

Life Lessons from a PALS

Ellen Norwine isn't afraid to tell you that being diagnosed with ALS has presented her with many new challenges and a sense of loss; however, she also isn't afraid to tell you that there is more to life than having this devastating disease.

Born and raised in Alabama, Norwine has been a resident of California for twenty years. After being diagnosed with ALS in November of last year, she moved to Sacramento from her home in Southern California in order to live with her son. Norwine has a great support network that not only includes her son but also her other caregiver and friend, Sue Combs. Norwine stated that Sue "... has been a godsend ... It's been a real blessing to have her here."

Norwine's professional life focused on instructing and helping others. She taught language for seventeen years to children from the 5th grade to freshman students in college. She is fluent not only in French but also Spanish and even knows a bit of Turkish. She also worked as a marriage and family therapist for seven years in Southern California.

Norwine's love of language translates into some of her favorite hobbies. When she isn't spending time with family and friends, she enjoys working on word puzzles, crossword puzzles, and exploring the pages of a good book.

This devastating disease has the power to ruin a person's spirit and love of life, but Norwine says you have to "remember to keep a sense of humor and find the absurd side of every situation." In a jovial tone of voice, she added, "I never knew how many spots a person has to itch on their nose until I put on a Bi-Pap machine."

After attending their first Patient Support Group Meeting, Norwine and her son left with a sense of being up-lifted and encouraged by the other patients and caregivers, staff and volunteers. They were very impressed and grateful to have such a great group of people as an extended support network.

Norwine continues to live her life to the fullest and understands the importance of keeping in touch with loved ones. Her advice to other people who are being affected by ALS is to "take advantage of the time you have to let people know how much they've meant to

you in your life, and how much you appreciate their attention and love."

Norwine's positive outlook on life, even in the face of such a challenging disease, is a true testament to her courage and love of life – a model for all of us to live by.

Interview by Lisa Kassis



Ellen Norwine

A Big Thank You

Every month the PALS Caller Committee phones all 104 patients to make contact and determine if there is any assistance needed with durable medical equipment, respite care, and many other services. These callers donate their time to assist us with this important connection. Our PALS are better serviced with this time and dedication. If you would like more information about being a PALS caller, contact Leslie at the Chapter office.

"We can do no great things, only small things with great love." Mother Teresa

Pals 4 PALS

The Chapter office is developing a volunteer program to assist our PALS. If you have time, skills, or patience, please call the office to join our "Pals 4 PALS" program. We currently have the need for Pals to drive PALS to support groups, help with housework and yard work, and assist with grocery shopping. For more information, please call Patient Care Manager Leslie Price, (916) 979-9265.



8th Annual Evening of Hope

Please join us for the 8th Annual Evening of Hope. This black-tie gala event will include dinner, dancing, a multi-media presentation, and a live and silent auction. John Alston from KCRA-3 will be our master of ceremonies and our speakers will be Eric Hanson, husband of PALS Shelly Hanson, and Tyler Cross, grandson of Keith Cross. Funds raised will be used for patient services such as the respite care program and durable medical equipment, as well as research in hopes of finding a cure. The event will be held April 1, 2006 at the Memorial Auditorium. The cost for PALS and their caregiver is \$75 per person (regular price is \$150). For ticket information, please call the Chapter Office (916) 979-9265 or toll free (866) 979-9265.

Can't attend the Evening of Hope but still wish to make a contribution? Create a unique themed gift basket full of goodies to be used as a Silent Auction item. Call Kaela Nelson at the Chapter office at (916) 979-9265 or e-mail her at publicrelations@alssac.org for more information on what types of themed baskets are needed.

The Parable of the Mule

This parable is told of a farmer who owned an old mule. The mule fell into the farmer's well. The farmer heard the mule praying or whatever mules do when they fall into wells. After carefully assessing the situation, the farmer sympathized with the mule, but decided that neither the mule nor the well was worth the trouble of saving. Instead, he called his neighbors together, told them what had happened, and enlisted them to help haul dirt to bury the old mule in the well and put him out of his misery.

Initially the old mule was hysterical! But as the farmer and his neighbors continued shoveling and the dirt hit his back, a thought struck him. It suddenly dawned on him that every time a shovel load of dirt landed on his back, HE WOULD SHAKE IT OFF AND STEP UP! This he did, blow after blow.

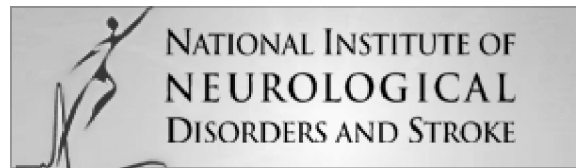
"Shake it off and step up, shake it off and step up, shake it off and step up!" he repeated to encourage himself. No matter how painful the blows, or how distressing the situation seemed, the old mule fought panic and just kept right on SHAKING IT OFF AND STEPPING UP! It wasn't long before the old mule, battered and exhausted, stepped triumphantly over the wall of that well!

Great Minds and NINDS

Now people with ALS and their families – and people without the disease – can give blood and clinical information to an NIH repository to advance the search for effective new treatment. Called the NINDS ALS Repository (NINDS stands for National Institute of Neurological Disorders and Stroke), it's a collaboration of health care and research centers including the ALS Research Group and the NINDS Human Genetics Repository.

The goal is to collect 2,000 blood samples from people with ALS and 2,000 blood samples from people who don't have ALS, forming a national resource for studies about the cause and treatment of all forms of ALS.

If you attend UCSF or Forbes Norris, simply inquire about it there. If you have a local physician, ask him/her to contact one of the San Francisco clinics who will send the physician the appropriate sample kit for the blood collection along with a FedEx air bill. Once your physician receives the material he/she can make arrangements with the person who wants to participate in the repository to have their blood drawn; the physician will then send the kit by FedEx to Coriell Institute Medical Research the physical site of the NINDS approved repository.



Amelia Frances Brozek

Vella Burzloff

Allan Greenwood

Dennis Hashikuni

Mabel Herndon

Karen Kaahui

Dan Loudermilk

Ron Stillwell

Leo Velasco

Caregiving 101

A family member has just been diagnosed with an illness that will eventually require round-the-clock care. Of course you want to be the one giving that care. This decision is usually made without hesitation; of course we want to be our loved one's caregiver. Who else could take better care of them? However, when the reality of your decision sinks in, your head will be swimming with uncertainty, anxiety, and maybe even fear. Certainly you will have many questions. Welcome to Caregiving 101, a primer for first-time caregivers.

First of all, arm yourself with knowledge. An old maxim states that "Knowledge is power," and it's true. Knowledge will empower you to take the best care of your loved one and yourself. Learn all that you can about your loved one's condition, illness or disease. There are local branches of national organizations like the Alzheimer's Association and the Cancer Society all over the country. Use them as a tool to find out all about your loved one's present condition and what the future may hold for both of you.

Another reason to learn is to take better care of your loved one. You may educate yourself through health care manuals, books and videos. The Internet is also a good source of information, but navigate carefully through that material because not all of it is valid. Also, ask lots of questions of your health care professionals. They are the best people to show you proper techniques like transferring, lifting and bathing. When you learn all that you can, you will be more confident in your caregiving abilities.

Caregiving can be an isolating experience, so it's helpful to talk to others who are, or have been, in your shoes. You will feel that you are a part of a growing community of caregivers. You may also learn about options and community resources that you were not aware of from other caregivers. These people can also help with difficult decisions concerning your loved one. Determining your responsibilities will probably be one of the first things you struggle with, so talk to others who've been there before.

You must remember to take regular breaks from your caregiving responsibilities. You can't be good to someone else if you're not good to yourself. Use your relatives. They can help in several ways—financially, socially, and as respite support. If relatives are unavailable or do not exist, try community services like a volunteer group at your local church. Try and follow these guidelines for caregiving breaks: take half-an-hour a day to practice yoga, meditation, needlepoint, reading, etc.; spend a couple of hours a week away from the house at the mall, coffeehouse, library, etc.; monthly you should have an evening out with friends, go to a play or concert, etc.; on a yearly basis you should go on a well-

planned (and well-deserved) vacation. These guidelines will help in avoiding "caregiver burnout."

Your community most likely has organizations about which you never gave a second thought until now. These may include, but are not limited to, Meals on Wheels, day care centers, and home care agencies. If applicable, contact your local Area Agency on Aging for a list of services and organizations. Your local medical supply store may have gadgets and devices to enhance your loved one's abilities, at the same time making your life a little easier. You might also inquire about local, state or federal programs that might provide financial aid for you and your loved one. As needs increase, so do costs. Understanding which programs can help and what you can afford, will allow you to plan for the future.

One way to deal with the emotional roller coaster you may experience is to get your feelings down on paper. Some journal entries might address the following subjects: How do you feel now? What are your fears and/or concerns? What outcomes would you like? What losses have you noticed so far? What changes in your relationship with your loved one have caused you to feel sad? What changes have given you comfort? Journaling is a healthy way to put your feelings "out there" and to possibly alleviate some of the anger, frustration and helplessness you may be feeling.

Caregiving need not be a lonely and emotionally debilitating experience. According to the latest statistics on caregiving for the National Family Caregivers Association, nearly half of the U.S. population has a chronic condition. From that number 41 million are limited in their daily activities while 12 million are unable to live independently or even leave the house. One can deduce from these numbers that there are millions of family caregivers out there. So keep in mind that you are not alone, and best of luck to you and your loved one.

Article written by Michael Plontz, from caregiver.org.

Del Oro Men's Caregiver Support Group

3rd Tuesday of the month

2:00 – 3:00 PM

El Camino Gardens

2426 Garfield Avenue, Carmichael

Kendra Micka, MSW is the facilitator and
she can be reached at
(916) 971-0893 ext 104

Calendar of Events

February

27 Sacramento Clinic Day at Forbes Norris, San Francisco

March

3 Sacramento Clinic Day at UCSF, San Francisco

18 Patient Support Meeting, Sutter Cancer Center
Patient/Caregiver Breakout

April

1 Evening of Hope, Memorial Auditorium

15 Patient Support Meeting, Sutter Cancer Center
Dallas Forshaw, RN, The ALS Center at UCSF

17 Sacramento Clinic Day at Forbes Norris, San Francisco

18 Sacramento Clinic Day at UCSF, San Francisco

ALS is so Limited

It cannot cripple love,

It cannot shatter hope,

It cannot corrode faith,

It cannot eat away peace,

It cannot destroy confidence,

It cannot kill friendship,

It cannot shut out memories,

It cannot silence courage,

It cannot invade the soul,

It cannot reduce eternal life,

It cannot quench the Spirit.

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