

# 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*

**Follow this proven 6 step process on how to be powerful, in control, influential and have PEACE OF MIND if your loved one is a long-term Patient in Intensive Care or is facing treatment limitations in Intensive Care**

Ok, welcome to another Ebook in INTENSIVECAREHOTLINE.COM's Ebook series. And once again, congratulations on taking action in getting informed and taking control! Just by doing that you stand out from the rest of 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 find **your voice, will help you to have control and power so that you can influence decision making**, in the jungle of complexities surrounding Intensive Care.

**You are outside of your comfort zone and what you need to do about it**

If your loved one is a long-term Patient in Intensive Care or is facing treatment limitations in Intensive Care, chances are that you feel outside of your comfort zone, you feel challenged, you feel vulnerable, you feel frustrated and you feel like things are out of control. This very often **“once in a lifetime”** experience in Intensive Care, also increases the likelihood that you feel like you don't have any control, power or influence over the situation and that you don't have any peace of mind during this often stressful and unpleasant experience in Intensive Care.

In order to have more influence, power and control regarding the decision making process regarding the care of your critically ill loved one in Intensive Care and in order to have more peace of mind regarding the care your critically ill loved one receives in Intensive Care, follow the 5 steps you are about to discover and you will find that with the insights, the proven strategies and the tactics you are discovering that you'll be in a much better position to feel like you are in control, that you have power and that you can influence the situation and the outcomes.

So let's dive right into **“The proven 6 step process on how to be in control and influential if your loved one is a long-term Patient in Intensive Care or is facing treatment limitations in Intensive Care”**

**1. Discover that accepting quickly that what has happened to your critically ill loved one is the way it is.**

I know this sounds harsh, but the sooner you deal with and accept reality as it is, the sooner you can deal effectively with the issues at hand.

Being a (long- term) Patient in Intensive Care is an extremely stressful event and stressful situation in your critically ill loved one's, in your and in your Families' life.

It is never a pleasant situation to be in, however in order to achieve control, power, influence and peace of mind you need to accept the realities around the situation and you need to deal with it.

Once you have decided that you can accept those realities, you can then move on and make decisions. You will be unable to make decisions, you won't have control, power or influence if you haven't accepted the reality that you are dealing with and that you are facing.

**2. Discover to ask the right questions.**

Once again, chances are that you are in a position right now, where you feel like the world is tumbling down on you. Your critically ill loved one is in Intensive Care and you haven't slept properly, you haven't eaten properly and you are neglecting some other important areas of your and your Families' life, because you are spending a lot of time in the Intensive care unit, in order to be with your critically ill loved one.

Chances are that you are feeling overwhelmed by all the information you have received by the doctors and the nurses. Maybe a social worker has been involved in eliminating some of the financial worries you and your Family might have. Social workers are usually pretty good in giving the right sort of advice when it comes to dealing with financial and other support issues.

Some of the important questions you need to ask the nurses and the doctors in Intensive Care are dependent on the nature of the injuries, diagnosis, sickness and/or prognosis etc... your critically ill loved one has been admitted with,

however a few standard questions you should always ask and that will help you to stay in control are

- Is my loved one receiving the right treatment for his or her condition?
- Will treatment be extended if the current treatment is ineffective?
- Will treatment be alternated, should the current treatment be ineffective?
- What happens if my critically ill loved one is not improving?
- Will my loved one be given enough time if the road to recovery is delayed?
- Will my loved one be given the best and full treatment, even in the event of his or her condition deteriorating or are there any treatment limitations?
- If there are any treatment limitations, what are they and what is the rationale for them?

(for more information about this hot topic of **“treatment limitations”** and **“withdrawal of treatment”** also read our special Ebook on **“The 5 things you need to know if the medical team in Intensive Care wants to limit treatment, wants to withdraw treatment or life support or wants to issue an NFR\*(not for resuscitation) order for your critically ill loved one in Intensive Care”**

**\*some hospitals might refer to NFR also as DNR(Do Not Resuscitate)**

I have to stop here for a minute and talk about **“treatment limitations”**. **“Treatment limitations”** are one of the most challenging issues in Intensive Care and I believe also one of the most emotionally charged issues, for all parties involved.

**So what are the real reasons behind “treatment limitations”? Is there something you are unaware of or something that the Intensive Care team is hiding?**

In case your critically ill loved one is facing any **“treatment limitations”** or **“withdrawal of treatment”**, there may or may not be a good clinical reason for it. One of the reasons could well be **“Futility of treatment”** (treatment that is non-beneficial for a Patient).

But it could also be because of the negative mindset or the negativity that is prevalent in an Intensive Care Unit. Furthermore, time and resources are very often crucial factors. Many Patients in Intensive Care, especially after head injuries or other complications do not improve or recover quickly and not until weeks or sometimes months have passed after the complications and/or head injury.

And some Intensive Care Units are not giving Patients the necessary time to recover, for a variety of reasons.

Resource pressures are often at the centre of the decision making process and are often taken into consideration, when ***“treatment limitations”*** are considered, as beds in Intensive Care and staff in Intensive Care are an expensive scarcity and therefore an empty bed in Intensive Care is a precious resource that can be used for the next sick Patient. Or to put it the other way round, an occupied Intensive Care bed with a Patient who is going through a lengthy and unpredictable recovery, may be perceived as an expensive resource.

Whether there is or there isn't a good clinical reason for ***“treatment limitations”***, you as your loved one's Next of Kin(NOK) and your Family need to be fully informed about and involved in the reasoning behind any ***“treatment limitations”***, ***“withdrawal of treatment”*** and/or ***”NFR”*** (not for resuscitation).

The Intensive Care unit that you are dealing with is having a policy in place when it comes to ***“treatment limitations”*** and when it comes to ***“NFR”*** (Not for resuscitation) orders. You or your critically ill loved one in Intensive Care- if conscious and in a position to make his or her own decisions- must be **fully informed and consented** about any ***“treatment limitations”*** that may be put in place. Do not hesitate to ask this very question about ***“treatment limitations”*** or ***“withdrawal of treatment”*** and what the process regarding the limitation is. It very often requires a signature and consent of the NOK(Next of Kin) or the Patient itself.

### **The process is never black and white and is always challenging**

The decision making process around ***“treatment limitations”*** or ***“withdrawal of treatment”*** can be ethically, morally and legally challenging for all parties involved. It is often presented to Families of critically ill Patients in what “maybe” in your critically ill loved one's ***“best interest”***.

If there are ***“treatment limitations”*** that you, your Family and your critically ill loved one(if conscious) do not agree with, ask for another meeting with the most

senior ICU consultant/ Physician and also seek a second opinion. And most of all, do take your time to think thoroughly about what you, your Family and your critically ill loved one would want if he or she was in a position to make their own decisions. Do not rush into making any decisions. Take your time and don't let the Intensive Care staff pressure you into making a decision.

Unfortunately in more than 15 years Intensive Care Nursing in three different countries I have seen many situations where the Intensive Care team has pressurised Families of critically ill Patients by painting a ***“doom and gloom”*** picture of their critically ill loved one's diagnosis and prognosis, whereas in reality the Intensive Care team's negative positioning and negative framing of the situation is a direct result of

- the financial budget of the Intensive Care Unit
- a negative mindset and a negative culture
- not being prepared “to do whatever it takes” to get your critically ill loved one on their way to recovery
- other Patients awaiting admission to Intensive Care and therefore competition for scarce and precious ICU beds
- your critically ill loved one not fitting some other criteria that would warrant a continuation of treatment from the Intensive Care team's point of view, I.e. your critically ill loved one's case might not fit some research criteria that the ICU is currently involved in and gets funding for, therefore other cases might get preference

Most of the decision making process however, is based upon the current mindset prevalent in Intensive Care and what people think is possible within Intensive Care. Mindsets in Intensive Care Units are different and can range from positive to negative, from ***“yes, we can do”*** to ***“no, we can't do”***. Pay close attention to those either positive or negative mindset because the Intensive Care team's mindset can make all the difference.

In any case- if you are in doubt that the right and correct processes are being followed, you should ask for the hospital or the Intensive Care unit's policy regarding ***“treatment limitations”***. Do not hesitate to do so, should you have any concerns, regarding the care and the treatment of your loved one. If your critically ill loved one is unconscious- and if you are reading this, chances are that your critically ill loved one is not in a position to make his or her own choices- you want

to make sure that you understand the very process, the legalities and the framework around the decision making process. Go and ask for the hospital/ Intensive Care Unit policy regarding **“treatment limitations”** and in some instances for the **“end-of-life care”** policy.

You want to have peace of mind that in such an important, unique and often **“once in a lifetime”** situation in your and in your Families life, you understand the implications those crucial decisions have on your, your Families and on your critically ill loved one’s life!

**3. Discover that what may be in your critically ill loved one’s “best interest” from a hospital or Intensive Care Unit point of view, may actually not be in your critically ill loved one’s “best interest”.**

Look, you have come to this site because you are looking for answers. Whilst I can’t give you all the answers, I believe I can give you useful advice and insight, based on more than 13 years international Intensive Care nursing experience in three different countries.

As mentioned before, being a long- term Patient in Intensive Care is a very challenging situation to be in.

And I have mentioned before that sometimes, Intensive Care staff may perceive a situation a certain way, because *“this is the way we do things around here and this is the way we perceive things to be”*.

Different Intensive Care Units have different ways of doing things and they have different ways of looking at things. They usually differ in their approach towards critical issues, especially when it comes to long- term Patients and to **“treatment limitations”**. It is a bit like the *“glass half-full vs glass half- empty”* analogy.

- The Intensive Care Units with the *“glass- half- full”* mentality have a far more positive outlook on your critically ill loved one’s recovery vs the *“glass- half- empty”* ICU’s. I have seen both approaches in different Intensive Care Units.
- The ICU’s with the *“glass- half- full”* mentality will usually be more open and more compassionate towards your concerns

regarding the long- term prognosis of your critically ill loved one. They are usually also pretty good and open in communicating “*treatment limitation*” issues with you and they usually consider your opinion. They generally opt for full disclosure of all processes and are transparent

- The ICU’s with the “*glass- half- empty*” approach usually have a far more negative outlook on your critically ill loved one’s recovery. They usually present the situation in a very “*matter-of- fact*” approach that is usually based on a scarcity and a “*black- and -white*” mindset. They usually will have standard answers to your questions that are based on their limited and negative mindset, but do not necessarily address your individual concerns and questions regarding the prognosis, diagnosis and ongoing treatment of your critically ill loved one. Their goal is often to “*keep you at arms length*” so that you don’t have control, power and influence. Those Intensive Care Units tend not to follow open disclosure and are not transparent in their decision making process
- The ICU’s with the “*glass-half-empty*” approach are not that great when it comes to discussing treatment options and/or “*treatment limitations*”. Those limitations might- in some instances- already be documented, without seeking the discussion and without seeking the approval and consent from you in the first place. It is often a case of “*how we do things around here*” and “*we don’t really want you to ask too many difficult questions, because at the end of the day we know what’s best and we know what we are doing*”.

Your job in those difficult circumstances is to not take “no” for an answer and you need to continue to be difficult and demanding, because if you’re not, the Intensive Care team will walk all over you and your Family, because there are just too many other moving parts behind the scenes that you have no awareness about that most of the time influences the Intensive Care team’s decision making process. Your job is to make sure that the Intensive Care team has really acted “***in your critically ill loved one’s best interest***” and has not acted out of self interest because they have competing interests, because of bed pressures and because of competing research interests etc...

#### **4. Discover that being a long-term Patient in Intensive Care is challenging and that despite the challenges of being a long-term Patient in Intensive Care your critically ill loved one can get better**

Look, being a long-term Patient in Intensive Care is a challenge, there is no doubt about it. However, depending on the Intensive Care team's outlook, mindset and also depending on the moving parts in an Intensive Care Unit that are happening behind the scenes some Intensive Care Units are simply putting more efforts and resources towards some critically ill Patients, even though it means that they might go through a lengthy recovery. It also means that those Intensive Care Units tend to be more Patient and Family focused.

I have also seen many critically ill Patients in Intensive Care where the Intensive Care team wasn't prepared to give some critically ill Patients *"a fair go"* because other competing interests such as the financial viability of treating a Patient or other Patients awaiting admission to an already fully occupied ICU have taken the upper hand in the battle for scarce resources.

Furthermore, sometimes Intensive Care Units also have a shortage of staff whether it be doctors or nurses and they therefore have difficulties in filling some of their shifts. As a rule of thumb, if you can sense that the Intensive Care Unit has a staffing shortage or even a staffing crisis you may start wondering why this may be the case? I can almost guarantee you that an Intensive Care Unit with a staffing crisis is having lots of challenges retaining their staff and I can, again almost guarantee you that the reasons are rooted in a negative culture. And as I have highlighted in other Ebooks, a negative culture in an Intensive Care Unit generally speaking reflects negatively on Patient care as well.

Coming back to being a long-term Patient in Intensive Care, there are certainly many challenges that would have to be considered and some of them that stand out are

- Depression for Patient and Family
- No Quality of life
- Lack of privacy
- Lack of dignity
- Confusion and agitation of Patient
- Lack of day and night rhythm
- Uncertain outcomes

- The time spent by Families in Intensive Care when their loved one is a long-term Patient can be taking up a lot of time and energy and Families therefore are suffering as well
- Little moral and practical support available for Families of the long-term critically ill

Despite all the challenges that I listed, if you feel and if you think that ongoing treatment for your critically ill loved one is the right thing to do, irrespective of the **“doom and gloom”** of the Intensive Care team and irrespective of the possibility that the Intensive Care team is positioning your critically ill loved one’s prognosis and diagnosis in a negative light then you should push forward

I can tell you that I have seen many Families over the years who wanted to have their critically ill loved one treated irrespective of all the **“doom and gloom”** and irrespective of the negative positioning of the Intensive Care team, because it’s the Families who know their critically ill loved one best. And it’s the Families who know how their loved one can deal with adversity, despite all the clinical facts that the Intensive Care team will continue to point out!

#### **5. Discover that every Patient in Intensive Care is different and that you can never compare one Patient with another**

Many Patients go through Intensive Care every single day. This means a variety of clinical pictures, but it also means a variety of very different individuals. No Patient is similar to another Patient. Patients might look similar from the outset and they might have things in common such as gender, age and they may well present with similar clinical pictures, however they may vary greatly in their personalities, in their coping strategies, how they deal with adversity and this very often can make all the difference.

I have witnessed in some instances that some Patients with similar clinical pictures, similar age and similar gender, receiving similar treatment, varied greatly in their recovery. Some Patients died quickly, whereas others miraculously survived their ordeal.

Moral of the story? Withhold your judgement, as anything can happen and anything is possible. Positive and negative. Intensive Care is a very unpredictable and volatile environment.

Listen to what your gut is telling you. Your gut never lies. The doctors and the nurses might be telling you that your critically ill loved one has a poor prognosis and you might think and feel that your critically ill loved one can generally deal well with adversity. The doctors and the nurses can be very academic and also judgmental in their approach and they often do not consider their intuition and/or their gut feeling.

Moreover, they don't know your critically ill loved one personally, whereas you do know your critically ill loved one and this can make all the difference. Has your critically ill loved one in difficult situations before? How well does your critically ill loved one deal with setbacks generally? If you are positive that your critically ill loved one is somebody who can beat the odds, then your job is to let the Intensive Care team know that, irrespective of what clinical prognosis your critically ill loved one has been admitted with, he or she can beat the odds!

## **6. Discover that “*truth*” is a very thin concept in Intensive Care**

We all strive to learn the “*truth*” about something. It gives us satisfaction having “*cracked the code*” on something. Chances are that if your critically ill loved one is a (long-term) Patient in Intensive Care, you haven't found the “*truth*” as yet.

Intensive Care is a very challenging, unpredictable and volatile environment. Tight deadlines, dealings with life and death are some of the grim realities the Intensive Care staffs are dealing with every day.

Everybody is challenged on a moral and an ethical level. There is also the reward side, which can be massive and that reward side is directly linked to somebody's “*truth*”.

Many staff in Intensive Care, including myself, find it very rewarding working in such a challenging environment. They find reward in helping people in need. They find reward in helping people getting better. But they also find reward in helping people on their last journey. Having been part of a successful recovery of a critically ill Patient in Intensive Care is a fantastic experience and a blessing.

But everybody who has been part of a tragic death and who has been involved in end-of-life care can find massive rewards there too. If you can be part of making that last part of somebody's life journey dignified and private and also help the family to come to terms with the inevitable, and if I can help the family finding

peace of mind with their loved one's last journey, it is a tremendous privilege to be part of.

“*Truth*” therefore is a very thin concept and the less you think in “*black and white*” terms the better this serves you and your family in your journey through the Intensive Care landscape. This landscape can be very rugged, full of steep climbs, with wind, rain and snow, sometimes no sunshine for many days. But there is always hope! Even if your critically ill loved one in Intensive Care is not getting better and maybe your loved one is even approaching their end of life in Intensive Care, go and find some meaning in it. What is the meaning behind the tragedy?

I can't answer that question for you and I believe that you can!

Don't forget to shine the light on what is important for you, for your critically ill loved one and for your Family during this difficult time in your life and more importantly challenge the Intensive Care team on every level if you feel like your critically ill loved one is not getting the care they deserve.

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](mailto:support@intensivecarehotline.com) if you have more questions

Sincerely, your friend

Patrik Hutzl

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