



The Lighthouse

Coastal Empire Polio Survivors Association, Inc.
Newsletter June, 2010

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Shining light on post-polio health
www.coastalempirepoliosurvivors.org



The President's Message...

For those of you that missed our dinner fund raiser at River's Edge, you missed a fun time. Janet did a fabulous job of organizing, coordinating and emceeding a great evening. We ate dinner and then Janet had a load of door prizes, I gave a very short talk, and the highlight of the evening was Dan demonstrating to us all how the IRON LUNG saved the lives of so many of us when we contracted polio. He climbed in and showed us how it worked. Through Janet's efforts CEPSA raised nearly \$700.00!!! Thank you, Janet.

While I was not at our May meeting, Diane's program was SOS – Sharing Our Strengths. She found that the main PPS complaints were suffering from fatigue and breathing problems. With this in mind, Diane found the article below on fatigue and we are hoping to have a pulmonologist speak at our June meeting concerning breathing problems. - Jim Vecchia

Fatigue was one of the main Post-Polio symptoms that frequently came up during our S.O.S. – Sharing Our Strengths discussion at the May meeting. While working on a history book from CEPSA's early years, I found an article that addresses the cause of PPS fatigue, pain, and weakness and what we can do to reduce these symptoms. Take time to study the article... you are worth it!!

God Bless,
Diane Davis, Vice-President

Changing Your Life by Conserving Energy

by Mavis J. Matheson, MD - Revised May 1995

Polio survivors need to learn to conserve energy if they are to control their symptoms of pain, weakness and fatigue. [1] It takes effort and a change in attitude to learn to use energy conservation to our greatest advantage. Using our energy well can allow us to do more and do it better. [2] This article suggests four principles of energy conservation and three techniques for making the necessary changes in our lives. Many of us don't have the strength and energy that we used to have so it's time we started taking better care of ourselves.

Why Should We Learn to Conserve Energy?

In a study by Peach and Olejnik,[1] recommendations for change included "decreasing overall daily activities, a change in job, work environment modifications, a decrease in work hours, a decrease in social and recreational activities or taking rest breaks. New or additional orthotics were also recommended to effect safer, less painful and more functional gait patterns. In some patients, a component of disuse weakness was noted. In these cases, appropriate aerobic exercises were recommended, carefully avoiding over-exercising paretic extremities. A number of these patients had become overweight so a weight loss program was recommended." [1] Those who made recommended changes showed either improvement or resolution of symptoms of weakness, fatigue and muscle and joint pain. Those who didn't make changes found symptoms were either unchanged or increased.

Those with post-polio syndrome who were able to make changes and successfully control the factors responsible for overuse did not lose muscle strength. Polio survivors who didn't make changes knew what they needed to do. Many simply refused to make changes in the behaviors that lead to overuse.

Doing More With Less

Agre and Rodriquez [2] noted that the amount of isometric "work" performed during interval exercise was significantly greater (237% on average) than during constant exercise. (Interval exercise was simply the constant exercise divided into quartiles by 2 minute rest breaks or into 20 second intervals with 2 minute rest breaks.) They also found that those with symptomatic post-polio were able to monitor local muscle fatigue and avoid exhaustion. Symptomatic post-polio subjects also recovered strength significantly less readily than a control group. If we allow ourselves to become overtired it takes us longer to get our strength back. By changing our activities to include rest breaks we may find we can do more with less effort.

Changing Your Attitude

Change is not always easy. In fact many polio survivors find change very frightening. Change requires examining the attitudes and beliefs that keep us from feeling well. We can change the quality of our lives by changing the way we look at our circumstances. Creative people are most successful at doing this over the long term. They see opportunity, where others see insurmountable problems. There is no reason we cannot see ourselves as creative and start making our lives better. Creative people are simply those who see themselves as creative. [3]

The way we see ourselves may interfere with our ability to change. One approach to the whole issue of activity is to be kind, positive and gentle with ourselves. The person behind the pain and fatigue, the real you, is a capable, worthy, individual and a beautiful human being. It's time to start treating ourselves like the wonderful beings we are. It's time to start taking care of ourselves as if we were precious possessions.

Only you can decide to be sore and tired or relaxed and comfortable. You must decide if you want your weakness and fatigue to progress. You are responsible for what you do. You have no control over anyone other than yourself, and only when you are clear about who is responsible for your activity will you have the power to master it. You have the capacity to recognize fatigue and overuse. [2] You must decide how much you will or will not do.

Your mate, your friends, your boss, your doctor, your physiotherapist and your occupational therapist can only advise you. When you go on Dr. X's Program, you may lose the power to choose when, what and how much you're going to do. It may carry with it the terrifying feeling that you are back in the polio ward again and someone else is in charge of what you do. It also gives you someone else to blame for your weakness and fatigue: Dr. X's Program didn't work. You have given your power away to Dr. X. Dr. X may have some useful suggestions, but only you can decide what works for you.

Four Principles of Conserving Energy

The main principles of conserving energy include (1) doing what you most want to do, (2) planning activities for times when you have most energy, (3) learning what your maximum work is and respecting the signs of fatigue you experience and (4) stopping before you become exhausted. Before you begin any activity you should think about whether you really want to do it at all. Don't ask yourself what you should do; ask yourself what you want to do. It is important to be flexible. Let others in the house or office help you with the jobs you find tough. Delegate tasks whenever possible.

Plan your activities for when you have the most energy. Most people don't think about doing things if they are tired. Don't waste energy by trying to do more than your body can comfortably do. If you are tired by noon, plan activities for the morning. We take a long time to recover if we allow ourselves to become exhausted. Learn what you can do without pushing yourself and respect the signs of fatigue (including muscle soreness, tiredness, muscle weakness, change in quality of movement, grimacing, etc.). Work simplification is an important tool to use in reaching our daily and long term goals in life. Work at a comfortable easy pace and avoid tension. A moderate work pace uses the least amount of energy and you will make fewer mistakes. Alternate heavy with light work each day and throughout the week. Break up heavy jobs over several days. Sit for as many jobs as possible. Allow time for interruptions and emergencies. If you find walking difficult, take along a wheelchair or get a scooter and save your energy for more important things. Pay attention to your body's signals. Care enough about yourself to listen to the messages of pain and fatigue.

Plan rest periods during the day and STOP before becoming exhausted. When taking a rest, relax completely with your feet up. Try resting 10-15 minutes between each hour or two of activity. It will probably take some trial and error to determine what is best for you. If you get tired in the middle of the day, have a one hour sleep early in the afternoon.

Don't expect the impossible, because even with a good plan, there will be setbacks. There are things we can't change and accepting these will help make our lives work better. Sometimes we have to be willing to do a job less thoroughly than usual so we will have the energy to spend on our family or friends. Other times we may choose not to do the job at all!

Three Techniques To Help Us Make Changes

Kohl [4] suggests three techniques that we could use to help ourselves make changes. These are push to avoid pain, blank pad and plain talk. The push to avoid pain system acknowledges the amount of energy that we must generate in order to reduce our activity level. It is a statement of action, not of failure or backing down. It means that we are dedicated to taking care of ourselves. Other people, obligations and commitments will be prioritized according to pain thresholds and those actions that reduce pain. To delegate is action; to use respiratory equipment is an action with enormous consequences; to retain authority in a seated position requires great assertiveness. Taking care of ourselves is not giving in but rather a restatement of control. The pain will not control us, we will control the pain.

The blank pad method of documenting accomplishments during the day reinforces a sense of purpose. Instead of making list after list of things to be done and then crossing off what has been completed, use a blank pad to record all you have done. It is a great training exercise for developing awareness of all the energy expenditure that does occur. It also saves us from devaluing ourselves for that which was not done. The goal is to avoid negative feedback at the end of the day and replace it with positive feedback.

Plain talk was developed in response to people asking how to keep themselves and others from feeling manipulated. If someone does not respect a simple "No" in response to a request, we may have to ask "Why do you want me to be in pain, more tired, overextended, not able to enjoy our time together, etc.?" We need to practice simply worded responses that will increase the other person's awareness of the impact of their requests without creating defensiveness.

Taking Care of Yourself

You have changed physically. Your old coping strategies don't work anymore. You must decide if you want your weakness and fatigue to progress. You are responsible for what you do. When you are clear about who is responsible for your activity you have the power to master it. You can live better if you adapt to the changes in your body. Energy conservation can help you feel better and do more with less. Only you can make the decision to take control and take care of yourself.

References

- Peach PE, Olejnik S. *Effect of treatment and non-compliance on post-polio Sequelae*. *Orthopedics*. 1991; 14:1199-1203
- Agre JC, Rodriguez AA. *Neuromuscular Function in Polio Survivors*. *Orthopedics*. 1991; 14:1343-1347
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Kohl SJ, *Emotional Responses to the late effects of Poliomyelitis*, in Halstead LS, Weichers DO, eds., *Research and Clinical Aspects of the Late Effects of Poliomyelitis*. White Plains, NY: March

of Dimes Birth Defects Foundation; 1987:135-

143

CEPSA has already initiated the wheels turning for our major fund raiser, "Heel to Toe for Polio" walkathon. We are starting much earlier this year in order to try and double the amount of money we raised last October. I have already attended four meetings with the five Rotary clubs that we are partnering with. One of our objectives is to get sponsors from the business community of Savannah. If you have dealings with any businesses, doctors or therapy groups that you feel will support us please approach them for a donation. Once again this year you will receive a printed form from your Care Team Leader encouraging you to reach out to family and friends for support in sponsoring you in this walkathon. Everyone makes donations throughout the year. Try to have them include ours on their list. Remember, their donation is tax deductible. Not only are these donations going to help us, but they are helping eradicate polio from this planet!! Thank you, Jim

CEPSA Minutes for May 22, 2010

The meeting was called to order by Vice-president Diane Davis in the absence of the president, Jim Veccia. Delores McIntyre introduced her guest from Brunswick, John Blanton. Lorraine Frew led us in the Pledge to the American Flag. The inspiration was given by Adrienne Stallworth who shared a story from an African mission trip to a hospital. A newborn baby's need for a hot water bottle was met by a gift box prepared months before by children in an American church activity. Her point was clear: God uses us to minister to those in need even when we are not aware of it.

In the business meeting, the minutes were approved as printed in the April newsletter. Marty Foxx gave the treasurer's report which was also approved. As we listened to the Care Team reports, we learned about various health issues: heart problems, broken leg complications, pinched nerve pain, bronchitis, daily struggles with "simple" daily activities, and depression. Other members were out of town with family events, entertaining houseguests, and attending 50th high school reunions. Ruth Parham showed us a business-sized card which contained health information related to a polio survivor. She suggested that we consider having some printed for us all to carry in our wallets in case of emergencies. Diane will research the source and report back to us soon.

Cheryl Brackin explained a publicity issue with the Savannah Morning Newspaper; the address of 5356 Reynolds Street is required for our announcement about our meetings in the Candler Heart and Lung Building. The deadline is two weeks before the event. Other public announcement outlets were discussed. Tom Schendorf suggested that we place brochures in pharmacies, in doctors' waiting rooms, and in rehabilitation offices. This is an on-going effort which needs attention by us all. Under old business, Harvey Varnadoe suggested we put the t-shirt order on hold until a later time due to lack of interest. The polo style t-shirt with our CEPSA logo on it cost \$25.00. This project is not a fundraiser; its purpose is public awareness for our group.

Diane thanked all those involved in the River's Edge Fundraising Dinner held on May 11. The event was a wonderful success with 50 guests enjoying a delicious meal as well as a very informative program on the Iron Lung by Dan Shehan. Janet DiClaudio and the River's Edge staff did a fantastic job planning and organizing the evening's activities. Richard Graham arranged for transportation of the iron lung to and from storage. Thanks go out to Tom and Eunice Newcomer for keeping the iron lung at their residence over the past several years; it is now stored with our other equipment at the Quick Lock Storage unit in Garden City. The dinner brought \$660.00 into our treasury! We are grateful to those who donated our fabulous door prizes

LoCost Pharmacy on Paulson Street

Crystal Beer Parlor: Phil Nichols

River's Edge bus driver Lanelle Reynolds River's Edge Retirement

Sher Blackwelder of "Wake Up...Feel Good"

Elizabeth Colson Glenda Wilson of Dove Chocolate Discoveries

JANET DICLAUDIO!!!!

After a brief recess, we began the program, “**Sharing Our Strengths.**” Each person shared personal post-polio related issues with the group offering helpful advice and support. As we shared our challenges and successes, we learned anew how wonderful this support group really is. A summary of comments is given below.

- Exercise some, but don’t overdo.
- Realize that we expend great amounts of energy with just daily activities.
- Low blood pressure and low thyroid may be related to our fatigue and lethargy.
- High blood pressure can be caused by combinations of medications.
- Ask yourself if this problem is post-polio or something else. Get it checked out.
- If I exert myself one day, I plan to pay for it the next day by having to rest all day. Just plan for it.
- Water exercise helps, but getting to and from the pool adds greatly to the exertion required.
- Avoid stumbling by slowing down. Don’t get in a hurry. Take more naps.
- Just 2 or 3 pounds of weight gain makes breathing harder.
- She lost 26 pounds on a special diet plan; it cost about \$50 a pound. [It’s only money.]
- Three liters of lemon water a day will flush cholesterol out of your blood.
- Getting out to the Senior Citizens is the best thing for me right now. Don’t isolate yourself.

The meeting was adjourned at 12:30.

Respectfully submitted,
Marty Foxx secretary/treasurer

Attendance:

Diane Davis, Marty Foxx, Cheryl Brackin, Lorraine Frew, Adrienne & Ed Stallworth, Sissy Morel, Betty Goff, Ann Chance, Delores McIntyre, John Blanton, Ruth Parham, Archie Ivey, Harvey Varnadoe, Dan Shehan, Tom Schendorf

The members of CEPSPA would like to thank the **New Jersey Department of Health and Senior Services** for their donation of 200 wallet-anesthesia & PPS warning cards that alert emergency and medical providers of polio survivor’s unique health care needs. In addition, a special thank you goes to **Ruth Parham** for giving the information about these cards to CEPSPA at the May meeting. The cards will be available at CEPSPA’s June meeting. Those who are unable to attend the meeting will receive their card in the mail. Diane Davis

Our next CEPSPA meeting is June 26th. Again, we are looking forward to seeing everyone. We all need each other for help and support.

Happy Birthday ...

June

Delores McIntyre – 10
Ed Stallworth – 12
Ruth Parham – 14
Janet DiClaudio – 17
Harvey Varnadoe – 22
Joey Carroll – 29

July

Joan Page - 17
Cornelia Rollins – 21

August

Gene Goff – 7
Angelo Foster – 8
Tony Calandra – 11
Idella White – 21
Ron Gay – 26
Jim Veccia – 27
Bob Parkhurst – 29



Everyone have a great Birthday!

Let’s get together!!!

Everyone enjoyed our summer luncheons last year so we will continue it this




July and August. The dates will be July 24th, and August 28th. We will meet at Johnny Harris restaurant, 1615 E. Victory Drive, Savannah. You can call (912) 354-7810 for directions. Of course it will be “Dutch Treat.” This gives us the chance to catch up with each other during the summer months.

Members Concerns

Danny Jenkins Hattie Evensen
Lorraine Frew

Thought for the month



Flag Day  is observed in the United States on June 14th. It commemorates the day in 1777 when the Continental Congress adopted the Stars and Stripes as our flag. It then had only 13 stars to match the 13 strips. It is not an official national holiday but in Pennsylvania it's a legal Holiday. It was first observed to celebrate the 100th anniversary of the selection of the flag. President Harry S. Truman officially recognized June 14th as Flag Day by signing the National Flag Day Bill.



SPECIAL CONTRIBUTIONS

Memorial Gifts:

Tony and Lavonne Calandra asked that remembrances for Tony's mother, **Mary Rose Calandra**, be sent to the Coastal Empire Polio Survivors Association. As a result, CEPSPA has received donations in memory of Mary Rose from the following:

Arthur and Molly Gignilliat, Janet DiClaudio
Mr. and Mrs. William Austin, Cheryl Brackin
Beverly and Gene Jarvis, Marty Foxx
Fay K. Crowe, Betty and Gene Goff

Donations of supporters:

Diane Davis Velma Underwood Kenneth Salter Ann Chance
Adrienne Stallworth

Honorary donations:

- Frances Hodgkins in honor of Jim Veccia
- Nance Sherland in honor of Jim Veccia
- Gordon and Terry Sherland in honor of Jim Veccia
- Pamela Coffield in honor of Cheryl Brackin
- Doyle Foxx in honor of Marty Foxx
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Total number polio cases	YTD 2010	Total 2009
Globally	237	1604
In endemic countries	52	1256
In non-endemic countries	185	348

CONTRIBUTIONS

The Coastal Empire Polio Survivors Association is a non-profit corporation which is tax exempt under IRS code 501c(3). We have no paid employees, only volunteers dedicated to helping all polio survivors.

Your financial support is appreciated at any level suggested below:

- * CEPSPA Member - \$15.00 annual voluntary donation
- * CEPSPA Supporter - \$25.00 \$50.00 \$100.00 \$300.00
- * CEPSPA Memorial or Honor Gift - any amount
- * CEPSPA Sponsor – any amount

Your contributions are tax deductible and will be acknowledged appropriately.

Please complete this form and mail it along with your check to: **CEPSA, Marty Foxx, 23 East 61st Street, Savannah, GA 31405.**

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____ E-mail _____

Are you a relative or friend of a CEPSPA member, if so _____

Name of member

Thank you for your support and encouragement.