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

7 answers to the 7 most frequently asked questions, if your loved one requires ongoing mechanical ventilation with Tracheostomy in INTENSIVE CARE

Ok, welcome to another Ebook in INTENSIVECAREHOTLINE.COM's Ebook report series. And once again, congratulations on taking action in getting informed and taking control! Just by doing that you stand out from the rest of the Families in Intensive Care and it will give you an edge when dealing with the challenges, difficulties and complexities in Intensive Care. Our Ebook series will help you find **your voice** 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 ventilated Patient with Tracheostomy 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, I want to give you **"The 7 answers the 7 most FAQ's if your loved one requires ongoing mechanical ventilation with Tracheostomy in INTENSIVE CARE"**

You are about to discover and you will find that with the insights, the proven strategies and the tactics 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 if your loved one remains ventilated with Tracheostomy in Intensive Care.

1. **Will my loved one require mechanical ventilation and a Tracheostomy for the rest of their life?**

Look, mechanical ventilation and Tracheostomy are life preservers in the first place and are a good thing. They generally stabilise your critically ill loved one's condition in Intensive Care and usually make further treatment, therapy, diagnostics and assessments possible. Mechanical ventilation and a Tracheostomy is a good means on your loved one's way to recovery in Intensive Care.

It gives your loved one the opportunity to be taken off the ventilator and breathe spontaneously, as soon as practically possible, due to the fact that sedation and opiates usually can be minimised after a Tracheostomy has been inserted, to the point where your loved one might be ready to come out of the induced coma and he or she might not need any sedation at all and he or she is on their way to be gradually weaned off the ventilator. This is the good side of the coin.

The other, more negative side of the coin is that mechanical ventilation and Tracheostomy are invasive, meaning a foreign body(=the Tracheostomy tube) plus a machine(the ventilator) is doing something as forceful as ventilating your loved one's lungs.

Weaning off the ventilator can be difficult and lengthy

Now, the tricky part is that depending on any other injuries, illnesses, pre medical history, length of stay in Intensive Care and so on, weaning off the ventilator can be a lengthy and difficult process and in some instances it might take a few attempts for your loved one to be non- ventilator dependent. This sometimes can go on for weeks or even months until your loved one can be without a ventilator for more than 24 hours.

If your loved one has been off the ventilator and has been spontaneously breathing for more than 48-72 hours, a de-cannulation(=removal of the Tracheostomy) can be achieved if the medical team and speech therapy think your loved one is able to protect his or her own airway, i.e. is able to cough up and clear any secretions and is able to swallow.

Once the Tracheostomy has been successfully removed, your loved one would be ready to be discharged to the ward in normal circumstances.

Even with a Tracheostomy in place, your loved one might be able to go back to a ward, as long as he or she has been non- ventilator dependent for at least a couple of days, better 3-4 days.

There are those usually rare instances, however, as briefly touched on before, where your loved one might be in a condition where it is difficult to wean him or her off the ventilator. This might be the case if your loved one has

- Caught an infection, i.e. Pneumonia
- been immunosuppressed after lung, kidney, liver, bone marrow or heart transplant or is suffering because of Chemotherapy, Radiotherapy, Leukaemia, HIV or any other form of cancer
- Asthma, COPD, Emphysema, Chronic Bronchitis, pulmonary fibrosis, cystic fibrosis and/or pulmonary hypertension
- Neuromuscular diseases such as *Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's Disease), cerebrovascular accident (stroke), Parkinson's disease, multiple sclerosis, muscular dystrophy, myasthenia gravis, Huntington's disease (Huntington's chorea), and the Creutzfeldt-Jakob disease*
- High spinal cord injuries, with inability to breath(Paraplegia or Quadriplegia)

The list is not exhaustive and may include other diagnosis or issues that may impact on your loved one being ventilator dependent with Tracheostomy

Are there genuine alternatives to a long-term stay in Intensive Care?

In those rare circumstances, a prolonged or even life- long dependency on mechanical Ventilation and Tracheostomy goes hand in hand with a prolonged stay in Intensive Care, as ongoing mechanical ventilation with Tracheostomy requires

specialist medical and specialist nursing skills that can usually only be found in Intensive Care, as nurses, doctors and Physiotherapists have to go through specialist training.

You might wonder what the options are for your loved one if he or she falls into the category of long- term mechanical ventilation dependency with Tracheostomy that is ongoing requires ongoing specialist skills like ventilator skills?

Are there any perceived alternatives and options?

Here is the thing- pretty much until now, my experience in Intensive Care Units have shown me that very few perceived options and alternatives may exist for your critically ill loved one. And this is a massive challenge for the Patients, their Families and for health professionals in Intensive Care.

My experience has shown me that the longer your loved one might stay in Intensive Care on a Ventilator with a Tracheostomy, chances are that your loved one will get anxious, depressed, apathetic, usually due to the sterile environment, the dependency on other people, the lack of control, with decision making in the hands of other people and due to the lack of privacy and the lack of dignity and most of all due to the lack of Quality of Life in Intensive Care.

With all those things that I have just mentioned going against your loved one in Intensive Care, he or she is often running out of time and he or she may deteriorate and may lose the will to live. This is very sad and tragic and in more than thirteen years of nursing experience in Intensive Care, I have watched some Patients and their families suffer terribly. Very often, the Intensive Care team's perception in those instances is that there are no perceived alternatives, but to withdraw treatment, making sure your loved one is comfortable and let him or her approach their end-of-life in Intensive Care.

Thinking outside of the box?

Coming back to the initial question that I set out to answer, whether your loved one requires mechanical ventilation for the rest of their life, depends on those factors I explained. Please keep in mind that most current Intensive Care mindsets or paradigms do not factor in, any external specialist home care nursing services that may eliminate the suffering for your loved one in Intensive Care, depending on mechanical ventilation with a Tracheostomy.

Having said that, please keep in mind that depending on where you live, some countries have already adopted and embraced Home care for long-term ventilated Adults& Children with Tracheostomy, usually with great success for the Patients and their Families.

If you are living in Australia find more information on home care options for long-term ventilated Adults& Children with Tracheostomy at

www.intensivecareathome.com.au
If you are living in Germany, find more information on
www.intensiv-kollegen-gesucht.de

If you are living in Austria you can find information on

http://www.gt-heimbeatmung.at/

In case your loved one is facing the prolonged Intensive Care stay with mechanical ventilation and Tracheostomy, depression, lack of privacy, lack of dignity, lack of control, lack of independent decision making and most of all lack of Quality of Life make your critically ill loved one's stay in Intensive Care extremely burdensome.

You need to ask the Intensive Care team questions regarding the immediate future of your critically ill loved one, especially if they suggest a ***"withdrawal of treatment"***.

You need to be aware that hospitals have policies and procedures to follow and unless treatment is being considered as futile, **you as the Next of Kin, as well as your loved one**, if fully conscious and in a position to make decisions, need to be involved in the decision making process when it comes to ***"treatment limitations"***, ***"withdrawal of treatment"*** or ***"NFR"*** (Not for Resuscitation) orders.

In my experience, most Intensive Care Units are pretty good and open about their processes regarding ***"NFR"***, ***"Treatment limitations"*** and End-of-life approaches, however **you as the Next of kin need to be involved in this process and no treatment should be withdrawn without your or your loved one's consent.**

The whole process around *"NFR"*, *"Treatment limitations"* and end-of life needs to be transparent and ethical and should not be finalised in one

meeting, nor should you feel pressured to make a decision. It usually takes time to come to a conclusion to what is best for your loved one.

You can also find more information about ***"treatment limitation"***, ***"withdrawal of treatment"*** and ***"NFR"*** in our Ebook "The 5 things you need to know if the medical team in Intensive Care wants to limit treatment, wants to withdraw treatment or wants to issue an NFR(not for resuscitation) order for your critically ill loved one in Intensive Care"

2. **Will my loved one die because of the ongoing mechanical ventilation and the Tracheostomy?**

Facts& Figures from the 2010 ANZICS Report: total admissions to Intensive Care in 2010 in AUS& NZ 110,191- the number of Patients receiving invasive ventilation was 43,330 or 41.6%- ICU Mortality during first ICU admission 6.6% or 7,272 out of all admissions to ICU

Unfortunately, to my knowledge, there are no credible statistics that tell us how many ventilated Patients in Intensive Care die, in comparison to non- ventilated Patients in Intensive Care. From experience, I would estimate based on more than 13 years Intensive Care experience that the vast majority of Patients that die in Intensive Care have been invasively ventilated at some stage.

Even though this sounds fairly bleak, you have to put things in perspective. A lot of Patients in Intensive Care are only short term ventilated. I would consider short term ventilation anywhere between <24 hours hours to one week, sometimes up to two weeks. This is my own opinion and based on my experience.

Mechanical Ventilation and Tracheostomy as such are generally not lethal. There are some instances where your loved one might have severe lung failure(ARDS) and despite advanced and sophisticated treatment such as V-V ECMO, Oscillation ventilation, prone positioning, Haemofiltration etc… your loved one may die as a cause of the lungs failing.

However, if your critically ill loved one is in Intensive Care due to other issues, injuries and illnesses that are very severe and life threatening in nature, your loved one might die, despite the mechanical ventilation and the Tracheostomy.

But always keep the bigger picture in mind that "only" around 6-10% out of all Intensive Care admissions are not going to survive. That's a pretty low figure,

considering the large number of critically ill people going through the Intensive Care doors.

3. **Is it painful for my loved one to have a Tracheostomy and ongoing mechanical ventilation?**

A Tracheostomy and mechanical ventilation are usually not painful. It is very likely to be uncomfortable. It does take time to get used to it, however most Patients in Intensive Care requiring ongoing mechanical ventilation with Tracheostomy, are entirely pain free and usually do not require any pain medication, only because they are ventilated. If they do require pain medication, it is usually because of other issues.

As you may have seen, whilst your loved one has been a Patient in Intensive Care, the bed side nurse usually needs to regularly suction sputum or secretions off your loved one's chest via the Tracheostomy. This procedure is making your loved one cough and neither does it look, nor is it comfortable for your loved one. Many Patients describe this as 'feeling suffocated'.

Unfortunately the suctioning of sputum and secretions is necessary in order to maintain a clear and patent airway and avoid any sputum plugs blocking the airway.

4. **What are strategies to improve my critically ill loved one's situation while they are in Intensive Care ventilator dependent with Tracheostomy?**

In order to look at strategies that work in an Intensive Care environment I have found that the following strategies tend to improve your critically ill loved one's situation if they are ventilator dependent with Tracheostomy.

- having regular and experienced nursing staff looking after her(some units have a tendency to let their junior staff or agency staff look after their long-term Patients, as the more experienced staff tend to look after more acutely unwell Patients)
- make sure that your critically ill loved one is getting regular natural daylight such as having visits outside as soon as their condition allows or simply ask for a room with natural daylight

- Put up some Pictures of your Family and of your loved ones around the bedspace
- Look at things that your loved one likes such as smells, taste, radio, TV etc…
- can your critically ill loved one have a quiet room with natural daylight or is your loved one exposed in the middle of a busy unit with no natural daylight?
- Make sure that the Intensive Care team is on top of things. Again, some Intensive Care Units have the tendency to almost neglect their long-term-ventilated Patients, as the Intensive Care staff get frustrated as well
- Ask the Intensive Care team whether your loved one might be better off with antidepressants in the interim. Antidepressants are not a long term solution though and they can only be a "bridge" to either a transfer home or to get your critically ill loved one off the ventilator in ICU
- No matter how difficult the situation, stay positive, your critically ill loved one will feel the positive vibes coming from you and your Family
- The longer your critically ill loved one stays in Intensive Care, the higher the risk of them catching an infection, therefore a side room with no or limited exposure to other Patients and therefore bugs might be an advantage as well

5. Is it possible for my critically ill loved one to have Quality of Life with ongoing mechanical ventilation and a Tracheostomy?

Look, the reality is that there is usually very little quality of life in Intensive Care, due to the inhibiting, limiting and controlled environment. I guess, especially in the acute, critical, life threatening phase, this is not really that important, as the Patients are usually sedated and in a medically induced coma.

As time goes on however, and your critically loved one is coming out of the acute and life threatening phase, but still requires ongoing mechanical ventilation with Tracheostomy, this is a critical and a "make or break"question.

As you might have seen, despite the nurses, the doctors, the Physiotherapists and everybody else involved in the care of your loved one, trying extremely hard to

make life as easy as they possibly can, there is only so much Quality of life your loved one can have in Intensive Care.

Once again, there will be a point where anxiety, depression, apathy, due to the sterility of the environment, the dependency on other people, the lack of control, the lack of self directed decision making, the lack of privacy and the lack of dignity will inevitably lead to no or very little Quality of life in Intensive Care. No Quality of life and the prolonged stay in Intensive Care may lead to your loved one getting depressed, anxious and he or she might be losing the will to live and he or she might end in a downward spiral.

Quality of life is difficult to quantify, as Quality of Life is a very subjective experience. The only way Quality of life for your loved one, requiring ongoing mechanical ventilation with Tracheostomy can be restored is in a safe home care environment, with specialist nursing care. This will ease the burden of being hospitalised in Intensive Care for your loved one, as well as for you and your Family and gets them in a safe and familiar environment, where Quality of life and in some instances Quality of-end-of-life can be restored for your loved one and for you and your immediate Family.

6. **Will my loved one never get out of Intensive Care because of the ongoing mechanical ventilation and the Tracheostomy and will my loved one ever be able to get off the ventilator?**

If your critically ill loved one has been long-term mechanically ventilated with Tracheostomy in Intensive Care, current hospital and health service paradigms are that there are very few or no perceived options and/or alternatives for your loved one, but to stay in Intensive Care for however long it takes to wean your loved one off the ventilator.

If your loved one is to stay in Intensive Care, because of the ongoing mechanical ventilation with the Tracheostomy and is otherwise clinically relatively stable, it's usually because of

a) Lack of shifting paradigms or lack of "thinking outside of the box" to look at possible and genuine alternatives
b) Current hospitals and Intensive Care realities

c) Health professionals(doctors and nurses) convenience
d) Lack of specialist home care nursing services such as www.INTENSIVECAREATHOME.com.au
e) Intensive Home Care Nursing is not perceived as an alternative as yet and/or not available in all countries
f) Hospitals and/or health services do not want to confront you with offering a "low- level care" alternative, such as substandard nursing homes or substandard home care, with no specialist skills
g) The issue of ***"withdrawing treatment"*** is too difficult to approach
h) Resources are unavailable for specialist home care nursing

To answer the question I set out to answer, your loved one does not have to stay in Intensive Care indefinitely, despite the ongoing mechanical ventilation with Tracheostomy.

Despite current hospital realities in most countries, for example countries like Australia, Germany, Austria and Switzerland are offering tailor made Intensive home care nursing services with the appropriate specialist nursing skills to provide Quality of life and/or Quality of-end-of life for your loved one in their own home, as a genuine alternative to a long-term stay in Intensive Care.

I have personally worked with long-term ventilated Adults& Children with Tracheostomy in their own home as a genuine alternative to a long-term stay in Intensive Care and there is no long-term Patient in Intensive Care that can't be looked after at home. If people are telling you something different, they have never been exposed, worked with or even thought about new models of care that are far more Patient and Family centred.

In Australia you can find more information on www.intensivecareathome.com.au

In Germany you can find information on

http://www.intensiv-kollegen-gesucht.de/

In Austria you can find information on

http://www.gt-heimbeatmung.at/

The other question I set out to answer was how long it would take for your critically ill loved one to be weaned off the ventilator and whether your loved one will ever get off the ventilator?

The answer to this question is that it depends. Most long-term ventilated Patients with Tracheostomy in Intensive Care will eventually be able to breathe by themselves, without ventilator support, but sometimes this can take a very long time, sometimes weeks and sometimes even months. Sometimes it also means that the Tracheostomy needs to stay in place, without the ventilator support at least in the interim.

From experience, the timeframe where I believe it gets critical and the timeframe where you should definitely be concerned about whether your loved one will be able to be weaned off the ventilator is around the day 40-60 mark in Intensive Care.

The reality also is that sometimes the weaning off the ventilator is not 'straightforward' and there can be many setbacks, including infections, depression, lack of privacy and lack of dignity in Intensive Care. There can also sometimes be the psychological ventilator dependency.

It is very hard to put a time frame on how long it takes for your critically ill loved one to be taken off the ventilator and breathe independently again. It depends on a number of factors including your loved ones

- Admission diagnosis
- Premedical history
- Emotional and psychological condition
- The level and quality of care your loved one gets

If your loved one has been in Intensive Care for 40-60 days or even longer that's when you need to start asking questions and that's when you need to start thinking about possible alternatives.

Fighting the depressive Intensive Care environment

Chances are that if your critically ill loved one has been in Intensive Care for 40 days or more, he or she is getting depressed and you and your family might be getting depressed too. There is usually no Quality of Life in Intensive Care for your loved one and you and your family have no Quality of life too. You and your family are probably spending far too much time in Intensive Care and you are stressed and you also might be neglecting your professional and your personal life. You might not be able to look after your children properly and/or you might not be able to look after your elderly parents properly. You are probably fed up with the whole situation and there is no or little help in sight.

After having worked in Intensive Care for more than 13 years, I can tell you from experience that taking your loved one home, despite the ventilator dependency is the best option to pursue, because of the much improved

- Environment
- Quality of Life(for your loved one and for your family)
- Individualised, holistic and Patient focused care
- Psychological condition

Just imagine what positive psychological difference and impact it would have, to take your loved one out of Intensive care, back into their own home.

It's massive.

Just think what difference it would also make to your and your Families life. You could stop worrying about going to Intensive Care every day and you could go back to a normal life and enjoy the things that you want to do and you can set your own agenda. You and your Family will be less dependent on other people, compared to a hospital environment!

That would still leave you worrying about your loved one of course, but imagine how much easier life would be if your loved one was at home with specialised nursing care, as a genuine alternative to Intensive Care?

Most hospitals in Australia know of the availability of such services and they usually support the approach of taking long-term ventilated Adults& Children with Tracheostomy out of Intensive Care, as it has proven to be very reliant and effective.

7. **Will my loved one catch an infection because of the Intensive Care environment?**

I guess the answer to this one pretty much goes like this: The longer your loved one stays in Intensive Care, the more likely he or she is to catch an infection. This is due to the nature of the environment, with lots of very sick people with lots of different bugs in Intensive Care floating around. Even though the Nurses, the Doctors and the Physiotherapists take precautions(hand hygiene and universal precautions) to prevent your loved one from an infection, just by the nature of

being a long- term Patient in Intensive Care and being weakened, depressed, anxious, apathetic, suffering from lack of dignity and lack of privacy, having other people making major decisions about your loved one and the general lack of control, are major psychological factors that can generally not be underestimated and usually increase the likelihood of your loved one ending up with an infection and therefore unnecessarily prolonging your loved one's stay in Intensive Care.

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