Second Wind
NEWSLETTE

March 2005

PERF, The Pulmonary Education and Research Foundation, is a small but vigorous non-profit foundation. We are dedicated to providing help, and general information for those with chronic respiratory disease through education, research, and information. This publication is one of the ways we do that. The Second Wind is not intended to be used for, nor relied upon, as specific advice in any given case. Prior to initiating or changing any course of treatment based on the information you find here, it is essential that you consult with your physician. We hope you find this newsletter of interest and of help.

Key Words: Terri Schiavo, life support, feeding tubes, extraordinary care, euthanasia, advanced directives, living wills, 5 wishes, reducing stress

Like everyone else in this country and much of the world, we have been caught up in the firestorm of divergent opinions and strong feelings about the Terri Schiavo end of life conflict. The medical members of the PERF Board of Directors have all had extensive experience in intensive care units as well as with end of life issues…and in all the different vagaries this subject can present. Unfortunately, we all have been involved in cases like Terri's, which means we have informed opinions on this tragedy. And a tragedy it is for everyone involved. In response to the intense interest that has been expressed, we asked **Dr. Petty** to write something on this subject for us. As a pulmonologist, he has often worked with grieving families, been on many ethics committees and has survived personal experience with near death on several occasions. We feel he is uniquely qualified to address this subject.

May We Die in Peace?

A peaceful death is the hope of all who must die, and this includes us all. The prophecy of life for three score years and ten is offered by the 90th Psalm, with the encouragement, "If by reason of strength (life span) may be four score years." "But then the spirit dies and flies away." This is where the term "passing away" is derived. The "passing" means something different to various cultures, beliefs and religions, but no religion denies the fact of death. Indeed every society has found the

need to create a "higher belief," which I believe to be a spiritual religion, at least in part, to deal with the inevitable. Terri Schiavo's life was tragically shortened at the time of her cardiac arrest, which was due to a serious chemical (electetrolyte) disturbance, at a time that she was drastically dieting to lose weight. This led to a sudden and irreversible damage of the thinking and functioning part of the brain, and left her in the persistent vegetative state that became so controversial. Anyone with knowledge of her medical condition, as well as the extensive studies which showed no remaining thinking or feeling functions, knew this was so. Many self styled "experts" got involved and created a controversy which should never have happened.

Sadly, Terri Schiavo has been denied peace in death. But even in her vegetative state, she is denied the death of her remaining body by many because of a lack of understanding about the certainty of her never being able to recover enough to participate in her environment.

She is entitled to the right to self-determination, and to the right to privacy by the US Constitution and the Common Law. Her husband knew her wishes and properly acted as her surrogate decision maker. Too bad that she did not have a living will, or a durable power of attorney. But in fact, the bond and understanding between Terri and her husband was properly handled by the only person charged with this responsibility.

Tragically, this case got to the courthouse, and to the Florida State Legislature and amazingly, to the legislative and executive branches of our Federal Government. Even worse, it became a feeding frenzy by the press. This is particularly troublesome, because no national media, or newsprint media, that I saw ever produced a group of credible physicians, armed with her CT scan which showed little thinking cortex, if any, remaining! I finally saw her CT scans on local TV last night. Earlier electroencephalogram tests showed no significant higher brain activity. Thus the press became part of a conspiracy to maintain a contrived controversy about her life and death processes. Fortunately the judicial branch of our Government has been responsible to an extreme, and Terri and her husband have had due process. The wisdom of our Founding Fathers, who established the principle of separation of powers, continues to hold!

The feeding tube was a life support measure for her, just like hemodialysis or a respirator is *for patients who are capable of recovery*. These technologies are used to "buy time" to allow for nature's healing processes, in cases of acute organ system injuries. The respirator is connected to the airway of a patient to provide for oxygen to reach the tissues for the purpose of metabolism of food for energy production. The tube and respirator are removed when recovery has occurred. Sometimes the tube and respirator are discontinued in states of futility. This is the appropriate use of the feeding tube and respirator. In Terri's case the feeding tube in her stomach provided food and water to be metabolized in the tissues for energy production. This life support kept her

body going for 15 years during which there was no recovery. Respirators are only used temporally until the patient recovers. Respirators should not be used to extend death in futile situations. In Terri's case the feeding tube has been in place far too long, because of the futile situation. Terri's prolonged feeding tube use is considered "extraordinary care" in most ethical and religious circles.

Other principles have been violated. *The principle of "distributive justice" means that everyone has a right to the financial, and legal resources that Terri has*. These limited resources should not be squandered on one individual, when their use is futile. The principle of reason, i.e. common sense, was abandoned. Terri has not been alive in the normal sense for years. In this dilemma, she cannot live, because her mind and soul have gone. But she can't die finally, in the somatic sense, because of massive parental and governmental interference. The husband, family and friends cannot have a funeral. They cannot come to closure with this tragedy. What could be worse?

The concerns about dehydration or starvation need to be set aside. I have had many patients, and personal medical friends, choose not to drink or eat because they find pain and suffering in continued existence, and relief after they no longer eat or drink. In these cases and in other chronic states of illness, such as in advanced cancer, renal or liver failure, and failure of respiration the body pours out nature's opiates, called endorphins, and Indeed it becomes a "good death" and people can die in peace. Terri finally "died" after 15 years of struggle. May everyone learn from this sad experience.

Thomas L. Petty MD

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We Get Mail

Tom asks, "Is it ethical to remove a feeding tube, even to prevent further suffering? Isn't this euthanasia?"

Dear Tom,

Your concerns about euthanasia versus preventing suffering are similar to those that I've heard physicians and members of the clergy debate many years ago. I have sat through so many hours of ethics discussions on this over so many years that it is difficult to condense it all into a few paragraphs. It is not at all surprising that you have concerns also.

Very few members of the medical community would be willing to participate in euthanasia, *even if legalized*, no matter how much they might sympathize with the suffering of the individual requesting it. Euthanasia is the deliberate ending of life with a drug or device that has no other purpose but to cause death. Doctors will, and should, do all in their power to relieve *suffering*. That is quite different from deliberately ending a life. Over the years it has gradually become accepted that God did not necessarily mean people to suffer. Slowly it became okay to provide relief from the pain of childbirth. Yes, there was a time when the bible was interpreted to prove this was wrong.

Then this was extended to relieving the pain of someone dying from cancer. As their pain increased so did the need for medication. A few rigid health care providers protested, "But they will become addicted!" As if this could be a legitimate reason to ignore suffering in someone with only a few months to live! Concerns about addiction are no longer an excuse for not relieving pain.

The next barrier to break was providing enough medication to relieve pain even if that medication also started to compromise breathing. It took years to get past that concern. It is now accepted that the relief of pain in the TERMINAL patient is always the primary goal. If that compromises breathing, it is a secondary result, not primary, and so is acceptable, even if it possibly hastens death.

Finally, of great interest to all of our readers, medical science now recognizes the shortness of breath of end stage patients dying from emphysema or other lung diseases as a form of pain. This step took a long time, or so it seemed to those of us working for its recognition. Now patients at the end of their life span with emphysema no longer need fear suffering with severe shortness of breath, even though the medication used to *prevent* it also may compromise their already limited ability to breathe. The irony of this accomplishment has been that these patients often now live longer and more comfortably with regular doses of morphine or similar drugs … drugs that supposedly make their breathing "worse"… than they did when they suffered severe shortness of breath without these drugs.

As these goals were accomplished, we had to start working on giving our patients the option of coming off of life support when there was no chance for any improvement or a meaningful life. This is commonly known as "pulling the plug". I cannot begin to tell you the fear my patients used to express in pulmonary rehab that they might be put on a ventilator and never get off until they died months later. For this reason, many refused even temporary ventilator assistance of a few days to recuperate from an acute infection. They died rather than taking the chance that ventilator support might be needed permanently, despite the possibility that temporary assistance might have enabled them to live good lives for years longer. Now that any patient has the right to request removal of the ventilator, this fear no longer need exist. Now even severely compromised patients are willing to "try it" for a few days, knowing they can be taken off at any time they desire it.

Finally it was also accepted that in some cases IV's, antibiotics and feeding tubes were also artificially extending life.
When the terminal patient finally decides to be taken off the ventilator to die peacefully we have again seen a great irony. Many patients actually *improve* for a few days, or even longer, when first taken off the ventilator that was supposedly necessary for life. With the assistance of small doses of morphine to relieve their shortness of breath, they are often able to rest comfortably and quietly, and to peacefully say farewells to their families. They no longer suffered the frustration of trying to communicate

around the intubation tube and over the noisy ventilator.

We were not put on this earth to live forever. In very few countries other than the United States is artificial extension of life continued for any length of time after it is determined that nothing can be achieved. Removing artificial support is not a decision made lightly or quickly. Various tests are required to document that the patient is terminally ill OR wishes this done. Depending on the individual case, several doctors may be called in to concur in their interpretation of the physical exams, CT scans, EEG's etc. The extent of this varies with the individual diagnosis, the age, previous advanced directives, as well as family disagreements. It was a simple, uncomplicated decision for my 92-year-old mother, who was terminally ill. A few weeks earlier she had flatly refused a feeding tube. She had clearly written advanced directives and a family who supported her wishes.

It is often very difficult for a family to accept that the end is near. They beg their loved one to “hang on” It is painful beyond words to give that loved one permission to stop fighting and to sleep in peace if that is what is wanted. People have been dying quietly since the beginning of time. I would like the same for myself. I do not want any of the miracles of the 20th and 21st century keeping my body alive with “heroic measures” month after month when nature has decreed it is time to go. *However*, this is a decision that each of us is able to make for ourselves, no matter what your state on consciousness might be at that time. You can still remain in control of your body and the decisions made about it if you complete an Advanced Directives.

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Advanced Directives

Out of all this pain and controversy has been born one very positive outcome: a national awareness of the need for Advanced Health Care Directives. To read an additional wonderfully written article on this by Dr. Petty, we suggest that you look in the January 2004 Second Wind (this can be found on the PERF website, www.perf2ndwind.org). We now reprint part of this on the Five Wishes Living Will Program, as recommended by Dr. Petty, which will help you with Advanced Directives.

If you’re wondering what the Living Will or Advanced Directives this will help. The **Five Wishes Living Will** helps you to understand this whole process much better. This Five Wishes Program embodies and clarifies or expands on the advance directives that can be used to guide surrogate decision making. Details follow:

There are a few **states** (about 10) in which *Five Wishes* does not yet meet the legal requirements. These states either require a specific state form, or that the person completing an advance directive be read a mandatory notice or "warning." Residents of these states can still use *Five Wishes* to put their wishes in writing and communicate their wishes with their family and physician. Most health care professionals understand they have a duty to listen to the wishes of their

patients no matter how they are expressed.

Laws vary from state to state. Many states have Living Wills or Advanced Directive forms available from the state Thoracic Society or from the individual State Government. Some of these are free and others also charge about $5.00. An example is the one that can be gotten for $5 from the California Medical Association at www.cmanet.org/bookstore.

The only important thing is to make sure that you and everyone in your family over the age of 18 seriously considers filling out one of these advanced directives so that no matter what state their body is in, they remain in ultimate control.

Five Wishes:
Because there are many aspects of life that are out of patients' control, especially when serious illness is present, the Five Wishes booklet was created as an easy-to-complete form that allows the patient to say exactly what he or she wants. The beauty of the document is its simplicity combined with sensitivity and specificity. It was written with the help of **The American Bar Association's Commission on the Legal Problems of the Elderly, and the nation's leading experts in end-of-life care.** Five Wishes is for anyone 18 or older. Because it works so well, lawyers, doctors, hospital, hospices, religious institutions, employers, and retiree groups are handing out this document. Unfortunately each state has different laws and about 10 have restrictions on the use of only this advanced directive.

Wish 1:
The person I want to make health care decisions for me when I can't make them for myself.
This is selecting a durable medical power of attorney. An explicit discussion of whom the patient should select and the specific things the patient wants his or her agent to do are listed.

Wish 2:
My wish for the kind of medical treatment I want or don't want.
This is equivalent to a combination of the classic "living will" and the "advance resuscitation directive." Included in this section is a discussion of "what life-support means to me." It explains what Do Not Resuscitate (DNR) means in simple but explicit lay terms. Specifics of what the patient wants done in the following settings are listed:
1. Close to death
2. In a coma and not expected to wake up or recover
3. Permanent and severe brain damage and not expected to recover

Wish 3:
My wish for how comfortable I want to be.
This specifically requests enough pain medicine to provide comfort, a desire for hands-on care such as bathing, massages; for soft comforting music to be played and for spiritual needs to be fulfilled.

Wish 4:
My wish for how I want people to treat me.
The selections under this wish have to do with personal visitation, attitudes the patient wants conveyed at the bedside, the desire for prayer and spiritual

support and a clarification of where the patient wants to die (e.g., home).

Wish 5:
My wish for what I want my loved ones to know.
A wonderful selection of very personal requests is provided. There may be statements about how much someone is loved, a request for forgiveness, a request for family and friends to make peace and bond during the patient's dying process, and a request for burial vs. cremation.

For many patients, when the decision not to continue living has been reached, support from hospice and other homecare agencies may be welcomed. Patients have the choice of spending their final days at home or in a facility operated by hospice. Hospice workers offer quality of life, compassion and dignity. Physical, emotional and spiritual support is provided. Control is returned to the patient.

The use of advanced directives clarifies what patients want regarding their medical care. Their purpose is to make certain each individual's desires and wishes are followed. Advanced directives do not remove hope or the desire for life. They simply give patients control, freedom, comfort and peace.

If you would like more information on this subject, or a copy of ***Five Wishes***, go to the website of http://www.agingwithdignity.org. You may also write to:

Aging with Dignity, PO Box 1661
Tallahassee, FL 32302-1661
Phone: (850) 681-2010
Fax: (850) 681-2481.

Five Wishes is $5 for one copy, or 25/$1 each.

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B*arbara White Haggerty made a donation in loving memory of* ***Dorothy Hall*** *while* Virginia Elson made a donation for **David Elson**, and Barbara Borak for **Maceo Doyne,** *and Mary Burns for* **Richard Davidson.**.

Joyce Cook made a donation in memory of ***Dorothy S. Weidner*** *as did John Rux, The Winding Ways Homeowners Association, Mike, Bridget & Gage Pankey, FSU Connect of Florida State University, Judy & Chuck Ehrhardt, Helen and Mr. & Mrs. Gerard Martin.*
Neilson, Alison Chacona, RRT of Long Beach Memorial Pulmonary Rehab and Wayne Chinen of Hawaii *for their donations to PERF.*

We'd like to add how very much we appreciated the letters we received from Alison Chacona RRT and Sister Thanks to Norma Burns, *Terry Mary John, Sisters of Little Company of Mary in Laguna Hills. These two letters were keepers, to be read and savored more than once. Thanks!*
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To those of you who count on getting enews we are having a temporary problem due to spam and false email addresses swamping us. We hope to get this remedied soon!
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Do you get stressed every once in a while? Sure you do. After all this controversy about end-of-

life issues we thought we would give you some tips to help you relax.

Stress Management
A lecturer, when explaining stress management to an audience, raised a glass of water and asked, "how heavy is this glass of water?"

Answers called out ranged from 20g to 500g. The lecturer replied, "The absolute weight doesn't matter. It depends on how long you try to hold it." "If I hold it for a minute, that's not a problem. If I hold it for an hour, I'll have an ache in my right arm. If I hold it for a day, you'll have to call an ambulance. "In each case, it's the same weight, but the longer I hold it, the heavier it becomes."

He continued, "And that's the way it is with stress management. If we carry our burdens all the time, sooner or later, as the burden becomes increasingly heavy, we won't be able to carry on." "As with the glass of water, you have to put it down for a while and rest before holding it again. When we're refreshed, we can carry on with the burden." So, before you return home tonight, put the burden of work down. Don't carry it home. You can pick it up tomorrow. Whatever burdens you're carrying now, let them down for a moment if you can." Relax; pick them up later after you've rested. Life is short. Enjoy it!"

And then he shared some ways of dealing with the burdens of life:

1. Accept that some days you're the pigeon, and some days you're the statue.

2. Always keep your words soft and sweet, just in case you have to eat them.

3. Always read stuff that will make you look good if you die in the middle of it.

4. Drive carefully. It's not only cars that can be recalled by their maker.

5. If you can't be kind, at least have the decency to be vague.

6. If you lend someone $20 and never see that person again, it was probably worth it.

7. Never put both feet in your mouth at the same time, because then you won't have a leg to stand on.

8. Since it's the early worm that gets eaten by the bird, sleep late.

9. The second mouse gets the cheese.

10. Nobody cares if you can't dance well. Just get up and dance.

11. When everything's coming your way, you're in the wrong lane.

12. Have an awesome day and know that someone has thought about you today.....we did. ♥♥♥

Snowdrift Pulmonary Conference

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Senior Moderator

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Dear Friends:

DIET AND VITAMINS FOR YOUR HEALTH
(MORE OR LESS)

More and more diets are being proposed for those who are overweight. The ATkins, Ornish, Weight Watchers, and Zone diets are popular, yet they are quite different in composition. For example, the ATkins diet is known as low carb and the Ornish diet restricts fat. Other diets use different strategies. But they all are intended to reduce calories and thus promote weight loss. So far only the Weight Watchers program has been proven to be associated with significant weight loss and also a greater reduction in heart attack risk factors compared with the other diets. Unfortunately, adherence to all diets is poor, which is the story that is well known to most people who try to lose weight. The yo-yo effect is considered bad in any case.

The so-called Mediterranean diet, which is high in unsaturated fats (e.g., olive oil, fish, poultry and nuts) seems to protect the heart in the Mediterranean regions. It also encourages the liberal use of red wine which, itself, is known to reduce the risk of heart attack and stroke due to various mechanisms that reduce oxidant damage to the lining of vessels known as the endothelium in both the heart and brain.

And now the vitamins. In 2003 $18.8 billion were spent on vitamin supplements alone. Also in the year 2003, approximately 22% of the adults over the age of 55 took vitamin E (usually 400 units). Vitamin E is also known as an antioxidant. In a review of all of the outcomes of Vitamin E supplementation, the bottom line is either no benefit or even, perhaps, an increase in overall death rates from a variety of causes. I think we can rely on our food supply to give us plenty of Vitamin E. Save your money! The multiple vitamins that contain the B complex probably reduce one of the risk factors in heart attack known as homocystine in people who have elevated values. Thus I continue to think that a multiple vitamin B complex containing some minerals makes sense. Certainly at least a gram and one-half of calcium is important to prevent osteoporosis and if you can't get this in dairy products, calcium supplements with Vitamin D are recommended. Calcium and Vitamin D are proven to reduce fractures.

So what is the message? We should apply common sense and prudence in diet without any expectation that there will be a magic diet or vitamin supplement that will lead to the fountain of youth.

I'll be in touch next month.

Your friend,

Thomas L. Petty MD
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