

Pathways

SERVING FAMILIES AND CAREGIVERS OF BRAIN IMPAIRED ADULTS AND THE FRAIL ELDERLY

WINTER 2007

Coping with Huntington's Disease

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Joan and Dan have been married for twenty years. They met in high school and got married shortly after graduation. Dan works at a local computer company and Joan is a busy stay-at-home mother of a teenager.



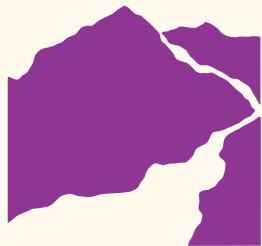
Recently, Joan noticed that her detail-oriented husband was having some difficulty recalling simple details. She also noted a seemingly involuntary twitching motion in his right index finger. When she approached her husband about her observations, he confided in her that he too had noticed the subtle changes. Dan decided to go to his doctor, who ultimately referred him to a neurologist. The neurologist conducted several tests, including a blood test. The neurologist confirmed that Dan has Huntington's disease. After diagnosis, Dan had many questions and concerns, including that of defining Huntington's disease.

Did you know that the Huntington's Disease Society of America (HDSA) estimates that Huntington's disease affects 1 in 10,000 people in the United States? Despite the prevalence, common knowledge about the disease is minimal. Huntington's disease (HD) is a progressive degenerative disease characterized by an abnormally high repetition of a specific DNA pattern on chromosome four. The onset of the disease usually is in adulthood, between the ages of 30 and 50 years old, and strikes men and women equally. Since HD is genetic, children of an affected parent have a 50% chance of inheriting

the fatal disease. Unfortunately, there is no cure for HD and the disease will progress over the course of 10 – 25 years. Individuals will die of complications associated with the disease.

While no two individuals will have exactly the same symptoms and progressions of the disease, in general, the individuals will progress through three stages of the disease. In the early stage, there will be changes in coordination and difficulty with thinking and reasoning. Depression and irritability also accompany this stage. In the middle stage of the disease, individuals will experience an increase in chorea. Chorea is defined as quick, jerking and uncontrollable movements, especially in the trunk, limbs and face. Individuals may begin having difficulty with walking and may be mistaken by others as being drunk, as their walking pattern is erratic. Difficulty with thinking and reasoning skills progress in this stage. The final stage of HD is marked by severe chorea, especially with voluntary efforts to move. There also is a weight loss due to the extreme caloric burn caused by the chorea. Individuals are not able to speak but

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DEL ORO
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Pathways is published three times a year (winter, spring and fall) by Del Oro Caregiver Resource Center. We welcome your comments. Please send letters and change of address notices to Del Oro Caregiver Resource Center, 5723A Marconi Avenue, Carmichael, CA 95608, (916) 971-0893 or via e-mail to crc@deloro.org. Material in Pathways may be reproduced only with permission of Del Oro Caregiver Resource Center.

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ABOUT DEL ORO CAREGIVER RESOURCE CENTER

Del Oro Caregiver Resource Center is an independent, private, non-profit program funded through a contract with the California State Department of Mental Health, grants and private donations. Our mission is to improve the well being of caregivers and provide support throughout the caregiving process.

PROGRAM SERVICES:

- Information and Referral
- Family Consultation
- Counseling
- Respite Care
- Legal/Financial Consultation
- Education & Training
- Support Groups

For information about eligibility for our program, contact Del Oro CRC at (916) 971-0893 or (800) 635-0220 or the Grass Valley Office at (530) 274-1005.



Huntington's Disease . . .

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they still are able to comprehend language. Additionally, they are totally dependent on others for transfers and all activities of daily living such as bathing, eating and dressing. The third stage is followed by death due to complications of HD. Such complications can include pneumonia, infection or choking.

While there is no cure for HD, there are interventions that can assist with the symptoms and management of HD. Pharmacological agents can assist with moderating the involuntary movements. Medications also can be used for the emotional disorders associated with HD. Nutritional counseling, physical therapy, occupational therapy, speech therapy and music therapy are other modalities that can be employed to assist both the patient and the caregiver.

Although the case of Joan and Dan is fictional, it is not atypical of individuals affected by HD and their caregivers. There is a tremendous emotional, mental and physical toll on both the patient and caregiver. For the patient, adjusting to the physical, mental and emotional changes can be frustrating and challenging. For the caregivers, eventually the loved one will become totally dependent on them for assistance with all aspects of life.

Throughout caregiving journeys, one aspect remains constant: Caregiver support groups can be a vital emotional and mental support link for caregivers. Support groups provide a forum in which to share frustrations, fears, experiences and concerns with others in a similar situation. Support groups also provide an opportunity in which to learn helpful tips. In conjunction with the Huntington's Disease Society of America's Northern California Chapter, Del Oro Caregiver Resource Center assists with facilitating a HD support group for both loved ones and caregivers. Lorraine Chew, Family Consultant with Del Oro Caregiver Resource Center facilitates the caregiver support group.

"For families affected by HD, support groups serve as a critical 'lifeline' from which knowledge and skills are gained," states Lorraine. She continues, "More importantly, support is provided and shared among those who understand and empathize with those living with HD. No one feels alone in a support group."

We invite you to attend the HD support group. If you are a caregiver of another neurological disorder, we encourage you to attend support groups dedicated to caregivers of that specific diagnosis. For a complete listing of support groups, please peruse our website, www.deloro.org or call our office, (800) 635-0220.

—Heather Longo, Editor

HD SUPPORT GROUP

Meets 2nd Wednesday of each month from 7- 8:30 p.m.

UCD Ambulatory Care Center, Ellison Building

Room 3015A

4860 Y Street, Sacramento

For more information, contact Del Oro CRC (800) 635-0220

UPCOMING HD SUPPORT GROUP GUEST PRESENTATIONS:

Feb. 14, 2007 – Palliative Care

May 9, 2007 – Del Oro Caregiver Resource Center services

October 10, 2007 - Humor

A Lesson For Me: "You"

Whenever I talk to friends or even strangers and tell them my husband had Alzheimer's disease, the first question they ask is, "Did your husband know you were his wife?" or "Did he recognize you?"

Here is how my husband helped me learn a very important lesson about those very questions. Of course, I was also very concerned that my husband of 42 years would always know I was his loving wife. My anxiety increased as he continued in his cognitive decline.

I cared for my husband for 10 years while the glowing light of remembrances faded from his memory. Later on as he had trouble walking and conversing and then was unable to leave his bed, I became more distressed that he wouldn't remember me. Yes, but I knew all about him. I recognized his contribution to our marriage and his considerate nature that helped so many people over the years. I saw his inner being although he could hardly speak and was physically incapacitated.

One day toward the end of his life, I went to see him at his residential care home. I was increasingly concerned about his fading memory and finally positioned myself at the foot of his bed where he could see me better. His hazel roaming eyes finally rested upon mine. I anxiously asked, "Ray, do you know who I am?"

I intently awaited his reply. He paused and had a great deal of difficulty getting the important word out. With much effort but calm and clearly, he simply stated, "You!"

With his profound directness, his reply pierced my soul. He powerfully imparted the true essence of life. Everyday I endeavor to be the real me as I mourn the loss of my dear husband Ray. ■

—Marlene Dunaway

(Reprinted with permission from the author.)

Caregiver Website

Del Oro Caregiver Resource

Center and California Caregiver Resource Centers are pleased to announce a new electronic newsletter for caregivers. The California Caregiver is an information-packed newsletter that features practical advice, resources, news coverage, caregiving tips and policy updates. There also is an "ask the expert" column.

To view a recent issue, type the following link:

<http://www.cacrc.org/californiacrc/jsp/newsletter.jsp?nodeid=1623>.

To register for the newsletter, type the following link: <http://www.californiacrc.org/californiacrc/jsp/newsletter/registration.jsp>.

We assure you that your email address will not be shared with any other organization or company. ■

SUPPORT GROUPS

IF YOU ARE A SUPPORT GROUP FACILITATOR

and wish to have your support group in the news, please write an article with details about your group and email to Heather Longo at hlongo@deloro.org or send to 5723A Marconi Ave., Carmichael, CA 95608. Please include your name and contact information.

For a complete list of Support Groups in our service area, please visit us online at www.deloro.org.

There are a few NEW groups in our service area that we are pleased to announce:

THE MEMORY CONNECTION: A SUPPORT GROUP FOR EARLY-STAGE ALZHEIMER'S INDIVIDUALS AND THEIR FAMILY CAREGIVERS

This support group is for caregivers and their loved ones who are affected by early stage Alzheimer's disease or related disorders. The group is designed to be both educational and supportive with the affected individuals and caregivers meeting separately the first hour and then jointly the last half hour to provide a forum for enhancing communication and sharing.

TIME: 2nd Monday of the month, 10 – 11:30 a.m.

LOCATION: El Dorado Hills Senior Center
990 Lassen Lane (corner of Lassen and El Dorado Hills Blvd)

FACILITATOR: Genelle Smith, MSW, Family Consultant for Del Oro Caregiver Resource Center (facilitator for caregivers); Wanda Demarest (facilitator for the affected individuals)

CONTACT: Wanda Demarest, (530) 621-6180
(Placerville Senior Center)

SPONSOR: Del Oro Caregiver Resource Center, Senior Day Services of El Dorado County, El Dorado Hills Senior Center

DEMENTIA AND ALZHEIMER'S CAREGIVER WRITING AND POETRY SUPPORT GROUP

This support group will begin in April 2007! It is a caregiver support group for families, friends and caregivers of persons with Alzheimer's disease or a related disorder. It provides a safe environment for individuals to express feelings through writing; give and receive support; learn about Alzheimer's disease; and discover more effective ways to cope with and care for their loved one.

TIME: 2nd Tuesday of the month, 3:30 - 4:30 p.m.
(Begins in April)

LOCATION: Sylvan Oaks Library, Community Meeting Room
6700 Auburn Blvd (at Van Maren)

CONTACT: Denise Davis, Alzheimer's Association,
(916) 930-9080

SPONSOR: Alzheimer's Association



Caregiver Workshops Offered:

Del Oro Caregiver Resource Center is pleased to offer the following free caregiver workshops:

“HOW MANY HATS DO YOU WEAR? JUGGLING YOUR ROLES AS A CAREGIVER” (OFFERED TWICE)

Do you find yourself wearing many hats as you juggle your caregiving and personal relationship roles? Are you working full or part-time in addition to providing care for a loved one? Are there children or grandchildren also living with you? Do you find that you struggle with weaving your way through the different avenues of resources available to family caregivers? Do you have difficulty balancing all of your “hats”? Join us for a workshop presented by Brenda Stephens, Family Consultant. You will learn how to talk with family members to maintain relationships and effective time management strategies. Co-sponsored by the Alzheimer’s Association.

DATE: Monday, January 29, 2007

TIME: 10 – 11:30 a.m.

LOCATION: Cameron Park Library,
2500 Country Club Drive, Cameron Park.

To REGISTER: Contact Del Oro Caregiver Resource Center at (800) 635-0220. If you need someone to care for your loved one so that you may attend this workshop, limited in-home care is available. Please indicate your need for respite when registering.

DATE: Tuesday, February 27, 2007

TIME: 6 -7:30 p.m.

LOCATION: Somerford Place,
3530 Deer Park Drive, Stockton

To REGISTER: Contact Somerford Place, (209) 951-6500

“HOW TO KEEP WHAT YOU’VE GOT: MAINTAINING PHYSICAL AND MENTAL ABILITIES”

Are you a caregiver caring for someone with memory loss? Are you worried that it is “rubbing off” on you? Are you concerned about your memory? Current research says to “use it or lose it”. Alice Jacobs, Educational Physiologist and pioneer in the field of senior learning will explore how the memory works, how memory changes with time, factors that impact memory and techniques for improving memory.

DATE: Wednesday, February 7, 2007

TIME: 10 a.m. – 11:30 a.m.

LOCATION: St. Joseph’s Hospital Auditorium,
1800 N. California Street, Stockton

To REGISTER: Contact St. Joseph’s Medical Center
(209) 461-5061

“MOVEMENT WITH MEANING” – A MULTISENSORY PROGRAM FOR INDIVIDUALS WITH EARLY-STAGE ALZHEIMER’S DISEASE *a workshop for healthcare professionals*

Movement with Meaning is an innovative, therapeutic program designed for healthcare professionals and individuals diagnosed with Early-Stage Alzheimer’s Disease. This unique program immerses participants in a series of short, repetitive exercises that stimulate physical, mental and sensory awareness. Interactive by

nature, the program incorporates music, poetry, and specific sensory activities with breathing exercises, gentle dance movements and yoga-inspired poses. The workshop is taught by Barbara Larsen, MA, Ed, and Family Consultant for Del Oro Caregiver Resource Center. Co-sponsored by Alzheimer’s Association.

DATE: Wednesday, February 7, 2007

TIME: 9 a.m. – 1 p.m.

LOCATION: Maidu Community Center,
1550 Maidu Drive, Roseville

To REGISTER: Contact Del Oro Caregiver Resource Center
at (800) 635-0220.

“DIFFICULT CONVERSATIONS ABOUT DIFFICULT DECISIONS”

Are you caring for someone diagnosed with a chronic health condition, dementia or Alzheimer’s disease? After diagnosis, there are a myriad of difficult family conversations. Larry Dawes, MSW and CMC will present strategies for sharing caregiving roles and responsibilities and how to communicate with healthcare personnel. Co-sponsored by the Alzheimer’s Association.

DATE: Thursday, February 15, 2007

TIME: 10 a.m. – 11:30 a.m.

LOCATION: Davis Senior Center, 646 A Street, Davis

To REGISTER: Contact Del Oro Caregiver Resource Center at (800) 635-0220. If you need someone to care for your loved one so that you may attend this workshop, limited in-home care is available. Please indicate your need for respite when registering.

“DAILY DIFFICULTIES WITH DEMENTIA”

If you are a caregiver for a person experiencing memory loss, you’ve no doubt experienced some of the frustrations and difficulties associated with caring for a person diagnosed with dementia. In this workshop, Maria Cisocoe, Certified Activities Director will help you to discover behavioral interventions to assist in dealing with some of the daily challenges including agitation, resisting care and wandering.

DATE: Thursday, March 15, 2007

TIME: 9:30 a.m. – 11 a.m.

LOCATION: Amador Senior Center,
229 New York Ranch Road, Jackson.

To REGISTER: Contact Del Oro Caregiver Resource Center at (800) 635-0220. If you need someone to care for your loved one so that you may attend this workshop, limited in-home care is available. Please indicate your need for respite when registering. Co-sponsored by the Amador Senior Center.

“LEGAL AND FINANCIAL PLANNING”

Please join us for a workshop about a subject that concerns us all – how to effectively plan for our loved ones and ourselves as we meet the challenge of growing older and/or facing incapacity.

Presented by Attorney Trudi Riley-Quinn. Co-sponsored by the Alzheimer's Association.

DATE: Wednesday, March 21, 2007

TIME: 10 – 11:30 a.m.

LOCATION: Yuba County Senior Center,
938 14th Street, Marysville

To REGISTER: Contact Del Oro Caregiver Resource Center at (800) 635-0220. If you need someone to care for your loved one so that you may attend this workshop, limited in-home care is available. Please indicate your need for respite when registering.

“LEGAL AND FINANCIAL PLANNING”

Please join us for a workshop about a subject that concerns us all – how to effectively plan for our loved ones and ourselves as we meet the challenge of growing older and/or facing incapacity. Presented by Attorney Randall Rosa. Co-sponsored by the Alzheimer's Association.

DATE: Tuesday, April 17, 2007

TIME: 10 a.m. – 11:30 a.m.

LOCATION: Yolo County Department of Employment and Social Services, Community Room #167,
25 N. Cottonwood Way, Woodland.

To REGISTER: Contact Del Oro Caregiver Resource Center at (800) 635-0220. If you need someone to care for your loved one so that you may attend this workshop, limited in-home care is available. Please indicate your need for respite when registering.

“UNDERSTANDING MEMORY LOSS: A CELEBRATION OF CREATIVE APPROACHES”

Alzheimer's Association annual education conference for families and professionals will be held in May this year.

DATE: Wednesday, May 2, 2007

TIME: 9 a.m. – 4 p.m. (registration begins at 8 a.m.)

LOCATION: Lions Gate Hotel and Conference Center,
Garden Pavillion (former McClellan Air Force Base, Sacramento)

COST: Family caregivers \$25 (before March 30), \$30 (after March 30); CNA/HAA professionals \$60 (before March 30), \$65 (after March 30). BRN, RCFE, LMFT/LCSAW, NHA professionals \$75 (before March 30), \$80 (after March 30) Includes CEU certificate.

To REGISTER: Contact the Alzheimer's Association,
1-800-272-3900 or (916) 930-9080

“DEMENTIA AND DRIVING: A PERSPECTIVE AND CHALLENGE”

Struggling with the decision of when driving is no longer safe for a person diagnosed with dementia or Alzheimer's disease is a difficult decision. After all, driving provides a sense of pride and independence. However, when safety to self and others becomes

the issue, how do you determine and implement the next step in limiting or ceasing driving? Ruth Gay, MS, Director of Advocacy and Public Policy with the Alzheimer's Association will help you to address these concerns and others. Co-sponsored by the Alzheimer's Association.

DATE: Wednesday, May 23, 2007

TIME: 10 a.m. – 11:30 a.m.

LOCATION: Davis Senior Center, 646 A Street, Davis

To REGISTER: Contact Del Oro Caregiver Resource Center, (800) 635-0220. If you need someone to care for your loved one so that you may attend this workshop, limited in-home care is available. Please indicate your need for respite when registering. Co-sponsored by the Amador Senior Center.

A DOSE OF *Inspiration*

Is there a passage or quote that inspires you as a caregiver? We welcome your submissions and encourage you to help inspire other caregivers along the way! Please send your submissions to Heather Longo, Pathways Editor, Del Oro Caregiver Resource Center, 5723A Marconi Ave., Carmichael, CA 95608, or via email to hlongo@deloro.org.

The following quotes were submitted by readers of our newsletter, Pathways:

*“Where there is great love,
there are miracles.”*

—WILLA CATHER

*“True friendship is seen thru the
heart, not thru the eyes.”*

—ANONYMOUS

*“The family is one of nature's
masterpieces.”*

—GEORGE SANTAYANA

*“In the depth of winter, I finally
learned that there was in me an
invincible summer.”*

—ALBERT CAMUS

Movement With Meaning: *Innovation for Early-Stage Alzheimer's Disease*

Those of us in the field of dementia care are re-examining our philosophical beliefs and exploring practical, hands-on approaches in our relationships with individuals living with Alzheimer's disease. We are creating innovative programs and developing a new framework for preserving the emotional health, autonomy, and dignity of those who need us to walk hand in hand with them, witnessing the process of their experiences with empathy and respect.

Movement with Meaning is one such program. Designed for persons in the early stage of Alzheimer's, Movement with Meaning reinforces the remaining strengths and abilities of people with dementia by using a multisensory approach that stimulates all five senses. Practical and interactive by nature, the curriculum is ideal for physical therapists, recreational instructors, and activity directors in adult day centers and assisted living facilities, as well as health care professionals who are senior trainers, music or dance therapists.

As the mind begins to slowly unravel, the body becomes the refuge – the container – the ground and point of reference. In a Movement with Meaning class, the multisensory activities are divided into five segments that create choreography of movements in which short, repetitive exercises increase a sense of well being. The program introduces simple breathing techniques, poetry, music, movement exercises (bilateral integration exercises and yoga postures), and sensory activities. Once the person with



Movement with Meaning reinforces the remaining strengths and abilities of people with dementia by using a multisensory approach that stimulates all five senses.



Alzheimer's disease experiences a sense of his or her inner landscape, anxiety and confusion begin to subside. Movement with Meaning provides an opportunity for the participants to recognize the abilities and talents lying dormant behind the disease and find a new path to connect and communicate with each other and their families.

When the elements of Movement of

Meaning are put together in a daily program, attention is refocused back to the body of the person with Alzheimer's disease. For whatever was lost in the cognitive realm can be recalled through the senses. As one participant in a Movement with Meaning class stated when asked what she thought about the program, "I have enough to hold on to."

What an opportunity we have with the advent of early diagnosis for implementing new programs. So why wait? The time is now, in the early stage, to reinforce remaining strengths and abilities. The time is now, while the individual is aware of his or her own personal biography, to investigate the sense of how the individual's inner landscape is changing. The time is now to create an environment that strives to preserve the identity and dignity of each individual affected by Alzheimer's disease.

Barbara Larsen, M.A., Ed., and Family Consultant with Del Oro Caregiver Resource Center has

worked with caregivers for loved ones diagnosed with Alzheimer's disease and related dementias for the past 20 years. Her book, *Movement with Meaning* is a work from her

heart, dedicated to recognizing and celebrating individuals in early-stage Alzheimer's disease. Her book is available for purchase from Health Professions Press. To order a copy of the book, please contact Health Professions Press at 1-888-337-8808 or visit online at www.healthpropress.com. The ISBN number for *Movement with Meaning* is 1-932529-14-4.

—Barbara Larsen, Family Consultant

Donations

Your tax-deductible contribution will help fund critical programs for family members who are dedicated to providing long-term care at home. There are various ways to give to Del Oro Caregiver Resource Center:

- Donate by mail – make your check payable to Del Oro CRC and mail it to 5723A Marconi Avenue, Carmichael, CA 95608.
- Donate Your Automobile – Del Oro is now able to accept used car donations in California through the not for profit corporation, Cars 4 Causes. This agency handles all the paper-work, title change, free pick up and sale of the vehicle. Receive a tax

deduction for the fair market value of your vehicle. For more information call Cars 4 Causes at 1-800-766-CARE.

- Donate Stocks or Mutual Funds
- Donate Real Estate
- Donate online at www.deloro.org using your credit card. Del Oro CRC has partnered with Groundspring.org to provide a secure site for credit card transactions.

If you would like to discuss your donation in detail, please contact Michelle Nevins, Executive Director of Del Oro CRC at (916) 971-0893.

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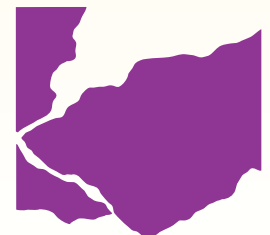
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**For information or assistance, contact Del Oro CRC at (800) 635-0220
or visit our website at www.deloro.org**

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