

Compassionate Care ALS Annual Report 2007

The Mission:

The mission of Compassionate Care ALS (CCALS) is to model compassion to those affected by ALS (also known as Lou Gehrig's disease) by providing educational and legal resources, respite opportunities, instruction and guidance, subsidy of living aids and assistance, and intimate dialogue with patients and their caregivers, families, and friends. Our approach draws from hands-on experience as we strive to continually understand the overwhelming dynamics ALS families endure.

The Need:

ALS is a degenerative and fatal disease that progresses unpredictably. The challenge of caring for an ALS patient puts an enormous strain on friends and family – emotionally, psychologically, spiritually, and financially. ALS can strike without warning: anyone- regardless of race, gender, income, education, or geography can be affected.

The CCALS Difference:

While many ALS organizations pursue a cure for future patients by focusing on scientific research, Compassionate Care ALS maintains a holistic presence with the patients and caregivers of today. We strive to accompany them on their journey, actively listen to their concerns, care for their needs, and equip them to face end of life issues with dignity and grace. Thanks to the support of foundations and individual donors, CCALS is growing, and in 2007 we were able to help more families than ever.

Funding:

In 2007, CCALS raised more than \$450,000 to support our programming. Sixty-one percent of our funding came from individual donor support, while 10% came from grants and 26% came from the hugely successful Falmouth Road Race fundraiser. We received grants from 10 foundations and increased individual contributions by 37%. We are constantly working to diversify and increase our base of support, because we know every dollar raised somehow touches a family devastated by ALS.

What your generosity accomplished in 2007:

- Allowed CCALS to purchase a new wheelchair accessible van to transport patients.
- Made us the top-earning charity at the Falmouth Road Race!
- Provided services to 172 ALS families including 76 new cases.
- Made possible 353 visits to patients and their families at home to provide guidance and emotional support, to assess their current circumstance and to deliver equipment.
- Conducted more than 1,000 phone consultations with ALS patients, families and friends.
- Met with caregivers one on one to listen and offer support.
- Arranged hands-on integrative therapy sessions from trained physical therapists, counselors and other healthcare professionals.
- Provided families with ramps, wheelchairs, shower chairs and other durable goods not covered by insurance or provided by other organizations.

Caregiver Support:

When a family receives the devastating diagnosis of ALS, they are faced with an overwhelming array of questions, paperwork, financial and logistical challenges, and life-altering changes. Conventional medicine does not begin to address the complexity of these needs. That is where the CCALS steps in to fill the void in services. Our *ALS Patient, Family, and Caregiver Support Program* includes making

home visits to meet with families face to face; engaging in intimate dialogue around disease progression, dying and death; helping families obtain durable goods not covered by insurance; and referrals to numerous specialists. In addition, we loan our wheelchair-accessible van to families for everyday needs and special trips. During the past year we have seen a 25% increase in our client base.

ALS Medicine Bag:

Over the years, one of the ways that we have supported ALS families is by providing them with equipment on an as-needed basis to help ease daily life around the house. CCALS has used our 10 years of experience working with ALS families to put together a collection of the best non-institutional resources that help bring dignity to those living with ALS. We have now compiled these resources into our new Medicine Bag, which we give to all new patients and families. It contains products like Transfer Belts and Transfer Slings, that help patients stand and transfer from one space to another, and Pivot Disks, on which the patient stands to move from one location to the next when they can no longer move their legs. The Medicine Bag holds items families might not anticipate needing when first diagnosed, but will be grateful to have at their disposal down the road.

Education:

Our hands-on experience with these families has given us wisdom and perspective we are eager to share with others. That's why we created the *Cultivating Compassion* education series, which informs patients, families, friends and healthcare providers about the realities of living and dying with ALS. The series consists of several different workshops on an array of topics related to the care of ALS patients. Attendees might learn about Living with ALS, Providing Compassionate Care, Awakening to Living and Dying, Care of the Caregiver, or Meditation and Contemplative Practice. CCALS also holds groups for specific populations like Men of ALS, Women of ALS, Beyond ALS (for those who have lost a loved one to the disease) and in-services for hospice organization staff. CCALS hosts many of these gatherings, while some are hosted and organized by health care agencies who want to educate their employees with the benefit of our expertise. During 2007, CCALS provided 15 workshops to more than 500 individuals.

Handicapped Equipped Van:

In the past year, we were able to purchase a 2007 Chrysler Town & Country van. The van is an integral part of our program that gives CCALS families back their mobility. Families use the van for everything from weekends away with loved ones, to grocery shopping and trips to the movies, everyday experiences often taken for granted until the ability to have them is gone. For some patients, this is the only alternative to costly ambulance trips for leaving the house. Our van was used by 12 different families during 2007.

The Future:

For patients with ALS, the future can be filled with fear, uncertainty, and dread. At CCALS we are working to transform that reality into one of peace, mindfulness and compassion. As we look ahead we hope to continue to expand our array of services and educational opportunities, to better equip families and patients living with ALS to face the future with hope and dignity. In the next year we will begin the work of raising funds for the CCALS Resource Center-a new site that will offer space for educational gatherings, Circles of Support, trainings, ALS family getaways and respite stays.

Special Thanks:

In 2007 CCALS received contributions from more than 1,700 individuals without whom we could not continue to offer our high quality programming. We would also like to thank the following foundations and corporations for their support: Christopher & Dana Reeve Foundation, ALS Family Charitable Foundation, Fish Family Foundation, The Leonard & Claire Tow Foundation, Stephen R. Baum Foundation, Mattina R. Proctor Foundation, Kenneth B. Schwartz Center, Cambridge Trust Company, Ride-Away, Patrick Murray Inaugural Fund, Figawi Charities, and the Hermann Foundation.