourself and your critically ill loved one a big favour and you'll shift dynamics immediately.

What might be the most frustrating part for you is the fact that the Intensive Care team most always will argue their case in what might be ***"in the best interest"*** for your critically ill loved one.

What exactly does that mean? It means that the Intensive Care team thinks from a medical standpoint that this course of action would be in ***"the best interest"*** for your critically ill loved one. It doesn't take into consideration how you feel and what your gut feeling is telling you about the situation and what your gut feeling is telling you about your critically ill loved one in this situation.

Also, keep in mind that the Intensive Care team argues strictly from an Intensive Care point of view and as I have mentioned in our other Ebooks, Intensive Care professionals often have no idea what is happening to Patients outside of Intensive Care and they most of the time don't know what happens to a Patient's recovery once they have left Intensive Care. Their arguing is often based on an Intensive Care mindset and paradigm and often leaves other points and opinions out of the equation.

Just consider this

Is it ethically and morally right to have an opinion about what is ***"in the best interest"*** of someone that's not your family member or close friend?

Some people, including Intensive Care staff might have an opinion what is in the ***"best interest"*** of someone, however nobody knows your loved one as well as you do and therefore you should have a strong point of view and a strong opinion of what you think is best for your critically ill loved one.

3. **How important are Intensive Care Units policies, procedures and guidelines around *"limitation of treatment"*, *"withdrawal of treatment"* and *"NFR"* and what do you need to know about it?**

Every Intensive Care Unit has written policies, procedures and guidelines around the decision making process regarding ***"treatment limitations"***, ***"withdrawal of treatment"*** and ***"NFR"***. Those policies, procedures and guidelines vary from Intensive Care Unit to Intensive Care Unit, but in essence entail similar steps in the process. The decision making process is usually outlined and justified by what is current perceived

- best Medical practice
- evidence based practice
- what is the perceived ***"best interest"*** for a critically ill Patient from a medical point of view

There can be of course deviations and different interpretations from the written policies, procedures and guidelines and they are often dependent on

- the individual moral and ethical values of the nursing and the medical staff
- the general culture and the general atmosphere in an Intensive Care Unit(positive vs negative culture or open minded vs closed minded culture)

***"Treatment limitations"*, *"Withdrawal of treatment"* and *"NFR"* can not be issued without your consent**

Most policies, procedures and guidelines around those issues also state that ***"limitations of treatment"***, ***"withdrawal of treatment"*** and ***"NFR"*** can not be issued without the acceptance and the approval of the critically ill Patients Family or next of kin(NOK).

The policies, procedures and guidelines are often not written to look at ethical and moral dilemmas that inevitably come with this highly emotionally charged territory.

It doesn't talk about how a Family might feel when presented with the stark realities of their critically ill loved one in Intensive Care.

It is therefore absolutely critical that you ask for the documents about ***"limitations of treatment"***, ***"withdrawal of treatment"*** and ***"NFR"*** and that you familiarise yourself with the aspects and the steps around the process. You also need to know about your rights around the process.

As I have said many times before, if you do just that, if you are standing your ground and you stand out from the crowd, just by simply asking the right questions, you immediately exercise more control, influence and power because you and your family will not give up lightly and you are not taking "no" for an answer.

I would never go as far and say that health professionals in Intensive Care are emotionally detached from issuing ***"treatment limitations"***, ***"withdrawing of treatment"*** and issuing ***"NFR"*** forms. I am however very aware of the competing interests, competing demands, the moving parts in the background and also of the Intensive Care team's often highly academic view of the clinical issues at hands, which often leaves a discussion about moral and ethical dilemmas out of the equation. This often highly and purely academic point of view of the medical staff and sometimes the nursing staff as well, leaves often no room for your gut feeling. It also leaves little room for you knowing your critically ill loved one best, because you know your critically ill loved one well enough and you understand how he or she can deal with adversity.

Unless you are persistent and vocal about your beliefs in your critically ill loved one to fight against adversity and against the odds, some of the members of the Intensive Care team might only look at the medical facts. So, your job therefore is to bring up your reasoning and to fight for your beliefs.

The Intensive Care team has their positioning worked out well in advance and you need to work your positioning out too

Because there are many competing interests in the background, the Intensive Care team has probably made up their mind already of

a) how to position the *"clinical facts"* they are going to tell you
b) how to position themselves and their management plan for your critically ill loved one

c) how to document in your critically ill loved one's medical and nursing notes their ***"withdrawal or limitation of treatment"*** plan, including ***"NFR"*** - even though this may violate Hospital/ ICU policies, procedures and guidelines, without your knowledge

It is extremely important for you to know that policies, procedures and guidelines are just that. They are policies, procedures and guidelines. They are written documents. They are not more and not less.

Keep that in mind and make your judgements accordingly. Know that health professionals in Intensive Care and doctors in particular often have a highly academic view of things. For them it is often black and white, whereas in your reality it's probably not black and white. It's often a grey zone.

Keep that in mind at all times and position yourself strongly and accordingly. Talk about your concerns, your fears and your frustrations. Be persistent and be vocal in demanding fairness and transparency in the process.

4. How to find your unique voice in the process(must read)

I see and I have seen a lot of Families struggling to find their voice in this process. They are struggling to find their voice because they are so overwhelmed, frustrated, fearful, vulnerable and they feel challenged. Moreover, because time is often their enemy, they lack the time to

- Make any independent investigations or find useful information in what to do
- Digest and understand what is really happening
- Feel like they have really been heard in the cascade of events and decisions
- verbalise their feelings and therefore make their views and concerns heard about their critically ill loved one's situation

Don't let fear, overwhelm and frustration stop you from speaking up and taking control!

As you can see I can write and speak about this topic for hours, because of the pain that I am going through each time I am confronted with end of life issues and also because of the pain I have been going through when dealing with death within my own Family.

For you it might be different. Unless you have been in a similar situation in the past, you may have no problem finding your voice in this process. You may know exactly what you want and you can verbalise it. Congratulations if you have found your voice already. You are well on your way to master the situation and the challenges.

But if you have never been in a situation like this before, you are of course struggling to either have a voice or finding your voice. You and your Family might still be overwhelmed and feel paralysed by the sheer frustration, the stress and the pain of the situation and now you are confronted with the next issue on a long list of issues.

You are not taking this issue lightly, but you don't know where to start. And usually time is your enemy. The situation demands a quick response from you. The challenge is that the Intensive Care team is often positioned to make a decision for you, for your Family and for your critically ill loved one. They appear to be in control and they have perceived power.

The challenge also is that you are not positioned to make a clear cut decision, because there are often too many unknowns and there are also unknowns that you don't even know are unknowns. In fact, you are facing far too many unknowns and complexities to deal with. Time is your enemy, because the situation doesn't give you a great deal of time.

It depends of course, but especially in end of life situations you may only have 24-48 hours left.

How do you find your voice in such a challenging and difficult situation?

The first step of course is to find as much information as possible about your critically ill loved one's situation. You should be able to get a great deal of information just from our free resources on our INTENSIVECAREHOTLINE.COM website.

Next, if you are not entirely clear on where you stand in terms of management of your critically ill loved one's care and/or his or her end of life care, try and buy some time. Hopefully you are in a position where you can have another 24-48 hours to think about the situation, by asking the Intensive Care team to keep your critically ill loved one alive.

If you are still unsure, take your personal values and beliefs, scrutinise them and base your decisions on your personal values and beliefs. I also can't stress enough that you should listen to your gut feeling. Your gut never lies.

Speaking from your heart is important

Next, speak from your heart and don't let the "clinical facts" or the academic view of the Intensive Care team stop you from having your emotions speak.

Your emotions are a healthy sign that you are positively engaged in the challenging situation. Don't think that just because you are dealing with "specialists" in Intensive Care that they know it all. They certainly know a great deal about Intensive Care and their craft within that environment, but once again that must not stop you from you giving your input into the situation.

Sometimes, just by you and your Family giving input and by making sure you are influencing decision making you might be in a position where you are "buying time" and sometimes by gaining extra time, your critically ill loved one may show signs of either improvement or deterioration. Especially in a perceived end of life situation this can be extremely valuable time to have.

Rather than rushing into a decision that you don't feel comfortable with, by buying time, the universe might give you the hints that you have been waiting for of which direction to take.

Do not give up, control reality and control the perceptions

Also, don't underestimate the level of power, influence and control you are exercising just by positioning yourself strongly, by not giving up and by not taking "no" for an answer.

The Intensive Care team has a certain view and certain perceptions about you and your Family. Those views and perceptions are often based on first impressions and they are also based on the Intensive Care teams perceptions of how you are dealing with this situation and how much they think you know and understand about the situation. Let me say this again. The Intensive Care team's views and perceptions are based on how they think you are dealing with this situation and how much they think you know and understand about the situation. That means it's not based on reality. It's based on perception.

So therefore if you change the Intensive Care teams perception about you and the level of influence you have and exercise, you automatically shift dynamics in your favour again.

I have seen too many situations where the Intensive Care team had all the power, because Families didn't think and didn't believe they could influence a situation. The minute that you think you can influence a situation you probably will and you probably can. The minute you think that you can't influence decision making you probably can't.

You therefore need to be able to control the three most important things in this situation, which are your thoughts, your brain and your beliefs. Do just that and you are well on your way to mastering the situation.

5. **Your critically ill loved ones age is not as important as you think it is in the decision making process**

As you have seen in the previous points in this article, I have given you a few real world examples about critically ill Patients in Intensive Care and I have given you examples about

- The Intensive Care teams positioning
- Your and your Families positioning
- How you can influence decision making
- How you can influence reality and perceptions in your favour

Furthermore, as you have seen in the real world examples that I gave you earlier, I have always included a critically ill Patients age. I have given you the critically ill Patients age so that you can see that a critically ill Patient's age in Intensive Care does not necessarily impact on the decision of the Intensive Care team to either go "full throttle" on a Patient's treatment or on the other hand, limit a Patient's treatment. A lot of those decisions from an Intensive Care point of view are based on their perceptions of the critically ill Patient's future, irrespective of the Patient's age.

Contrasting treatment options might go hand in hand with different age groups

As outlined in one of our examples, a previously fit and healthy 90 year old would be having cardiac surgery, despite his or her age, as long as there is perceived Quality of Life.

A 22 year old with severe head injuries might end up with treatment limitations if the perception is that there may be no perceived Quality of life.

The list could go on, but those two contrasting examples should give you an idea of where your critically ill loved one might fit in and more importantly you need to understand that it is only based on the Intensive Care team's perception. The Intensive Care team, once again, lives and breathes Intensive Care and generally speaking they have no idea how a Patient might fare outside of Intensive Care. The Intensive Care team are the specialists for Intensive Care and they are not the specialists for what's happening after or outside of Intensive Care!

By having that knowledge, you can position yourself accordingly during negotiations and meetings.

I can give you another real world example so that you can see how age is not a determining factor on the decision making process and what to do about it. A critically ill 41 year old lady with two young children has been admitted to Intensive Care after having been diagnosed with breast cancer two years ago.

Unfortunately the cancer has spread widely into her lymph nodes. The 41 year old lady is now rapidly approaching her end of life and she is expected to pass away within the next 2-4 weeks. The 41 year old lady is weak, but fully conscious in Intensive Care, where she is receiving intermittent Non-Invasive BIPAP ventilation and inotropic therapy for her difficulties that she has with her breathing and she is receiving the inotropic therapy for her low blood pressure.

Is the Intensive Care team breaching Intensive Care policies and procedures?

The Intensive Care team has already made up their mind in where to go or even more importantly where not to go with the treatment of this 41 year critically ill old lady, due to the limited life expectancy.

The Intensive Care team has already come to the conclusion that Invasive ventilation and intubation, unlimited inotropic support(for low blood pressure) and CPR(Cardiopulmonary resuscitation) in case the 41 year old lady's heart would stop beating, would not be ***"appropriate"*** for her. The Intensive Care team have already documented those ***"limitations of treatment"*** and ***"NFR"*** in the medical

and nursing notes of this critically ill Patient without informing the Patient and/or the Patient's family. Written Patient or Family consent has not been given for those ***"limitations of treatment"*** and therefore Hospital policies and procedures have been breached. What's even worse in this example is that basic human rights have been breached. The Intensive Care team thinks that these decisions are in the ***"best interest"*** of the 41 year old lady.

Discussions about ***"treatment limitations"*** and ***"NFR"*** are hard, difficult and confrontational discussions to have, especially when a critically ill Patient in Intensive Care is awake and fully conscious.

The Intensive Care team is avoiding difficult and challenging discussions with the Patient and the Family

The reality often shows however, that in order to not have those difficult and confrontational discussions that it is easier to just "document" those ***"treatment limitation orders"*** without talking to the people affected most by it, the critically ill Patient and their Family. Once again, the common view of the Intensive Care team is that "we know what is in the ***"best interest"*** of a critically ill Patient in Intensive Care". Furthermore, it would be difficult, even for the most experienced doctor or nurse to have such a confrontational discussion with an awake and fully conscious Patient. It is therefore often the ***"easy way out"*** to just document and inform the Intensive Care team and not the Patient and their Family.

I am not disputing the fact that in our real world example, the 41 year old lady is approaching her end of life. I am however strongly disputing the fact that

- Her and her Family have not been informed about the clinical decisions made by the Intensive Care team. Therefore Hospital/ ICU policies and procedures and basic human rights have been breached. An illegal process has been started
- by making those decisions it might limit the Patient's time spent with her husband and their young children. Even a few more days can be very important in such a situation

You see, if in our example we would be talking about your spouse, you would want to spend as much time with her or him as possible and more importantly, you would want to know what decisions might have already been made from a clinical perspective without you and your critically ill loved one being involved in the decision making process. Once again transparency and openness in the process is totally lacking.

I have given you this example because people often think or have an impression that age is more relevant in the decision making process.

Our real world examples have also shown you that you should question everything and that you shouldn't assume anything. Just be open minded and keep asking questions. Keep asking for documentation in your critically ill loved one's notes, especially if you are questioning the Intensive Care team's approach. If you keep doing that, you'll find out if the Intensive Care team has anything to hide or not. You'll see how open and transparent they will be in the process around ***"limitation of treatment"*** or ***"NFR"***. You'll also get a feel for the culture within the Intensive Care Unit.

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 **"your questions answered"** section. Find the links here

http://intensivecarehotline.com/category/blog/

http://intensivecarehotline.com/category/questions/

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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