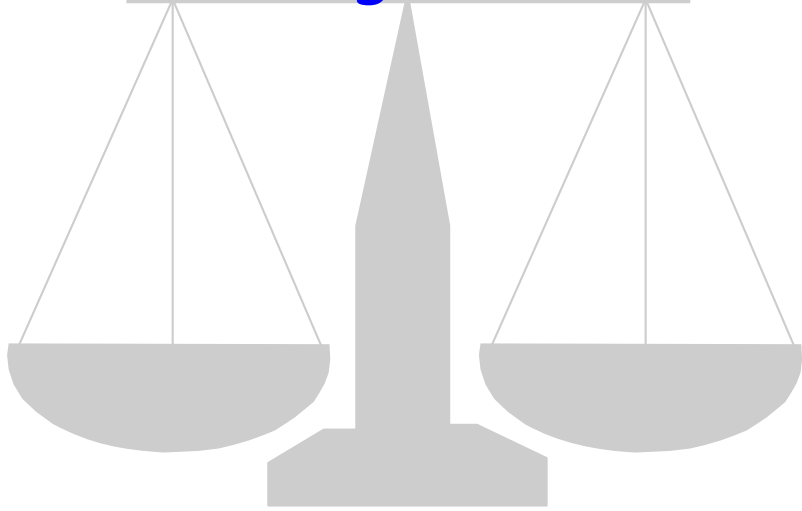


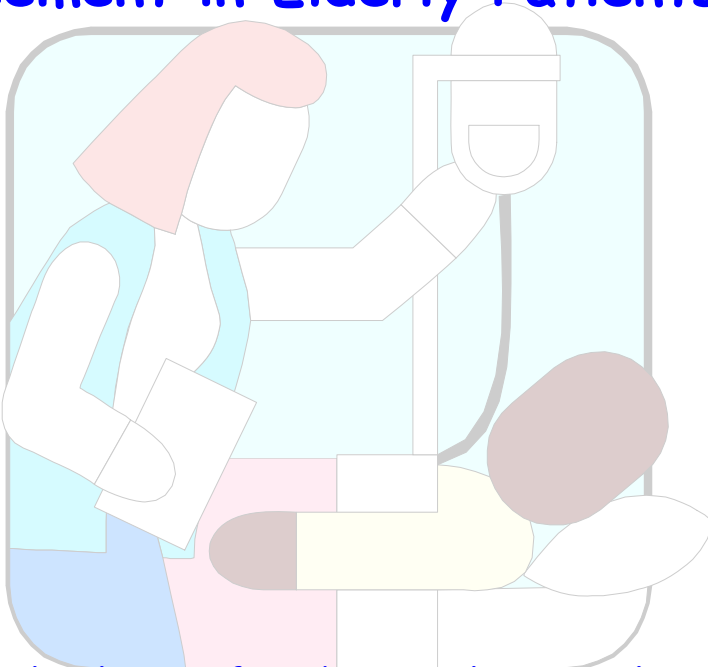
## Making Choices:



SL Mitchell MD MPH FRCPC  
JM Tetroe MA  
AM O'Connor RN PhD  
A Rostom MD FRCPC  
C Villeneuve BSc RD  
B Hall RN BScN

Geriatric Medicine, Epidemiology  
Health Research  
Nursing, Epidemiology  
Gastroenterology, Epidemiology  
Dietitian  
Geriatric Nursing

## Long Term Feeding Tube Placement in Elderly Patients



Division of Geriatric Medicine  
Clinical Epidemiology Program  
Ottawa Hospital – Civic Campus  
Ottawa Health Research Institute  
1053 Carling Ave  
Ottawa Ontario K1Y 4E9  
Canada

Telephone: 1-888-240-7002  
Fax: 1-613-761-5402

E-mail: [ohdec@ohri.ca](mailto:ohdec@ohri.ca)  
SL Mitchell: [smitchell@hrca.harvard.ca](mailto:smitchell@hrca.harvard.ca)

A booklet and audio tape for substitute decision makers

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The Ottawa Hospital | L'Hôpital  
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Canada's university



Regional Geriatric Assessment  
Program

Ottawa Health Research Institute



Supported by a grant from Physician Services Incorporated.  
Dr. Mitchell is a recipient of an Ontario Ministry of Health  
Career Scientist Award

## Welcome

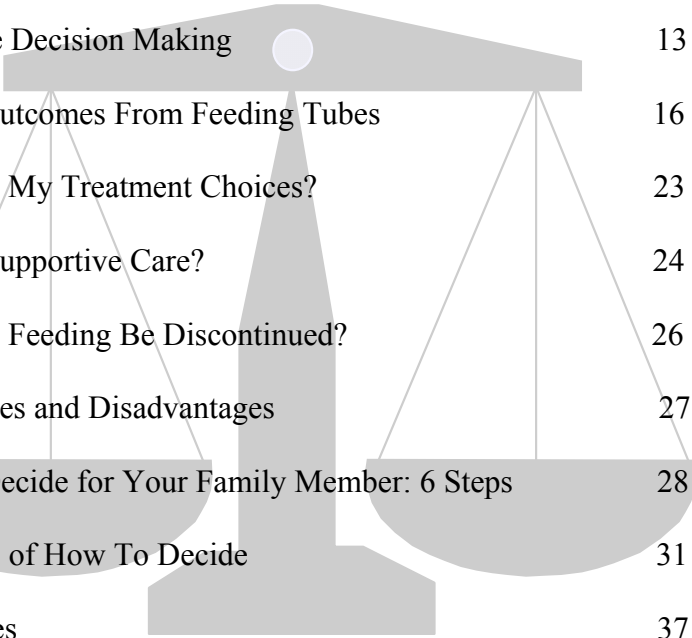
This workbook and cassette tape have been designed to prepare you for a decision about placing a feeding tube in an elderly patient. As you go through the booklet and tape, you will learn about substitute decision making as well as the advantages and disadvantages of placing a feeding tube in your friend or family member.

1. Set aside about 45 minutes
2. Listen to the cassette while reading through the booklet.
3. Please stay on the page until you hear the sound to turn to the next page.
4. Please fill out the worksheet.

Research studies that support statements in this booklet are referenced by numbers like this: <sup>1</sup>. The complete list of references is at the back of the booklet, starting on page 37.

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## This workbook is for **you** if:

- **you are the substitute decision maker for an older person who is *currently* unable to make his/her own health care decisions**
- you need to decide whether the person should have a long term feeding tube known as a gastrostomy tube (PEG) or a jejunostomy tube (j-tube)
- this workbook does not deal with the decision to place very temporary feeding tubes called nasogastric (NG) tubes

## You will learn about:

- eating and swallowing problems
- feeding tubes
- substitute decision-making
- advantages and disadvantages of feeding tube placement
- treatment options
- how to decide

## Why do people develop eating and swallowing problems?

Damage to the muscles and nerves needed for proper swallowing,

Possible causes are:

- Stroke
- Parkinson's disease
- Amyotrophic lateral sclerosis  
(Lou Gehrig's disease)

Inability to eat independently because of:

- Alzheimer's disease
- other dementias

Blockage of the esophagus (the tube that goes from the mouth to the stomach):

- cancer of the esophagus
- stricture

Severe loss of appetite or interest in eating:

- major depression

## How do eating and swallowing problems affect older patients and those close to them?

### PHYSICAL

**Aspiration:** Food or saliva may be inhaled into the lungs if the patient is very drowsy or if he has problems with the nerves or muscles needed to swallow. This may result in lung infections.

**Poor nutrition:** The patient will:

- become weaker
- lose weight
- become less aware of what is going on
- not recover as quickly from a sudden illness

**Comfort:** A patient who is very aware may feel hungry and thirsty. Patients who are not very aware may not feel hunger or thirst.<sup>1</sup>

## EMOTIONAL

Friends and family may find it difficult to accept a patient's serious illness. They may find it hard to see a person close to them not eat enough. They might feel worried that the patient may feel hunger or thirst.

## SOCIAL

- Eating is social and symbolic of care giving.
- Helping a patient to eat can be a pleasant way to interact with him or her
- If a patient cannot be hand fed, the family may feel a loss of this personal interaction. However, other ways of socializing with him or her are always possible.

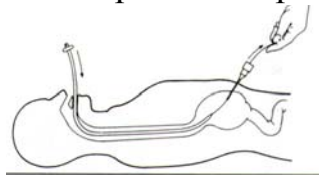
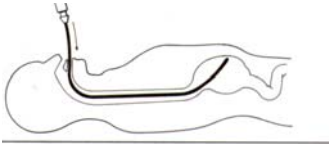
## What is a percutaneous endoscopic gastrostomy (PEG)\* tube?

- A tube placed directly into the stomach of someone with eating problems
- **An optional medical treatment**
- Percutaneous – through the skin
- Endoscopic – a doctor will put a tube with a camera in it (*an endoscope*) down into the patient's stomach to help guide the tube into the correct spot
- Gastrostomy – a procedure where a tube is put into the stomach through a small hole in the abdomen

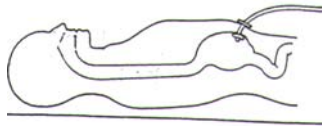
\* Another type of long-term feeding-tube called a jejunostomy tube may be offered to your patient. The procedure to place this tube differs slightly. You should ask your doctor about this.

## How is the tube put into place?

- The patient is mildly sedated (not put to sleep).
- The endoscope is placed through the mouth and into the stomach. This can be a bit uncomfortable, but it does not hurt. It is needed to see where the best place is to put the tube.



- The patient is given a local anaesthetic to freeze the skin on the abdomen so that a small cut can be made. The tube is inserted through the mouth and pulled out through the opening in the abdomen.

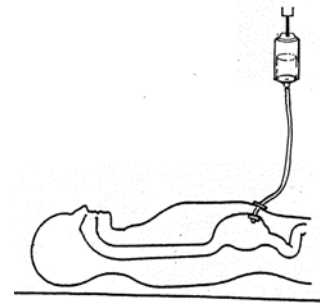


- This procedure takes about 15 minutes.
- Sometimes it is not possible to insert the endoscope because the esophagus is blocked by a growth or tumour. In these cases, the feeding tube would be placed surgically.

## How Does the person with the feeding tube get their food?

- Liquid food is put into a bag and then delivered into the stomach through a tube.
- The food is a commercially prepared liquid that provides a balanced diet for the patient. It is something like a milkshake.

- Most patients will be fed through the tube at usual meal times. The feeding will take about one hour. Some patients will receive continuous feedings in which the same amount of food is given, but at a slower rate over 24 hours.



- Medications as well as water will also be given through the tube.

## What is involved in the care of the tube?

- Care must be taken not to pull out the tube.
- The nurse will check for tube leakage, blockage and will make sure that the food is going in properly.
- The nurse will clean around the tube at least once a day and check the surrounding skin.
- The tube will usually need to be replaced within six months to one year.

## Will the person with a gastrostomy tube have to stay in bed?

No, the tube is very portable. When the tube is not in use, it will not restrict the patient's usual activities.

## What is "substitute decision making<sup>2</sup>"?

- deciding for others who are unable to make their own health care decisions
- what the patient would want may not be the same as what you would choose for yourself in the same situation
- substitute decision making can be very difficult and emotional

## Who becomes a "substitute decision-maker"?

- a person previously named by the patient (someone who has **power of attorney for health care**)
- next-of-kin
- appointed guardian

## What are the steps involved in substitute decision making?

- 1) Consider the previously expressed wishes of the patient from either:
  - living will (sometimes called an "advance directive")
  - previous discussions the patient had with you and/or others

These wishes should be respected, even if you do not agree with them.

- 2) Consider all you know about the values of your patient when she was well. From what you know do you think she would choose to get a feeding tube in this situation or not? This is called "substituted judgement".
- 3) If there are no previously expressed wishes and you cannot judge what your patient would want, consider what is in his "best interests".
  - what are the possible advantages of tube feeding
  - what are the possible disadvantages of tube feeding
  - how will this decision affect his quality of life

## Can a feeding tube be placed without the written consent of the substitute decision-maker?

No



## Possible health outcomes from Feeding Tubes

Tube feeding is a medical treatment that can have a variety of possible health outcomes or consequences.

These outcomes can be divided into two types:

- Specific complications from the feeding tube itself
- General health outcomes that most commonly come up in discussions about feeding tubes, for example:
  - ◆ survival
  - ◆ aspiration (breathing in of food)

In the next few pages, we will talk about these outcomes so that you can have a better understanding of the advantages, disadvantages and other considerations about tube feeding.

## Ranking studies about tube feeding

In order to learn about health outcomes, you need to understand about the different types of research studies that can be done. There are basically three kinds:

### Randomized Trials

Gold



- whether or not someone gets a feeding tube is based on a toss of a coin
  - patients with a feeding tube are comparable to patients without a feeding tube
  - more confident in the results
- (There are no randomized trials of tube feeding)

### Non-Randomized Trials

Silver



- patients who have chosen to have feeding tubes are compared to patients without feeding tubes
- tube fed patients may be different from patients without feeding tubes in ways that may affect the outcomes
- less confident in the results

Bronze



### Case Series

A group of patients with feeding tubes are followed over time to see how they do

## Complications from feeding tube placement

We have tried to summarize the studies for you so that you can have some idea of the chances of **your** family member having a complication. The numbers below are **averages** (taken from articles published in medical journals) which vary from patient to patient.

Type of Complication	How many out of 100 * patients might get it?
<b>Infections</b> <ul style="list-style-type: none"> <li>minor (skin)<sup>3,5-10</sup></li> <li>major (life threatening)<sup>4,5,8,9</sup></li> </ul>	4 out of 100 1 out of 100
<b>Bleeding</b> <ul style="list-style-type: none"> <li>minor (no transfusion)<sup>3,4,7</sup></li> <li>major (need transfusion)<sup>3,4,7</sup></li> </ul>	less than 1 out of 100 nearly 0 out of 100
Temporary diarrhea, cramping <sup>3,5,9,11</sup> Temporary vomiting, nausea <sup>3,5,11</sup>	12 out of 100 9 out of 100
<b>Tube problems</b> <ul style="list-style-type: none"> <li>minor (dislodgment, blockage, leaking)<sup>3-9</sup></li> <li>major (perforation of bowel)<sup>3,4,6-8,10</sup></li> </ul>	4 out of 100 less than 1 out of 100
<b>Death</b> <ul style="list-style-type: none"> <li>from putting the tube in<sup>5,8,9</sup></li> </ul>	less than 1 out of 100

\* These values are for PEG tubes only. The values may differ for jejunostomy tubes.

## Will putting in a feeding tube increase the patient's chance of survival?



Gold

There are no randomized trials comparing similar patients with and without feeding tubes to see who lived longer. Because of this, there is no straightforward answer to this question of survival.



Silver

Non-randomized trials in nursing homes have found that tube fed patients do not live longer than similar patients without feeding tubes. However, it is not clear how long these patients would have lived if they had never been given a feeding tube. It could be that patients who are given tubes are sicker than patients who are not given tubes.

Bronze



It is difficult to predict how long your patient would live with or without a tube. Case series of patients with feeding tubes have shown that those with the following characteristics have a shorter survival:

- very old patients (over 85 years)<sup>7,10,20,23</sup>
- patients who tend to aspirate (breathe in) their food<sup>10</sup>
- patients who are already very undernourished<sup>7,15</sup>
- patients with a previous diagnosis of malignancy<sup>20,23,33</sup>

## How long can I expect my family member to live?



This chart shows you how many out of 100 elderly patients who have feeding tubes will still be alive in 30 days<sup>4,5,7-9,10,12,16-25</sup>, 60 days<sup>4,12,18,24,25</sup>, 6 months<sup>5,12,25</sup> and 1 year<sup>10,12,13,20,23</sup>, after putting the tube in. The numbers on the chart are averaged over many studies. It is difficult to know for sure how long any one patient will live.

Prolonging life may or may not be what your family member would want. This may depend on his quality of life and personal values or beliefs.

## What is aspiration and how does it affect my family member?

- aspiration means that the patient inhales or breathes food or saliva into her lungs. This happens because the patient has trouble swallowing.
- it can be an uncomfortable feeling for patients to experience.
- It can also be dangerous because it can cause pneumonia, an infection in the lungs.

Gold



There are no randomized trials comparing the chances of aspiration in patients with and without feeding tubes.

Silver



Non randomized trials<sup>14,26</sup> comparing patients with and without feeding tubes show that patients with tubes are more likely to be aspirators. However, it is not clear from the studies if getting a feeding tube increases the chances of aspirating, or whether being an aspirator increases the chances of getting a feeding tube.

Bronze



It is clear from several case series<sup>23,27,28</sup> that putting in a feeding tube will not necessarily stop a patient from aspirating. More than half of patients in these studies who aspirated **before** they were given a tube, still aspirated **after** they were given a tube. On average, 16 out of 100 patients with a feeding tube will aspirate<sup>3,6,7,10</sup>.

## What other factors are important to consider when deciding about placing a feeding tube?

*Stroke patients* who have swallowing problems may recover better if the feeding tube is placed earlier on in their illness, rather than waiting a few weeks.<sup>32</sup>

Patients who have been *totally unaware* of their surroundings and dependent on others to look after their basic needs for several months are less likely to improve, whether they have a feeding tube or not.<sup>18</sup>

Whether or not a patient gets a feeding tube may determine what *kind of facility* he can live in. You should discuss this with the health care team.

Some patients with feeding tubes may become *agitated* and/or may try to pull the tube out. The health care team may suggest restraints or medications to stop the patient from doing this. As the substitute decision-maker, you should be involved in this decision. This should not happen without your consent.

## What are my treatment choices?

Because the person in your care is having eating and/or swallowing problems, the health care team is offering the choice of:

supportive care  
plus  
placement of a feeding tube

or

supportive care

## What is supportive care?

Supportive care involves:

1. hand-feeding if possible
2. other treatments to keep the patient comfortable

### 1. Hand-feeding

- patients with eating problems who do not receive a feeding tube may or may not be able to be hand fed
- some patients with a feeding tube may also be able to get some food by mouth

How is it decided if a patient can be hand-fed?

- members of the health care team (for example, doctor, nurse, dietitian, speech and language pathologist, occupational therapist) will decide how safe it is to hand feed a patient
- a special swallowing study may be done to see what consistency of food the patient can tolerate easily

Who hand feeds the patient?

- trained health care professionals (nurse, nursing assistant or aide)
- family, friends, volunteers

How are patients hand-fed?

- proper feeding techniques are needed to help prevent patients with eating problems from aspirating. These techniques include:
  - sitting her up in bed
  - choosing food of the right consistency
  - suctioning the mouth when necessary
  - hand-feeding a meal can take as long as two hours

### 2. Other treatments to keep the patient comfortable

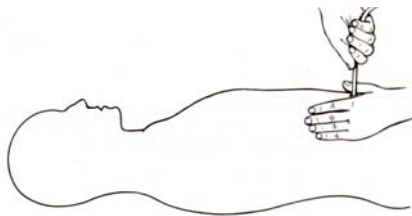
- keeping the patient's mouth moist with a glycerin swab or ice chips
- pain control, with medication
- oxygen, for breathing problems
- treatment of constipation
- spiritual or emotional support
- skin care

## Can tube feeding be discontinued?

*Before you decide to put in the tube, you may want to think about what may be involved in deciding to remove the tube or stop tube-feeding at a later date.*

### Technical Considerations

It is technically easy to remove the tube by:



- 1) pulling it out using traction – the tube is designed to be removed this way – it is safe, and nearly painless

or

- 2) cutting the tube on the outside, then using an endoscope to remove it through the mouth.

### Possible reasons for discontinuing tube feeding

- The patient may have improved enough to be able to eat normally

OR

- The patient may not have improved and the tube may no longer be in their best interests

As a substitute decision-maker, it is your choice to stop tube feeding. You should discuss this decision with the patients' health care team.

## What are the advantages, disadvantages and other considerations of feeding tube placement?

### Advantages

- + patient may improve enough to be able to eat again
- + patient gets more nutrition

### Disadvantages

- complications from tube feeding, such as minor or major bleeding, infections, tube problems or death
- may become agitated with the tube
- feeding tube may limit where patient can receive care

### Other Considerations

- will not prevent aspiration in those who are likely to aspirate
- certain factors are associated with decreased chances of survival
- feeding tube may or may not improve quality of life
- Steps to making the decision

## Steps To Making the Decision

- ❶ What is your family member's situation?
  - is the underlying condition causing the eating problem likely to get better?
  - is the feeding tube needed to help provide nutrition?
  - how concerned are you about specific complications of the feeding tube (such as minor or major tube problems, bleeding, infections)?
  - is the patient likely to become agitated with the tube and need to be restrained to keep it in?
  - will feeding tube placement make a difference as to where the patient can live?
  - is the patient an aspirator?
  - does the patient have any of the factors associated with decreased chances of survival?
  - how will the feeding tube affect quality of life?
- ❷ What would your family member want?
  - has she ever expressed her wishes (in a living will or previous discussion) about the use of medical technologies like feeding tubes?
  - what are his beliefs and values about end-of-life care?
  - if she could weigh the advantages and disadvantages, what do you think she would choose
  - what do you feel is in your family member's best interests?

- ❸ How the decision is affecting you:
  - feelings of guilt
  - feelings of pressure from others
  - conflict between your personal beliefs and those of the patient
  - worry about the future decisions regarding continuing with the tube
- ❹ What questions need answering before you can decide?
- ❺ Who should decide about placing the tube?
- ❻ What is my overall "leaning" about placing a feeding tube?

# Betty's Personal Worksheet

Betty had a sudden stroke a few days ago

We have developed a worksheet to help you as you go through the steps

Over the next few pages, we will show you some examples of substitute decision makers like you as they work through the 6 steps of making their decision about placing a feeding tube.

The examples are meant to show you how to record the facts about your patient and how to weigh all of the factors that might influence your final decision.

The examples are not meant to suggest a right or wrong way to make the decision.

## 1 Your family member's health situation

Advantages	Other Considerations	Disadvantages
<b>Improvement</b> <i>unsure</i>	<b>Survival</b> <i>-under 85</i> <i>-not malnourished</i> <i>-no malignancy</i>	<b>Complication</b> <i>small risk</i>
<b>Nutrition</b> <i>-not malnourished</i> <i>-hand feeding?</i> <i>-no bedsores</i>	<b>Aspiration</b> <i>no</i>	<b>Agitation</b> <i>unlikely</i>
		<b>Facility</b> <i>tube will mean move to a chronic care facility</i>
<b>Quality of Life</b> <i>-good quality of life in past 3 months</i> <i>-will the tube provide an acceptable quality of life?</i> <i>-if tube will help her regain her independence,</i>		

## 2 What would your family member want?

<b>Previous discussion-yes</b>	<b>Patient's feeling about feeding tube</b>  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> in favour                      unsure                      against
<b>Living will - no</b>	



# Harold's Personal Worksheet

Harold has had progressive Alzheimer's disease for eight years.

### 3 How is the decision affecting you?

guilt – *not much*                      pressure from others – *not much*  
 conflict – *not much*                      worry about future – *a lot*

### 4 What questions need answering before you can decide?

*How likely is she to recover from the stroke? If she doesn't improve in the next couple of months I doubt Betty would want to continue with the tube. Can we decide to remove it at that point? How hard is it to remove?*

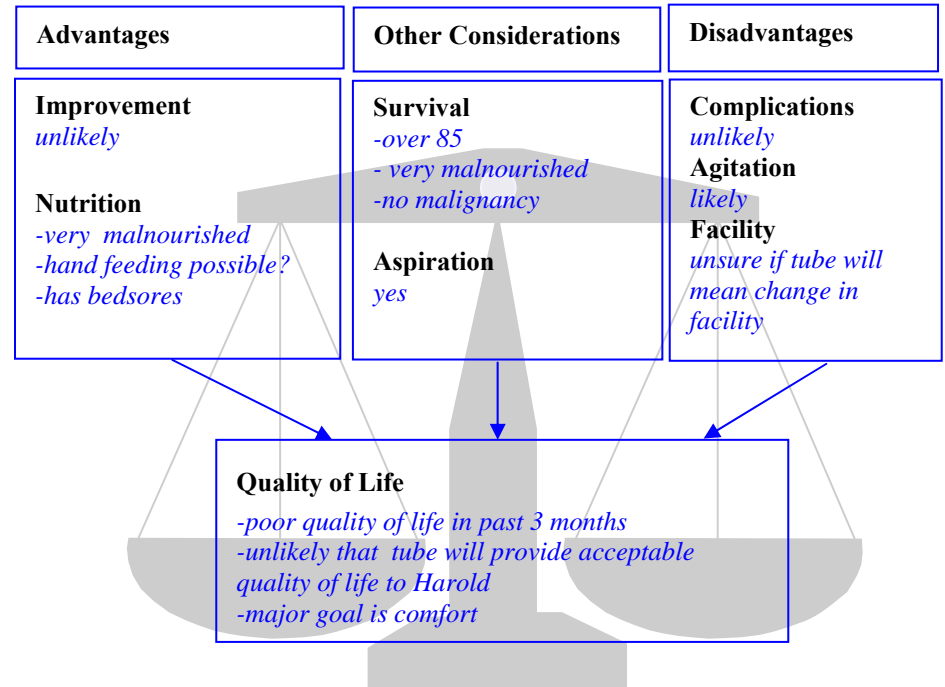
### 5 Who should decide about placing the tube?

Based on Betty's previously expressed wishes, her doctor and I will decide together.

### 6 What is my overall "leaning" about placing a feeding tube?

put in                      unsure                      supportive  
 tube                                           care only

## 1 Your family member's health situation



## 2 What would your family member want?

<b>Previous discussion</b> -no  <b>Living will</b> - yes	<b>Patient's feeling about feeding tube?</b>  <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> in                      unsure                      against favour
--	--

**③ How is the decision affecting you?**

guilt – *somewhat*                      pressure from others – *not much*  
conflict– *not much*                      worry about future – *not much*

**④ What questions need answering before you can decide?**

*Will Harold feel hunger and thirst without the tube?  
Does his nursing home accept tube-fed patients?*

**⑤ Who should decide about placing the tube?**

Harold hasn't told me what to do in this situation, so I must decide for him based on what I think he would want. I'll talk it over with his doctor who has known him for a long time.

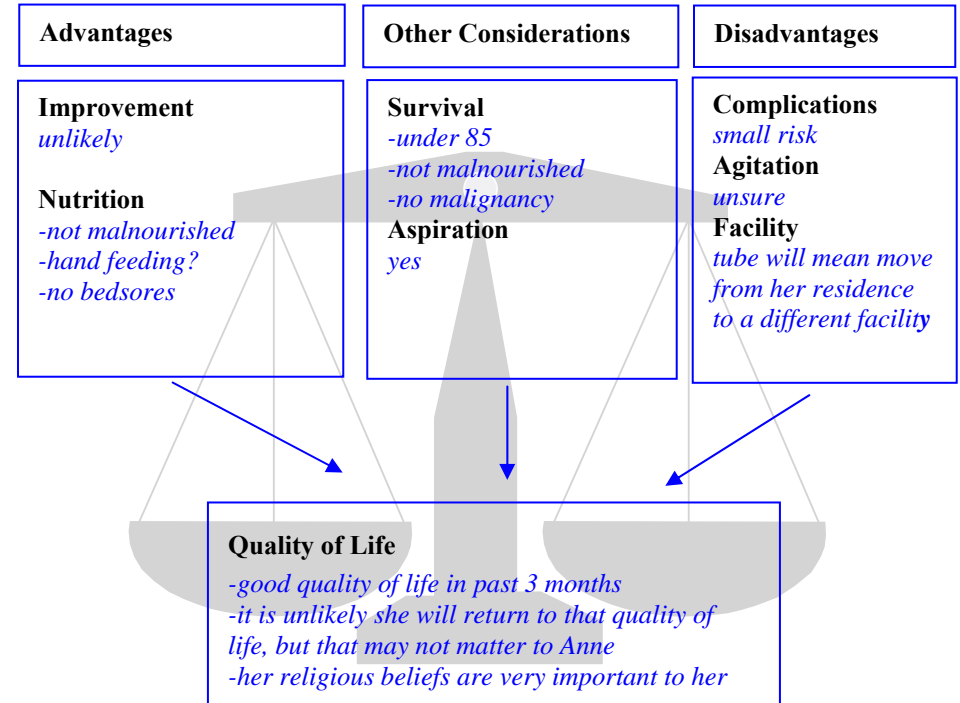
**⑥ What is my overall "leaning" about placing a feeding tube?**

put in tube                      unsure                      supportive care only

**Anne's Personal Worksheet**

*Anne had a big stroke 10 days ago. The doctor said that she may*

**① Your family member's health situation**



**② What would your family member want?**

<b>Previous discussion-yes</b>  <b>Living will - no</b>	<b>Patient's feeling about feeding tube?</b> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input checked="" type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> in favour                      unsure                      against
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## Notes and Questions



