

Facing Hard Choices



A GUIDE TO ARTIFICIAL
NUTRITION AND HYDRATION

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Introduction

At the end of life, patients and their loved ones are often faced with tough emotional decisions. If you're reading this booklet, you may be faced with hard choices about artificial nutrition and hydration.

Perhaps your loved one can no longer eat or drink without help. This may be the first time you've thought about using artificial nutrition and hydration. Or maybe your loved one has had a feeding tube for some time but still has not improved.

Your loved one may be in a nursing home, hospital, or at home. In any case, use this booklet as a guide to start talking about artificial nutrition and hydration. We hope it will give you the information you need to make the best decision for your loved one.

"What really makes these decisions 'hard choices' has little to do with the medical, legal, ethical, or moral aspects of the decision process. The real struggles are emotional and spiritual. People wrestle with letting go and letting be. These are decisions of the heart, not just the head."

— Hank Dunn, from *Hard Choices for Loving People*

Planning Ahead

Before making any healthcare decisions, it's important to plan ahead. The first part of planning is to know your goals of care. What result can be truly hoped for based on the patient's state right now?

Hank Dunn, best-selling author of *Hard Choices for Loving People*, writes about the 3 goals of health care:

1. **Cure.** The patient's disease can be cured by treatment. Most health care today centers on cure.
2. **Stabilize.** Many diseases can't be cured, but they can be stabilized, or maintained. Treatments don't cure, but they help the patient live with the illness. Examples of this are dialysis for kidney failure or insulin shots for diabetes.
3. **Prepare for a comfortable and dignified death.** When a patient's disease cannot be cured or stabilized, comfort care should be the focus. Hospice and palliative care teams can help. *Choosing this goal of care does not mean you are giving up.* Making choices about the end of life is an important part of setting care goals. A comfortable death at home, if that is the goal, takes planning.

At times, these goals might be combined. An end-stage cancer patient may choose to prepare for a comfortable death, but may also choose to cure a case of pneumonia.

What you can do:

- Learn about the patient's illness. Get information from the experts caring for the patient — the care team. The care team could be nursing home staff, hospital staff, a doctor's office, or a hospice team. This can prepare you for what's ahead.
- As with all health care, know that you have the right to a second opinion. You can choose to move care to another doctor at any time.
- Know about all of the treatment options. Ask the care team plenty of questions. When you've made an informed decision, clearly set the goals of care. This can make it easier for you, your loved one, and the care team to move forward.
- Reassess the goals of care often. The goals may change with the patient's health.
- Talk openly with everyone involved about the goals of care. Talk with the patient (if possible), the rest of the family, and the care team.
- Have the patient set up an advance directive, if possible. Advance directives are instructions patients leave for others when they cannot make health decisions. If your loved one has an advance directive, honor it.
- If you need to know more about advance directives, reach out to the care team. They can explain each kind of advance directive, answer questions, and help you fill in the forms.
- Contact the care team if you decide the goal is to prepare for a comfortable death. If you are not working with a hospice team, consider asking your doctor for a referral.

What Is Artificial Nutrition and Hydration (ANH)?

Artificial nutrition and hydration is also known as “ANH.” It is used when a patient can no longer eat or drink by mouth. ANH is medical care that can only be ordered by trained experts. It is often given by a tube or needle that is placed into the body. Liquids are then dripped or pumped through the tube or needle.

Artificial nutrition provides all the nutrients found in food (protein, carbs, fat, vitamins, etc.), but in liquid form. It can be given different ways, based on the patient’s needs:

- **Nasogastric (NG) tube:** A feeding tube is gently pushed through the nose, down the throat, and into the stomach.
- **Percutaneous endoscopic gastrostomy (PEG or G-tube):** “Percutaneous” means through the skin. A feeding tube is inserted surgically through the belly, into the stomach.
- **Percutaneous endoscopic jejunostomy (PEJ or J-tube):** A feeding tube is inserted surgically through the belly, through the stomach, and into the small intestine.
- **Total parenteral nutrition (TPN):** “Parenteral” means given by a shot. A needle is inserted into a large vein in the chest or arm. Liquids are pumped into the bloodstream, skipping the stomach and intestine.

Artificial hydration provides fluids and may be given with artificial nutrition or on its own. It can be given by:

- **IV line:** A needle is put into a vein in the arm. Fluids are dripped into the body through a small tube.
- **Hypodermoclysis:** Fluids are given by a shot straight under the skin. Common sites are the chest, belly, thigh, or arm.

When Should ANH Be Used?

Many people are not clear about what ANH does or does not do. This makes it hard to know if ANH should be used for their loved ones. ANH is meant for patients who cannot swallow or eat without help for a short time. For example, some patients can't swallow after a stroke. ANH and therapy can often help these patients swallow normally again.

ANH may also work well for some patients with a long-term illness who cannot eat or swallow. These patients otherwise have a good quality of life. They can interact with others and do things they enjoy. This includes some stroke patients and throat cancer survivors.

ANH is also used for patients in a persistent vegetative state (PVS). Some people compare PVS to a coma. It can be caused by brain trauma from an accident or illness. Unlike coma patients, patients with PVS seem to be more wakeful. But they still cannot see, smell, feel, or react to things around them.

It can take months to tell if a PVS patient has no chance of getting better. Many PVS patients can breathe on their own, but may have trouble swallowing. So it is common for doctors to order ANH until more is known about the patient's condition.

What you can do:

- **Always keep the patient's interests in mind.** Caregivers are often torn by doubt when making healthcare decisions for their loved ones. Always ask yourself, *"What would my loved one want? Would he/she want to live in this state?"* This is especially important for PVS patients who will not get better.
- Talk with the care team about ANH and your loved one's illness. Does ANH fit with the goals of care?

- Consider the patient's spiritual values. Certain faiths believe in using ANH (and other forms of life support) in some cases to maintain life.
- What if you feel that your loved one wouldn't want ANH, but that isn't in line with his or her faith? If you feel torn, talk to your spiritual counselor or a healthcare chaplain.
- Know about both the pros and cons of using ANH. Feeding tubes and IVs are known to cause burdens in end-of-life patients. See pages 9–10.
- Be aware that *withdrawing* (stopping) ANH may be a lot harder emotionally than *withholding* (not starting) it. If your loved one would not have wanted ANH, it is better not to start it at all.
- Be gentle with yourself as you make healthcare decisions. This is a heavy burden to bear. Do the best you can with the information you have. Whatever decision you make will be the right one.

“From a moral, ethical, medical, and most religious viewpoints there is no difference between withholding and withdrawing. Emotionally, there is a world of difference.”

— Hank Dunn, from *Hard Choices for Loving People*

Alternatives to ANH

You've begun to weigh the options, but you're still not sure if ANH is right for your loved one. There may be other things you can try. Check with the care team first to see if these other options are possible in your case.

What you can do:

- **Consider careful hand feeding** instead of (or along with) ANH. Hand feeding may take more work if your loved one is upset or confused. But it may help the patient avoid the burdens of a feeding tube. Ask the care team to teach you how to feed the patient safely.

If your loved one is already on ANH, involve him or her during normal mealtimes. Meals provide social contact that patients with feeding tubes often miss.

- **Ask the care team if speech therapy can help.** Some speech therapists are trained to work with swallowing issues. This may reduce or avoid the need for ANH.
- **Ask the doctor about a time-limited trial** to try ANH for a fixed time. The care team will work with you to set small goals, such as the patient getting more energy. A firm date will also be set to reassess the patient.

If the goals are met by that date, it may be advised to continue ANH. If the goals are not met, it may be best to remove it. Things to note:

- A doctor must approve a time-limited trial.
- Time-limited trials may not work in all cases. For some patients, it may only put extra stress on the body.
- Remember, once you've started ANH it may be harder on you emotionally to remove it later.

ANH with Advanced Dementia

Advanced dementia, such as end-stage Alzheimer's disease, is marked by the loss of bowel/bladder control, speech, and the ability to move around. Advanced dementia patients lose memory and the ability to focus and reason. They must rely on others for dressing, eating, toileting, and bathing. They may also have a hard time eating or swallowing.

Caregivers of dementia patients are often given the option to use ANH with their loved ones. Medical research has shown that feeding tubes offer no benefit to these patients. This is because *advanced dementia is a terminal illness*. Like all end-stage diseases, ANH will not cure dementia or extend life for these patients.

Some families of dementia patients do choose ANH. With so many difficult symptoms, it may seem like it is the best choice. But ANH may only add greater burdens — and could even do harm — in the final stage of life.

What you can do:

- **See “ANH at the End of Life”** (pages 9–10) when deciding on ANH for end-stage dementia patients. The same thought should be put into using ANH with advanced dementia patients as with end-of-life patients.
- Be aware of the burdens of ANH for dementia patients:
 - Advanced dementia patients may have to be restrained, or held down. Confusion may cause them to pull out tubes. This can cause even more stress for patients and caregivers.
 - Tube-fed dementia patients are especially prone to aspiration and pneumonia (see page 9).
- Ask the care team if careful hand feeding may be better for your loved one.

ANH at the End of Life

The death of a loved one is one of the hardest things to face. It is even harder when you have to make decisions about ANH. You may feel unsure and overwhelmed. It may be tempting to ask the doctor to do everything to keep your loved one alive. However, ANH does not help end-of-life patients. At times it can even be harmful.

You may not want to withhold or remove ANH because it seems like that would cause death. It seems it would “starve” the person. *But it is the disease — not withholding or withdrawing ANH — that causes death.* ANH at the end of life feeds organs that are shutting down. This can lead to painful swelling and discomfort.

The natural dying process is often more comfortable for the patient than if ANH is used. The person is not starving. As the body shuts down, there is less need for food and water. The body then releases pain-relieving chemicals. This creates a sense of well being. Using ANH delays this process. Also consider:

- **The burdens of feeding tubes at the end of life:**
 - Aspiration (see below) and pneumonia (lung infection)
 - Other infections
 - Nausea and vomiting
 - Ulcers (tears in the stomach lining)
 - Bedsores and stiff limbs
 - Isolation, or loneliness
- **Tube feeding will not prevent aspiration.** Aspiration is when food (or other matter) is drawn into the lungs. It can lead to pneumonia, which can be deadly for very sick patients. Many people think feeding tubes keep aspiration from happening. But saliva, vomit, or stomach acid can still enter the lungs, even with a feeding tube in place.

- **IVs also cause burdens at the end of life:**
 - More fluid in the lungs/throat makes breathing harder
 - Painful pressure around tumors
 - More urine output and a bigger risk of bedsores
 - Uncomfortable fluid buildup in the body
- **ANH will not extend life for patients at the end of life.** Hand-fed patients and tube-fed patients live for about the same length of time. Some studies show that ANH can actually cause death to happen sooner.
- **ANH does not benefit frail end-stage patients.** These patients may decline for a number of reasons. Symptoms vary, but may include lack of appetite, weight loss, weakness, or depression. ANH does not help these patients regain appetite, strength, or other ability.
- **ANH is not legally required.** It is not illegal to withhold or withdraw ANH. The U.S. Supreme Court views ANH to be a medical procedure that can be refused at any time.

What you can do:

- Weigh the pros and cons of using ANH for your loved one. Write out a list. Are there more positives or more negatives?
- If you think ANH is not right for the patient, don't be afraid to speak up. If the doctor's goals are not in line with yours, remember that you can always ask for a second opinion.
- Know that the pros and cons of ANH are the same for children. Some may think ANH should be the first choice for a seriously ill child. It is an instinct to feed children and watch them grow. But as hard as it is to accept, ANH may not always be the best choice.
- Reach out to friends, family, a counselor, or the care team if you are struggling to decide to use or withdraw ANH.

Comfort Care at the End of Life

When the goal of care becomes preparing for a comfortable death, steps to cure the disease are stopped. Life support, including ANH, is often removed. The focus now is comfort care. Though nothing is being done to cure the illness, there is still a lot that can be done to make sure the patient is comfortable.

Many people fear that the patient will be in pain or suffer at the end of life. But death does not have to be painful. Pain at the end of life can be treated. Comfort care will not shorten life. In a few cases, comfort care can extend life.

What you can do:

- Do not be worried when your loved one stops wanting food and water. It is part of the natural dying process.
- Let the person be the guide. Do not force food or drink. He or she will let you know if and when they are wanted.
- Give mouth care often. Keep the mouth moist with wet swabs or a washcloth. Use lip balm for chapped lips. Ice chips or small sips of water can help.
- Make your loved one's living space as peaceful as you can. Remove clutter, bring in fresh flowers, or put family photos near the patient.
- Tell the care team if there is any sign of pain. The natural dying process is not painful. But the disease, ulcers, or other factors may lead to discomfort. The team will check for the causes of pain and change drug doses as needed.
- Be present with the patient. Hold hands and speak softly to them. Ask the care team if there is anything else you can do at this time.

Anticipatory Grief

When deciding on ANH for a loved one, the coming loss may seem more real to you. You may feel helpless as you watch your loved one weaken. Making even small decisions can seem impossible.

You may start feeling grief symptoms even before the passing of your loved one. This “pre-grief” is called anticipatory grief. It’s a normal reaction. It is the mind’s way of adjusting to an approaching loss. Anticipatory grief comes with all of the same symptoms as normal grief. You may have trouble sleeping, eating, or focusing. You might get headaches or stomach pain.

Anticipatory grief can be harder to deal with than grief after loss. The fear of loss can cause very strong feelings of anxiety, guilt, anger, or concern for the dying person. Anticipatory grief may also make you feel even more attached to your loved one. This can make decisions about ANH even harder.

What you can do:

- Guilt from choosing to withhold or withdraw ANH can add to your grief. Trust that you made the best choice possible for the patient. Your courage freed your loved one from pain.
- Get rest so you can bear the physical symptoms of grief. Herbal teas or soft music may help. Rest is especially important when you are making healthcare decisions.
- Get routine exercise, eat healthy foods, and drink plenty of water. Healthy living will help keep you focused.
- Do not be afraid to cry. Tears help ease stress, lower blood pressure, and promote healing.
- Share your feelings with a trusted friend or a counselor.

Letting Go and Letting Be

It's hard to let go of a loved one, especially if there are feelings that still need to be settled. There may be guilt for not calling enough or anger over past wrongs. There may be sadness that it wasn't a good relationship.

These kinds of emotional issues can complicate ANH decisions. Working through them is tough. This may make it seem easier to just treat the patient, even if there is no gain. Whatever the case, try to let go of the past. Honor what your loved one would want right now. Do not use this time to make up for things you cannot change.

Fear of losing someone can make us hold on more firmly. But letting go allows the patient a more peaceful, natural death. *Letting go is not giving up.* Most people feel good knowing their loved ones were comfortable at the end of life.

When we let go, we can let be. By learning to let be, we can face our own fears about the end of life. Once we come to terms with death, we can learn to live life more fully and freely.


What you can do:

- If you are having trouble letting go, try to face those feelings now. Remember that a comfortable and dignified death takes planning. Give yourself time to plan.
- Keep asking, "*What would my loved one want?*" How would the patient feel about his/her quality of life? Are the goals of care in line with that? Stick to your decisions, as hard as that may be.
- Take it one day, one step at a time. Reach out to family, friends, and the care team for support. Talk to a professional if you are struggling. You don't need to walk this path alone.

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