

Customizing Your Tube Feeding Experience

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Learning Objectives

- Empower the consumer to customize their tube feeding in order to improve the quality of their lives and make the tube feeding work for them



Importance of Tube Feeding

- Source of nutrients, fluids and electrolytes; life sustaining
- Supplemental or total nutrition
- Necessary to improve or maintain adequate nutrition status
- May be permanent or temporary
- May be used prior to or immediately after reconstructive surgery or intestinal transplantation



Tube Placement

- Begin with a frank, open discussion with your physician, surgeon, and gastroenterologist about your needs and desires in choosing your ideal tube
- Consider comfort, body image, clothing (belt line), physical activities
- Do you need a skin level device which is easily hidden under clothing such as a “button” or would it be easier for you to have a tube that has a longer length which is easier to access?
- Large output ostomies: be creative in covering these with beautiful bags.



Formula Selection

- This category generally has the least amount of negotiation with your health care provider.
 - It is important to inform your health care provider of your tolerance of the formula.
 - If you are having gastrointestinal symptoms, you should inform them. They may be open to trying different formulas with you.
- Would you prefer a formula that is in a closed system which just needs to be hung versus a system where you have to open several cans and pour into a bag?



Infusion Rate

- Consumer has a great deal of control
- Once tolerance is established YOU decide when to start the infusion. PLAN INFUSION AROUND LIFE.
 - It is perfectly acceptable to stay out late to enjoy a night out on the town and start your infusion a little later. Or you can infuse your tube feeding a little earlier that day if you know you will go out.
- You can also increase the infusion rate as long as you tolerate it. There is nothing magical about 12 hours. You may be able to infuse in less time; you may need more time.
- There is also nothing magical about a straight continuous infusion. Although many patients tolerate this best, you can infuse the tube feeding for several hours, disconnect to do some other activity and then reconnect. This is referred to as an intermittent infusion.



Infusion Schedule

Is it OK to skip a day?

- This should be discussed with your health care professional.
 - tube feeding is not only a source of nutrients but also a source of fluid and electrolytes; people can become dehydrated quickly.
 - if you do consume and absorb some nutrition by mouth, you may be able to skip a day if you increase the amount of tube feeding the day before and the day after.



Infusion Pumps

- If you have to use a continuous infusion, how can you make it work for you so you can leave the house?
 - use a standard back pack or a designer bag draped over the shoulder
 - If this is too heavy there are bags on wheels that can be used. There are many new travel bags that can easily be converted for this use.
 - Don't be afraid to stop the infusion for short periods of time. You can always increase the infusion time later in the day.



Infusion Pumps



Designer Backpack



Designer Shoulder Bags





Infusion Pumps



Rolling Suitcases



Travel

- Being on tube feeding does not mean you are restricted to home
- You can safely travel on vacation, to visit family and friends
- Your home care provider can help you make arrangements for delivery of supplies
- Make certain your doctor knows you will be traveling





Flying



- Medicines should be in original containers with the prescription label
- For tube feedings, IVFs, or PN bring only what you will need for the flight and pack the rest
- You must have a note from your physician on his/her letterhead stationery stating that you must have this for the flight
 - Translate the letter if flying to a foreign country
 - <http://babelfish.com/>
 - <http://www.freetranslation.com/>
- You must declare this at the security check point



Having Fun



Can you run marathons, play tennis, baseball or dance?

- Sure! As long as your doctor feels you are healthy to do these things your tube feeding should not hold you back.
- You can disconnect your tube feeding for the desired activity



Having Fun

What about hot tubs and spas?

- water that is chlorinated
- public swimming pool
 - A proprietor may restrict clients from swimming if they have open wounds, drainage, infection or significant granulation tissue





Meal Times

- Food is more than nutrition
- Social, cultural, religious
- Spend time with family and friends during meals
- Consider infusing your tube feeding during this time
- “Taste” the food and expectorate if necessary





Other Infusions

Is it OK to infuse other things through your feeding tube?

- Sure! How about that morning cup of coffee...
- Just be certain to flush your tube with water afterwards





Attitude

- Life is about attitude
- Without tube feeding you would not be able to nourish your body
- Put a positive spin on it
- Tube feeding is freedom
- **YOU** are in control of your own nutrition
- Learn to incorporate these practices into your daily life





Attitude

- Adjust life goals and priorities
- Accept changes associated with illness and surgery
- Accept need for tube feeding
- Redefine “normal”





Conclusion

- With a few adjustments and some creativity you can make tube feeding work for you
- It is important to be responsible, but you can also be flexible



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