

# Should I Get a Feeding Tube?

## Questions & Considerations for Individuals and Their Healthcare Decision Makers:

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*This pamphlet will guide you as you make decisions about the possibility of getting a feeding tube. Our desire is to promote better communication between you, your healthcare decision maker, your team and your medical provider. We chose to use questions rather than providing answers because there are many ways to answer each question. More important, we believe the answers to these questions should be based on your needs and your circumstances.*

You may be experiencing difficulty eating or drinking by mouth. How do you know if this is a problem and reason for concern? The following list of symptoms can help you understand if you have eating and drinking problems. People with eating or drinking difficulty frequently experience a combination of these symptoms. Do you:

- Experience fatigue while eating?
- Cough or choke while eating?
- Have heart burn often?
- Find you are losing weight and you do not know why?
- Take more than one hour to finish your meal?
- Did someone on your team tell you that you have *dysphagia* (trouble with swallowing) or *aspiration* (food goes into your breathing pipe)?

If so, you can:

- Ask your medical provider if you need a swallowing study or other tests and referrals;
- Ask for a Speech Therapist consultation;
- Ask for a S.A.F.E. Clinic evaluation (you do not need a referral).

If you are told that you have Dysphagia, now what? The following are some questions to ask your team and physician:

1. Can I eat or drink anything safely? If yes, what precautions are recommended?
2. If I cannot eat safely by mouth, how can I eat? What are my options?
3. How can I get enough nutrition and fluids if I am not eating or drinking by mouth?
4. What are feeding tubes?
5. What are the different types of feeding tubes and which one is best for me?
6. If I get a feeding tube can I ever drink or eat again?
7. What will happen if I decide not to have a feeding tube?
8. How will a feeding tube change my day-to-day life?

9. Do I have to get it right now?
10. Will the feeding tube prevent me from aspirating?
11. How will I take my medicines?
12. How will they put the tube in? Explain the surgery to me.
13. What could go wrong in the surgery? Afterwards?
14. What are the risks of having a feeding tube? Immediately and in the long run?
15. How soon after the surgery can I start receiving food and medicines through the tube?
16. Will I be able to go back to my home and what support will I need?
17. How do I take care of the tube at home? Will I need more nursing or can staff help me?
18. Does it need to be cleaned?
19. How will I know if something is wrong with the feeding tube?
20. Can the feeding tube get wet when I bathe?
21. Can I swim with a feeding tube?
22. What if the feeding tube comes out? Who puts it back? How quick must it be put back in?  
Do I have to go to the hospital or emergency room for this?
23. When do I need follow up? Will I always need to see a specialist?
24. Does the feeding tube ever need to be replaced? How often?
25. Will I have a feeding tube forever? Will I ever be able to eat or drink a little bit?
26. Does it hurt to have a feeding tube? How does a tube feel?
27. Will I still have to brush my teeth? How will my oral hygiene change?
28. How might my friends and family react if I get a feeding tube?
29. Given my medical condition, will having a feeding tube prolong my life?

If you, your team or your physician need help with these questions, you may call:

- **Supports and Assessment for Feeding and Eating (S.A.F.E.) –**
- **Pediatric SAFE: (505) 277-0111**
- **Adult SAFE Clinics: (505) 841-6188**
- **Continuum of Care Project: (505) 925-2350**
- **New Mexico Department of Health, Developmental Disabilities Supports Division (DDSD), Clinical Services Bureau: (505) 841-2948 or 1-800-283-8415**
- **DDSD Regional Office Nurses:**
  - Metro: 1-800-283-5548**
  - Northeast: 1-866-315-7123**
  - Northwest: 1-866-862-0048**
  - Southeast: 1-866-895-9138**
  - Southwest: 1-866-742-5226**