



Second Wind

NEWSLETTER

JANUARY 2004

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, or 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.

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This is a very special edition of the Second Wind. It is our privilege to present the following article written by Dr. Petty for the Second Wind.

END OF LIFE MATTERS

By: Thomas L. Petty, M.D.

“The days of our lives should be three score and ten years, and if, by strength, they may be four score years . . .” and then the spirit takes wings and flies away. (Psalms 90:1-10)

I am writing this article for a number of compelling reasons. Compelling to me at least, and probably to others. It is the issue of end-of-life care and how it is terribly mishandled so often. I write this from the perspective of a

pulmonologist who has practiced critical care medicine and ongoing care, including terminal care, for more than four decades. I am also chairman of the ethics committee of a Denver hospital. Medical ethics is one of my most important current interests.

Everyone does not get to live 70 or more years, now the expected lifetime of humans in this country. Trauma and disease may dramatically shorten life. *Life ends when there is no meaningful interaction between the patient, the family and the environment and after it is certain that basic mental functions will not return.* It is not difficult to know when the fact of cognitive life has ended. The “examples” of recovery from longstanding unconsciousness all have recognizable medical explanations. They are not relevant to well publicized, tragic cases of the past, such as Karen Quinlan and Nancy Cruzan. These disasters, celebrated in the media, continue to haunt me, as does the unbelievable and totally mismanaged (in my opinion) case in Florida of vegetative patient Terri Schiavo. But these are just the most blatant examples of what happens when end-of-life discussions and planning are not done, or done haphazardly and without considering the adverse effects on the dignity of the dying patient.

We all well understand that we are guaranteed to die, at some time of our life. “Nobody ever got off this planet alive”¹ is a quote from Woody Allen. He also said, “I don’t mind dying, I just don’t want to be there when it happens.” In my discussions about end-of-life matters with my patients, I rarely take a lighthearted approach. Dying is a serious matter that is the natural end of living. I do encourage my patients that “we will postpone death as long as is reasonable and possible.”

All patients should have discussions with their doctors, hopefully at a time when they are still healthy, about what is commonly called, “end of life decisions.” These discussions are important even if death itself is far in the future. These discussions should be done periodically. This is a good rehearsal for the time when death is near. I would prefer to term this “*decisions at a time of transition.*” This has religious connotations, which can be individually interpreted. Having a clear understanding about what YOU want done when facing a catastrophic situation, such as a persistent vegetative state, is of key importance. **Everyone should have a recording of personal wishes which are well**

documented in the form of a “Living Will,” or “Durable Power of Attorney.” These two documents provide for surrogate decision making in times of crisis. They do not and should not require a lawyer. As a matter of fact, end of life situations are often made worse by lawyers, and usually completely botched by the courts, that have no training or experience to make end-of-life decisions. Most lawyers understand this and most courts would like to stay out of the matter of end-of-life decisions. But when families bring suits, the court has no choice but to get involved. **DO NOT GET LEGAL ABOUT ANYTHING AS IMPORTANT AS END OF LIFE MATTERS.**

The principles involved are really quite simple. *The public expects and is entitled to the best life supporting care as long as a meaningful recovery is possible.* Beneficence is a long tradition of medicine as cited in the Hippocratic Oath “ . . . *I will come for the benefit of the sick.*” The Florence Nightingale pledge includes the phrase “ . . . *and devote myself to the welfare of those committed to my care.*” The autonomy of the individual is guaranteed by fundamental principles, which include the United State Constitution, which guarantees the right to privacy and

the common law, which determines the right to bodily self-determination.

Informed consent is another fundamental principle. Informed consent means truth telling about any and all possibilities that may occur during medical care. Informed consent is implicit in the living will and durable power of attorney. The patient consents to be treated or not, and the patient or a surrogate can demand that life support be withdrawn. **The President’s Commission has clearly stated that there is no moral, ethical, or legal different between withholding treatment and withdrawing them in hopeless situations.**

There is another principle that is commonly ignored. This is the principle of “Common Sense.” But, “*common sense is not common . . .*” Voltaire.

Finally, the principle of the patient’s best interest is intertwined in all of the above. Is it care or torture to continue life support for a patient in a persistent vegetative state with feeding tube or a respirator?

Who should be the decision maker for an unconscious or vegetative patient? It is only the surrogate decision maker, which

can be a spouse, a sibling, a child over age 18, a parent, or a friend. But NOT a hostile family or a court. When a spouse makes a surrogate decision that is directed by his loved one, the family has no standing, no moral or legal right to interfere. They have no responsibility at all. Yet they sometimes find lawyers to get them to the courthouse and here is where the whole thing fails. Perverted special interest groups often put pressure and even a medically unqualified and misinformed governor can make the wrong decision, give the wrong order. This creates chaos, causes harm and promotes suffering.

The day will come when we all must face our death. Very few of us “want to die.” Most of us are frightened by the concept of our death. We want to know: How will it happen? Will I suffer? Will I suffocate? Will I have uncontrolled anxiety? Will I writhe in pain? Will I agonize? Or, is it possible to face death with some control over these fears?

A frequent question for physicians treating patients with severe COPD is “Doc, how long do I have to live?” The honest response is “I don’t know.” Two patients with COPD may have identical seriousness of illness medically, yet one lives several

months, even years longer than the other does. It is difficult to explain why and how the human spirit wants to keep on living in some cases, far beyond what is “usual.”

All patients should know there are many medications that can control pain and anxiety. Patients do not need to have “everything done” to provide for their comfort and quality of life. A breathing machine may not be needed to stop the feeling of suffocation with a severe attack of COPD. Appropriate use of narcotics and sedatives can control shortness of breath and pain. The dying body prepares for death by gradually shutting down organ system functions, such as the kidneys and digestive tract. This does not cause hunger or thirst. It brings nature’s relief. *It is important for all to resolve that death is not the enemy.* Patients fear loneliness, pain and other suffering but not death itself. Death is a natural process, unless interference extends death and prevents its spiritual meaning.

For patients with severe COPD, there may come a time when quality of life is so poor, breathlessness becomes intolerable and life seems to have no purpose. At this point, the patient’s emotional and physical comfort *must* come first. The goal is no

longer to “grind-it-out,” but to find peace and comfort within one’s self, with family and with friends. This acceptance and use of comfort measures does not mean death is immediate. It means the patient has taken control. Neither COPD nor another disease controls their daily life and routine.

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.

Recently the **Five Wishes Program, Aging with Dignity (The Robert Wood Johnson Foundation, Princeton, New Jersey)** has been widely promoted and acclaimed. The Five Wishes Program embodies and clarifies or expands on the advance directive that can be used to guide surrogate decision making. Details follow:

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.

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.

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.

"The tragedy of life is not that it ends so soon, but that we wait so long to begin it." W. M. Lewis

Thank you, Dr. Petty, for this thought provoking article.

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 or Phone: (850) 681-2010 or Fax: (850) 681-2481. Five Wishes is \$5 for one copy, or 25/\$1 each.**

The Partnership for Caring is another site where you can get a *free* download of the Advanced Directive *specific to the laws of*

your state. Their website is at <http://www.partnershipforcaring.org/HomePage/>. If you don't have Internet access, you can obtain a printed set of their documents for \$10.00 (plus tax where applicable: \$.83 for New York State residents and \$.58 for Washington, DC residents).

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PERF received many donations over the holidays, which we appreciate, and gratefully acknowledge. 🙏🙏🙏

Mary was especially honored by the donations made to PERF in her honor by Tetsuji Watanabe of Tiejin in Japan, and by Dick and Ann Wentink. The beautiful notes enclosed were, if possible, even more appreciated. Donald Butler made a donation in honor of both Mary Burns and Dr. Rich Casaburi.

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*Very special thanks to **Hal Lichterman, Kevin & Judy Hettich and Kathleen & Frank Norulak!***

Memorial gifts were received from Carol Longo for Vince, Lillian Cane for Dr. Stanley Cane, Alvin Hughes for Dean O'Donahue, Gina Benoit for George Benoit, Rubye Richey for George, Jo Dutcher for Kenneth Dutcher, and Louis Rollino for Dorothy, Norma Burns for Gale Baker, as well as Gael O'Reilly in honor of Kathleen Williams. We at PEP also share special memories of some of these dear friends.

We know times are difficult financially for many of you. We appreciate your great generosity. We also appreciate the notes from those of you unable to contribute, but who let us know that you enjoy

the Second Wind. We are pleased to continue sending the newsletter to you.

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Are you a health care professional interested in a seminar on pulmonary rehabilitation?



Join us at the **California Society for Pulmonary Rehabilitation (CSPR) annual meeting April 22-23** at the Long Beach Hilton, in Long Beach, California. You will hear internationally renowned physicians like Dr. Rich Casaburi, but also meet physicians from Norway, Russia, Japan and Hungary, who will be joining us for an exchange of ideas. For fun mixed with science don't miss Dr. Greg Mason's talk on "Pulmonary Pachyderm Mysteries, TB or not TB" or Dr. Bill Stringer on "Mozart and Medicine". Come network with a great group! For more information, call Jim Barnett toll free at **(877) 280-2777**. Don't miss this meeting!

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The pulmonary rehab community has lost a very special friend. **Jo-Von Tucker**, poster "girl" for the Helios and co-author of that wonderful book "**Courage and Information for Life with Chronic Obstructive Pulmonary Disease**" has died from the complications of COPD and

diabetes. She was Mary's dinner partner at the Washington COPD meeting so her death a few weeks later was even more sadly felt. It would require several pages to list all of her achievements before and after she developed COPD. At the 2001 COPD/emphysema program in Norwalk, CT, she received an award as "*the COPD patient who has done more for COPD patients than any other patient in the nation.*" It can't be said any better. We will miss you, Jo-Von.

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Toll Free Hotline for Air Travelers with Disability

The U.S. Department of Transportation asked us to distribute the following information: For education, or for help in resolving disability-related air travel problems, call **1-800-778-4836** between 7 a.m. and 11 p.m. EST. While there was a menu with options for different kinds of problems, we were unable to connect with a "live" person when we tried out this number. This may have been because we had no specific complaint to resolve so, if you have a problem, give it a try. You may also email airconsumer@ost.dot.gov or postal mail to: Aviation Consumer Protective Division
U.S. Department of Transportation
400 7th Street, S.W.
Washington, DC 20590



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Dr. Tom Petty has won another prestigious award to add to his large collection. In November, he became this year's *Jimmy A. Young Medallist* when his achievements were acknowledged by the



American Association of Respiratory Care (AARC). Congratulations Dr. Petty, for another well deserved award!

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Did you make the usual New Year resolution to do something about your weight? It might help that resolution if you know what your **BMI** is.



What is BMI? That stands for **body mass index** and is what doctors use to gauge whether or not you are overweight or obese. Being too thin is of great concern when you are a pulmonary patient, but being too heavy can also have a negative impact on your breathing. You may only need a mirror to tell you in which category you belong, but there is now a shortcut formula that you can use to determine this more accurately. **Multiply your weight (in pounds) by 705; divide the result by your height (in inches); then divide again by your height. This will give you your BMI.** A "normal" or healthy range is between 18.5 and 24.9. Being between 25 and 29.9 is

considered overweight; 30 and above is called obesity; 18.5 or less and you are too thin. If you are a muscle bound weight lifter, you may have a BMI of 25 and still not be overweight since muscles weigh more than fat. Another caution! As we get older, we literally shrink. Don't use the height that you had in high school! If you haven't had your height checked recently, be sure to do so at your next physician visit. You may be surprised.

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Have you looked at the label on your newsletter and noticed the "expiration" and date at the bottom? That date is a year from the last time we received a subscription donation or heard that you wanted the Second Wind. If it is several months overdue, we will assume that you receive the newsletter by email, or that you no longer wish it. If you can't afford a subscription, but would like to get the Second Wind, let us know. We will keep you on our mailing list if we hear from you.

Until next time, stay well. ☺ ☺ ☺