



Common Parent Tube Weaning Fears

If you are a parent or caregiver thinking about beginning a tube weaning program for your child, it is normal to have a mix of emotions. You might be excited and hopeful about your child no longer needing the feeding tube, but you may also have concerns or even fears about tube weaning. It is important to know that you are not alone. Other parents have the same fears, especially about whether the tube wean will work. Even your child's doctors and therapists sometimes have the same fears! You do not need to act like you are not afraid. In fact, you can talk with your child's care team about the fears you have because they will be able to help you.

Members of our NPCQIC team have read well over 50 research papers about tube weaning and also talked with medical providers who have done a lot of tube weaning. We learned important things to keep in mind. Tube weaning works for children with many types of medical problems, including Congenital Heart Defects, and it can be done safely.

It can help you feel less afraid by reading this list of the common fears that parents (and some medical providers) feel, along with the information or ideas that can help you put those fears aside. First, notice when you are feeling afraid. Next, pay attention to the thoughts in your mind related to the fear (such as "what if the tube wean doesn't work for my child?"), and then use the information in the chart below that relates to your fear.

Are we ready?	
FEAR/CONCERN	THINK ABOUT...
Can my child tube wean if they have never drank from a bottle or eaten food? Is my baby's swallow safe?	<ol style="list-style-type: none">1. A child does not need to be taking much by mouth to start a wean because many children are not taking much from a bottle or cup at the start, but they often start doing so within 1 week or less. Some children take a bit longer, and your child's medical team will help along the way.2. The tube might be the reason your child is not taking anything by mouth (this is called tube dependency), so you will hopefully see this improve as tube feedings are taken away.3. Stay patient and persistent as your child learns to suck and swallow, something they may not have been able to do while the tube was there.4. The medical team can complete a swallow study to see if your child's swallow is safe.

<p>Are we ready? We just got through interstage, which was very stressful, and we don't know if we can now add the stress of tube weaning.</p> <p>Are we pushing our child too soon to tube wean?</p> <p>Is my child really ready for weaning?</p>	<ol style="list-style-type: none"> 1. As your child's parent/caregiver, you know the positive and negative things about tube feeding for your family. Thinking through these can help you decide if you are ready for weaning off the feeding tube. 2. Your child's medical team will consider important things about your child to decide if they are ready for tube weaning (this is called Tube Weaning Readiness and focuses on whether the child's heart issues are stable, if their swallow is safe, and if their nutrition status is stable). 3. When a child is ready for tube weaning, it is best to do it sooner rather than later because it helps the child's development get better and the family have less stress after the tube is out. 4. Be honest with the medical team if you don't feel ready to tube wean. The team can talk with you about this to make the best decision for your family. You really do need to be honest with the medical team in order for tube weaning to work. 5. If you participated in Interstage Home Monitoring or a similar program, this may have allowed you to develop a close relationship with your child's medical team. Because the medical team knows your family so well, they are probably in a very good position to guide you through the tube wean just as they guided you through interstage.
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Can the medical team support us and do they have experience?

FEAR/CONCERN	THINK ABOUT...
Can we do a wean 100% virtually if we live far away from the hospital?	1. Yes...this has been done in many research articles so you can ask if this is an option with your child's team.
Who is going to help us after-hours?	<ol style="list-style-type: none"> 1. Speak with your child's medical team about who to contact. Keep in mind that it is rare for serious issues to happen after-hours. 2. Your medical team can also help you understand what types of issues are emergencies and whether you should call in.
How do I know if my child's team has enough experience/that they can see my child through a wean?	<ol style="list-style-type: none"> 1. Tube weaning is often not complicated. Even if your child's medical team has never done a tube wean, there are many research articles they can read and experienced people for them to contact. If the team thinks your child is ready to wean, research shows that 90% or more kids are able to be tube weaned. 2. Every child and family has a different tube weaning experience. Your medical team is there to help problem-solve through the issues that come up.

What if this doesn't work?

FEAR/CONCERN	THINK ABOUT...
<p>What if the wean doesn't work (our child still needs the tube, the tube must be reinserted, the wean has to be delayed, etc.)?</p>	<ol style="list-style-type: none"> 1. Life with a feeding tube is very difficult. When children are ready for weaning, it is worth doing because most children thrive off the tube and live a better life without it. 2. While it is scary to try something when there is no true guarantee it will work, the odds are in your favor because 90% and more of kids are able to be weaned. 3. If your child cannot completely stop using the feeding tube after a wean, this does not mean that future attempts will fail! For example, children might catch a normal cold during a wean and may need to pause or restart a wean once healthy. This is not considered a failure. 4. Also, even if your child does not completely stop using the tube, there is a good chance they can use the tube much less than before their wean.

Will anything bad happen?

FEAR/CONCERN	THINK ABOUT...
<p>What if my child loses too much weight and the wean must be stopped? What if the wean creates problems for their development, weakens their immune system, damages their heart, etc.?</p>	<ol style="list-style-type: none"> 1. Weight loss is expected and accepted. The research notes acceptable weight loss of up to 10%, and your child's medical team will monitor this. 2. However, most kids do not lose more than 10%. 3. Your child's team will consider many factors during the wean, not just weight. For example, your child's energy level, number of wet diapers, developmental skills, and <i>quality</i> of feedings can show the team if they are doing ok. 4. In the research studies we read, heart problems did not cause problems during or after tube weaning. 5. Many children show <i>better</i> development after a tube wean.
<p>What if my child becomes dehydrated or constipated?</p>	<ol style="list-style-type: none"> 1. The risk of dehydration is much lower after the Glenn surgery. 2. Constipation can happen and should be addressed early. Your child's medical team will monitor this. 3. To decide whether a child needs more liquids, do not only think about what they drank. Your child's medical team will also think about the number of wet diapers, overall energy level, and if they are making tears while crying.

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These are some of the research articles we read to help us learn more about tube weaning.

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