



## AMDA Conference Call Transcript

### Session No. 6: The Preventions or Respiratory Complications

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Let me put this all in perspective. Your condition involves basically muscle weakness and the only way this condition can severely harm or kill anybody is because of the effect of the muscle weakness, in particular the respiratory muscles. Now, sometimes the heart being a muscle can be involved, but it is not nearly involved to any degree like the respiratory muscles in general.

Most people suffer from the involvement of the respiratory muscles.

What are the respiratory muscles? You need to think about 3 groups of muscles:

1. Inspiratory Muscles for breathing
1. Expiratory Muscles for coughing (*those are mostly the abdominal and some of the chest muscles*)
1. Bulbar Muscles or throat muscles

The throat muscles are largely spared in Pompe's disease. I don't know of any patients who have lost the ability to speak, swallow and then can't protect their airway such that they basically drown in saliva dripping in the airway. This is very different from many other neuromuscular conditions. For example, in Lou Gehrig's disease, there is a type that is called Bulbar ALS where people can walk around and even play tennis, however, they can't speak or swallow and eventually they will need to get a tracheostomy tube because they can't keep the saliva out of their airway.

The good news in Pompe's disease is that I don't think this ever happens, so nobody should ever need a tracheostomy tube or even develop respiratory complications if you are properly informed and equipped.

So what does this mean? There are people that get so weak that they really can't breathe effectively. If they can't take deep enough breaths the carbon dioxide in the blood goes up and causes many of the following symptoms:

- Morning headaches
- Daytime drowsiness
- Difficulty concentrating
- Depression
- Loss of libido
- Fatigue

Fatigue is the most subtle and the most common symptom of not breathing deeply enough to



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maintain normal carbon dioxide levels. In fact, for a comparison, it is like walking into a vat of fermenting wine, where the carbon dioxide is so high that it can actually turn off your breathing completely and you stop breathing.

What happens when you don't breathe deeply enough and your carbon dioxide goes up? Carbon dioxide is acidic. The kidneys have to retain bicarbonate so the blood does not become acidic. We can't permit the blood to become acidic. So the kidneys retain bicarbonate to neutralize the acid. What that does though is that turns off the brain's breathing apparatus, so that the brain doesn't expect to breathe deeply anymore and it is like a bad cycle. The carbon dioxide keeps getting higher and the bicarbonate keeps getting higher, and then what happens one morning is you simply just don't wake up. This happens to many people with neuromuscular disorders.

What happens even more commonly than that, especially in children, is that they get a cold or bronchitis or RSV. And because their abdominal muscles can be very weak, they may not be able to cough effectively, the sputum lies in the airway and the bacteria multiply causing pneumonia and then they get short of breath and go to the local emergency room and the doctor there gives them oxygen. That turns off their breathing even worse, the carbon dioxide goes even higher and they stop breathing and then they get a tube down their throat to be hooked up to a ventilator.

So, the two ways that people can suffer and die from respiratory muscle weakness is the inability to cough effectively (which is the most common problem resulting in pneumonias), and simply not breathing deeply enough. After we hit 40 we get fewer colds, sometimes only one cold in 5 -10 years, whereas kids get a couple of colds a year. So, usually for children that suffer from neuromuscular disease they usually do ok until they get a bronchitis, and then they get the pneumonia and go into respiratory failure. Whereas for older people, they may just gradually develop higher and higher carbon dioxide retention, until they become very symptomatic, and if they are not put on some type of night time ventilatory assistance they can literally not wake up in the morning and become comatose and either be rushed to the hospital or even die that way.

Now the good news is that the throat muscles are rarely affected, if ever affected, to the extent that people need tracheostomy tubes with Pompe's disease. But people do still get tracheostomy tubes anyway because the doctors often think that the inability to breathe, or inability to cough or clear the airway is an indication for a tracheostomy tube. And this is what you have to understand. I have had many patients who have had no ability to breathe; they have had zero vital capacity for over 50 years.

Vital capacity is where you take as deep a breath as you can and you blow it into a spirometer that just measures the volume of air that you are able to put into your lungs in one deep breath. That is called the vital capacity and most of you have probably had vital capacities measured. For a normal breath, we generally need about 500 to 600 ml of air. If the vital capacity is 600 - 700 ml of air then we can breathe without ventilators ok, although each breath is about 80% of our capacity. It does tend to tire our diaphragms out and so that is when the brain starts to allow us to breathe more shallowly and the carbon dioxide goes up. So many people whose vital



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capacity of 600 or 700 especially as we get older they may very well be retaining some carbon dioxide at a little higher than normal.

When you cough, an average cough is four times the vital capacity. So, if you have a vital capacity of 1000, they may have a normal carbon dioxide and be able to breath perfectly well. But when they get the flu, the first part of a cough is a deep breath, about 2.5 liters and everybody takes a deep breath when they cough. If you try to cough with your lungs empty, you will see that it is not as effective. So part of the reason the cough becomes less effective is because you can't take a deep breath.

I've had patients over 50 years with a zero vital capacity, which means they cannot breathe a single breath or even 10% of a normal breath, they can't breathe anything for over 50 years and yet none of them have tracheostomy tubes. They have a little mouth piece by their mouth that is hooked up to a ventilator on the back of their wheelchair or at the bedside, and they get deep breaths through the mouthpiece. The mouth piece is 15 mm and it is not in the mouth, but next to the mouth and they just grab it a couple times a minute to get deep breaths.

Some people with a little bit of vital capacity, they can breath on their own but their voice is very low because they don't breath to a deep volume to be able to speak loudly and when there is a lot of ambient noise it is impossible to hear them. So, we often get a ventilator like that, put the mouth piece next to their mouth and then they can grab it when they need a deep breath, when they need to raise their voice, or when they need to cough.

Now, one of the things that we teach our patients is air stacking. Air stacking is when the machine delivers a breath and you hold it with your throat and then you let it cycle another breath and you hold it doubling you volume. Then do it again for triple that volume, and you keep going until you fill your lungs with air. Now, this is extremely important because probably most of you understand what range of motion is because many of you are probably seeing physical therapists and they have taught you that if you don't stretch your ankles, they will get stiff and if you don't stretch different joints that have some weak muscles, they will get stiff. Well, the same is true for the lungs and the chest wall. If you don't fill your lungs completely to the predicted inspiratory capacity, then parts of the lungs close down and the chest wall gets stiff. If this problem becomes severe, then you can't get a real deep breath to cough effectively with, then you may die from a stiff lung.

So, the first goal for everyone is to find out what your vital capacity is. We look at it two ways, the absolute value of it, which could be 1000 ml, and also the percent of what it should be. If the percent of what it should be is less than 70 or 80%, then everybody should be doing range of motion for their lungs and rib cage. To do that is very simple. What you need to get is an ambu bag or manual resuscitator (it is one of those balloon things with a mouthpiece on the end), and you put it in the mouth and you squeeze it and basically inflate the lungs just like you would do to a balloon. You take a deep breath and hold it with you throat, take another deep breath on top of that and we call that air stacking and you air stack up to as much air as you can hold and that stretches out the lungs and the chest wall and keeps them healthy and elastic. Now as the vital capacity goes down further, the most important thing is not the vital capacity while you are sitting, it is the vital capacity when you lie down. In Pompe's disease there is



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a tendency for the diaphragm to be involved a little more than the chest wall muscles and that causes the vital capacity to be lower when you are lying down than when you are sitting. In fact the symptoms from that are people can breath ok when sitting but they can't breathe lying flat. That is very common and that is because of excessive involvement of the diaphragm. That is a very easy thing to take care of. Some of you are using bi-pap and that is ok. However, if the vital capacity is under 70% or so, I don't recommend bi-pap.

Now, for those of you who do not know what bi-pap is, in the 1970's, we discovered a disease that can be described a 150 years ago. This is where people have obstructive apnea when they sleep. And they may be very much over weight and not strong enough to move their diaphragm to inflate their lungs. They had C-pap at that time. C-pap stands for continuous positive air-way pressure. This is the same as breathing with your head hanging out of a car window going about 50 MPH. It should never be used for anybody with neuromuscular disease because it doesn't help anyone breathe. It is true that it helps if you have obstructive sleep apnea, but it doesn't directly rest the muscles or assist the muscles. And for those 500 lb people who still aren't strong enough to ventilate their lungs they would try C-pap with 50-70 liters of water. It is like exhaling against a tornado. It is like exhaling against a tremendous flow of air that makes it difficult to actually get the air out. It is uncomfortable and it doesn't do any good. So, Respironics developed the Bi-pap machine and Bi-pap stands for Bi-level positive air pressure. And what that does is a box that pushes out a constant stream of air like C-pap except that you can adjust the pressure separately when you are inhaling and when you are exhaling. If someone gives you air under positive pressure, to your nose and mouth and to your lungs or while you are inhaling it makes it easier to inhale. If they give you positive pressure when you are trying to exhale that makes it more difficult to exhale so you can lower that pressure. So for example you can give an inspiratory pressure of 10 and an expiratory pressure of 4 and then you are actually giving a pressure assist of 6 ( $10-4=6$ ). Now if I get hit by a truck and become a C-2 quadriplegic and I have a zero vital capacity you are not going to ventilate me or anyone else with a pressure of 6. I would die quickly at that rate, because you need a pressure of 18 to 20 cm of water for normally compliant lungs. So what typically happens to people is that their doctors send them for a sleep study, and that shows that there is some problem with breathing during sleep and they are put on bi-pap. But they are put on Bipap at a lower span (inspiratory pressure of 10, expiratory pressure of 5) that gives them help, that helps them a bit, but as they get weaker, their carbon dioxide goes up anyway, and eventually they will collapse and they are told they need a trach tube which is absolutely wrong. Once they do get a trach tube though and they are hooked up to a different type of ventilator and if you look at the gauge on the ventilator it always reads pressures of 20-30. While obviously if you gave the pressure of 20 or 30 non-invasively through the nose like the bi-pap machine the patient wouldn't have collapsed in the first place, be intubated and get a trach tube. However, most doctors don't think of that. They really don't. It's incredible how people go from bi-pap and then they develop a cold and can't cough, they develop pneumonia, develop respiratory failure and then they are told that they need to be trached.





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Patients that are sent for pulmonary function tests in laboratories are basically wasting their time and their money. The laboratories are designed for people with lung disease and airway disease. The same thing is true for arterial blood gases. Pompe patients should never need arterial blood gases and what should be done (and what Dr Bach does) is this: They have a little machine called a capnigraph that monitors, or measures, the carbon dioxide level of the air that you exhale from the nose. So we know the carbon dioxide, the oximeter tells the oxygen saturation and a spirometer is needed to measure the vital capacity. But not just when you are sitting, also when you are lying down. When that difference is 7% or less (that is normal), but often when you lie down the vital capacity is half what it is when you are sitting. And even if when you are sitting it is 3000 I can guarantee you pretty much that the vital capacity is less than half that, (and) when you lie down you can't breathe. Which means you can go to a laboratory and they will find that you have a practically normal vital capacity, but that you can't breathe lying down anyway. So the treatment is to use a ventilator to give nasal ventilation overnight or they can use a lip seal.

Ventilation can be given through the nose or through the mouth. Lip seal ventilation works better than nasal ventilation, but again doctors are not familiar with this. (Through) nasal ventilation the air can go through the nose and leak out of the mouth. Whereas with the lip seal, the air can't leak out of the mouth and the air doesn't usually go back up and leak through the nose. Anybody having difficulty with nasal ventilation and if they are still symptomatic there are 2 things to think about:

1. The settings are no good, they are much too low. So if anyone is using nasal ventilation with bi-pap and still feels symptomatic--they may be better but not completely better, may feel tired, etc.--the settings are probably too low. You should be on a span of well over 10. If the e-pap on your machine doesn't go below 4 then you have to be on an i-pap of 15 or more to get a span of 10 or 11. Number 1 you have to increase that span make that, if you can, 20 i-pap and an e-pap of 2 if you can, if the e-pap can go down that low

2. The second problem that you have to suspect is excessive leaks out of the mouth. Normally this only happens if people are taking sedatives, narcotics or oxygen.

None of you should be taking oxygen. Oxygen is like putting a Band-Aid on a cancer. The cancer is under-ventilation and airway secretions. If you don't correct the ventilation and don't remove secretions when you have them, the thing gets worse, you get worse and you end up going into respiratory failure. Oxygen turns off the brain's ventilatory drive and turns off the breathing, so it gradually allows the carbon dioxide to get higher and higher. So I'll tell you right now, nobody should be taking oxygen. If you are taking oxygen it is probably a substitute for good ventilation.

Now let's talk a little bit about the bi-pap machines. Bi-pap is a pressure cycled ventilator. You adjust the pressure and it delivers air 'til it feels that pressure then it shuts off. So for example: If you adjust it to 20, it will deliver a volume of air until it feels that pressure of 20 and then if you try to hold that air and try to air stack with it you can't do it because as soon as it delivers another volume of air it is going to sense the 20 immediately and won't give any air. So you



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cannot air stack with a bi-pap machine which is why I never prescribe it for anybody over the age of 5--with the exception of the bulbar ALS patients since they can't air stack anyway since their throat is too weak. The other type of ventilator which is more appropriate for all of you is a volume-cycle ventilator, where you simply adjust the volume instead of the pressure and the machine doesn't really care what the pressure is, since it will deliver the volume that you set it at. The main reason why this is more appropriate is because you can air stack, get deeper breaths, cough better and speak louder. The volume-cycle ventilators are quieter, they have more alarms which is not a benefit, since you have to turn them off all of the time, and it is more expensive than bi-pap, which is why everyone likes to use bi-pap. The volume-cycle ventilator is also more comfortable because you don't have to get e-pap, there isn't any e-pap, so it is more comfortable, they are more quiet, you can air stack with them and they are very reliable, but they are more expensive than bi-pap.

For anyone who cannot breathe lying flat should be using nasal ventilation or lip seal ventilation from a volume-cycle ventilator ideally. And if the carbon dioxide tends to go up during the daytime, usually people are not symptomatic provided that they are using something at night like some of you are, and that the daytime oxygen saturation is normal. Normal is 95% or more. Remember this, this is very important; the oxygen saturation can only go down below 95 for 3 reasons when you are awake:

1. If the carbon dioxide goes up high the oxygen goes down. This is prevented by getting deep breaths through a mouthpiece using a ventilator.

2. Mucus in the airway, which blocks the lungs respiratory exchange membrane. That causes the oxygen to go down without the carbon dioxide going up. The treatment for that is assisted coughing. If you can't cough deep enough on your own there is a machine called the cough assist. That machine gives a real deep breath and then the pressure drops from +40 to -40 typically, that causes an effective cough, which clears the airway brings the secretions up, and patients don't develop pneumonia.

3. If you don't use the cough assist correctly and you end up with pneumonia or atelectasis. Actually, this is inevitable for everyone because we peak in terms of our strength at the age of 19 and after that we all lose 1% or more liver, kidney, heart and respiratory function. Over 30% of otherwise healthy people die in nursing homes from pneumonia due to just not coughing effectively anymore. If you start off with a condition that makes your muscles weaker to begin with, then you end up in trouble sooner. That is the bad news, but the good news is that the trouble is preventable just by learning how to do manual assisted coughing and if that is not adequate to get at least 300 liters per second of cough flow and the cough assist is available.



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When patients come to us, we really measure 4 things:

1. Carbon Dioxide level (painlessly)
2. Oxygen saturation
3. The Vital Capacity (sitting and lying down) and also the air stacking capability (how high beyond the vital capacity you can go)
4. Cough flows (both spontaneous and assisted cough flows). If the unassisted cough flow goes below 300 liters a minute you run a significant risk for developing pneumonia when you get bronchitis. Teaching assisted coughing, getting those deep, deep breaths by air stacking and pressing on the belly to increase the cough flows. And if they are not adequate, then we teach patients how to use the cough assist and that will do the job.

Anybody who can speak, their throat muscles are adequate such that even if you can't breathe at all and can't cough at all there is no need to even think about a tracheostomy tube or to die from respiratory complications.

Many of you have heard of Duchene's Muscular Dystrophy, these are people who are supposed to die when they are 18-20 years old. But when they get trach tubes they survive an average 7 years, but then they die from complications of the trach tube. Our patients have survived into their 30s and 40s without trach tubes, and we haven't had to put a trach tube into one patient in over 25 years and no one has died from respiratory complications with Duchene's because of the cough assist and non-invasive ventilation.

Up until 10 years ago, we thought children with Vernig Hofman disease would die without trach tubes because they are born paralyzed, 90% are dead by 12 months of age, 100% by the second birthday, and they can't speak, can't swallow, and I had parents of two patients that refused trach tubes and those kids are still alive today, 10 years later. So as a result from what we learned from them, we aren't putting trach tubes in other babies with Vernig Hofman disease and most of them are surviving. It is all because of non-invasive ventilation, sometimes for as much as 24 hours a day, and the cough assist machine that helps them cough effectively.

Sometimes you are OK and then you have to have some sort of surgery, appendicitis, or a gastrostomy tube or whatever surgery you might need. Anything done under local anesthesia should not be a problem, but if you are given general anesthesia that causes airway secretions post-op, as well as tiredness, weakness, difficulty coughing and people can get pneumonia. It is extremely important for anybody with a cough flow under 300 liters a minute to see if there is a cough assist machine. The nursing staff does not have time to use this machine every 5 minutes, and doctors have a way of writing orders to give the treatment every 4 hours. But if you have bronchitis, can you wait 4 hours to cough? Of course not, sometimes you have to cough all the time and if you don't get help coughing when you need it, then that is when you get pneumonia. I always tells my patient's doctors to write an order on the chart that the family can help the patient with the cough assist ad lib, to be used as needed and they use the oximeter as



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feedback. Like I said before, a normal oxygen saturation is 95% or more. Nobody can ever develop respiratory failure with normal oxygen saturations unless you give them oxygen. Again, nobody should be getting oxygen even in the hospital that should be used as a last resort, but certainly at home no one should be given oxygen. We tell the family to watch the patient and if the oxygen saturations fall below 95% to immediately use the cough assist until the saturation goes back up to 95% or more and that is how to prevent patients getting pneumonia.

Now people who get gastrostomy tubes, at least at my facility they can get this done under local anesthesia. Actually for adults, many places do this. But for children there are only a couple of places in the country that can put in gastrostomy tubes under local anesthesia.

In my last book I described all the surgeries with the pictures and I tell people to copy out this information for their doctor and if their doctor can't do the surgery this way then they should come to my facility where they can do this surgery without the risks under local anesthesia. We also have patients come to them from all over the country for scoliosis surgery because we guarantee they will not need to have trach tubes. I can guarantee this because of the following:

We have patients come before the surgery and teach them non-invasive ventilation like bi-pap at night with the nose piece, mouthpiece ventilation and we teach them how to do the assisted cough so that they can use the cough assist machine. Once a patient knows how to use the bi-pap through the nose or mouth then I know that at the end of the surgery, even if they are so weak that they can't breath at all, that once their lungs are healthy, they can take the tube out without putting in a tracheostomy tube and ventilate them on non-invasive ventilation even 24 hours a day if necessary, or until they get stronger again and can wean back to night time ventilation only. Most other places when a patient is intubated after surgery when they are too weak to breath they think they need to trach them, and we know that we don't need to trach patients because they can't breath or they can't cough.

So, this is information to keep in the back of your mind, because once doctors start talking about trach tubes, if I were you I'd tell them I wanted out of there and to send me to a place where they can extubate me without traching the patient.

So, if you teach someone how to use non-invasive ventilation and assisted coughing in pre-op, even if they are so weak that they can't breath or talk post-op, you still don't have to trach them.

Let me tell you the problem with blood gases. 30% of the time people hyperventilate because of the pain, so the carbon dioxide will be artificially low. This is published in one of the two big pulmonary journals in the country, but doctors are still doing blood gases because they have got into that habit and they don't have carbon dioxide monitors even though they have been available for 20 years. The other reason doctors do blood gases like that is because they are used to treating people with lung disease, and when you have lung disease, capnigraph is not as accurate. So they don't even think about using a capnigraph because they don't usually have one. It really is not good to do blood gases because the blood gas carbon dioxide is not only artificially low sometimes, but it is only a one point in time measurement. Whereas if you moni-





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tor the carbon dioxide you can monitor it all night and it is painless.

Questions and Answers:

**Q: I can't breathe when I'm laying flat at all, and my fear is if I fall down during the day time I'll die since I can't breathe.**

A: Well you have pretty good bulbar muscles like most people with Pompe disease. One of the things that you can learn is glossopharyngeal breathing by using your throat, even lying down. A person can learn how to do this breathing sufficiently so they don't have to use a ventilator during the day. You can learn to do this by basically breathing like a frog. Frogs do not have diaphragms and they actually capture the air with their throat and they bring it into their lungs. They will take 3 to 4 gulps for their breath and that is what basically people do. Some people learn this on their own. 2 out of 3 people learn how to frog breathe immediately after watching me do it. Most people can learn how to do this by imitation.

**Q: You can tell I use my neck muscles to breathe by watching my neck when I breathe.**

A: Yes, but those neck muscles will get you tired. You are using accessory breathing muscles for breathing and if you are using these muscles during the daytime, that is tiring you out. I recommend, when you are sitting down, that you use a volume-cycle ventilator with a little mouth piece that you could just grab to get deep breaths. That will rest your muscles when you breathe and make you feel more energetic and less tired, and completely relieve your accessory muscles.

**Q: They put me on oxygen.**

A: Nobody should be on oxygen. You should be using a volume-cycle ventilator; there are many different types out there. However volume ventilators are more expensive than bi-pap machines.

**Q: You have given us so much information.**

A: Some of you have seen some of my websites, but the one I recommend you look at is [www.doctorbach.com](http://www.doctorbach.com). Now on that website the webmaster has put the templates for the typical letter of medical necessity that he uses for all of this equipment. Everyone should have an oximeter because if you get sick then you put the oximeter on and you don't let the oximeter go below 95. You use your ventilator, you use your cough assist, but if you wait until you are sick to obtain an oximeter, already your oxygen saturations could be 70% and you will have pneumonia even before you get the oximeter. It is very important for all of you with a weak cough to have an oximeter in the house. Not to use every day but to use when you get a cold. You just put it on your finger and you don't let it fall below 95.



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You can print out the sample letters of medical necessity and give them to your doctors and they can adapt them for your use.

**Q: Do you believe sleep studies are helpful for a patient who is not yet on a mechanical ventilator at night?**

A: That is a very good question. The answer is no and I will tell you why. Those sleep studies are about \$3500 and you go to the hospital where you can't sleep anyway, and then the doctor may find a sleep abnormality and may tell you have sleep disorder breathing and prescribe C-pap which is never appropriate for a patient with Pompe disease. Other times they prescribe bi-pap but they usually prescribe it at low spans and then the patients are using it and feeling better but then they get a cold and they go into respiratory failure, and then they go to the ER and end up getting a trach tube. Now the sleep study (or the night time bi-pap) is not the primary thing that people need to learn. They need to know what to do when they get sick. They need to know how to cough more effectively and also to maintain normal ventilation, not only at night but also during the day. So the reason I don't feel like these studies are useful is because they don't monitor carbon dioxide. Carbon dioxide is the most important thing to be looked at when you are sleeping if you want to know how someone is breathing. And we don't treat people even if the sleep study is not normal. We treat people if they are symptomatic, because when you become symptomatic, then you will want to use night time ventilation. If you are not symptomatic, but the sleep study is abnormal you aren't going to use the night time ventilation.

**Q: Can you have normal oxygen saturation at night and still have elevated carbon dioxide levels?**

A: Yes, but usually when this happen, patients are not symptomatic and usually are not treated. We only treat people that are symptomatic. Because when you become symptomatic then you will want to use night time ventilation. If you are not symptomatic but the sleep study is abnormal you aren't going to want to use night time ventilation, and why should you bother since there is no evidence that it is doing you any good.

------(Cross-Talk)-----

When you have had a trach tube, the trach can cause so much damage to the airway that it may be impossible to get rid of the trach, so it is always better not to get one in the first place. But most people with trach tubes, the trach tubes can come out. 20 to 70% of the people with trach tubes develop tracheal stenosis and if the stenosis is bad enough you can't remove of the trach tube. It is a question of how much damage is caused by the trach tube before it is time to remove the trach. The way we evaluate people to take out trach tubes is we put a fenestrated tube in and cap the tube and inflate the lungs with air, press on the belly and we measure that flow. If that flow is 160 liters per minute or more, then the airway is sufficiently clear (in other words the stenosis isn't so bad) and we can take the trach tubes out. Whether the patient can breathe or not, we will still take the trach tube out. But if the flow is not that high, then there has got to be some obstruction and you may be able to breathe around that obstruction but as soon as you got a cold the obstruction will not permit sufficient cough flows, so then we would not take out



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the trach tube under those circumstances.

**Q: Where would the stenosis be located? Above or below the trach?**

A: The stenosis would be below the trach tube. But you can also have an obstruction above the trach tube. If you don't use your vocal cords they become contracted.

**Q: Is it possible for someone who has had a trach for 13 years come off the trach tube?**

A: Absolutely. Sometimes people have damage after just a few months and others have a trach tube for 20 years with out any damage.