

VINEYARD GAZETTE

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Dilly Walsh Hosting ALS Fundraiser

by Maia Smith

Compassionate Care ALS represents a new, or perhaps ancient, approach to medicine. Focusing on health care rather than disease treatment, the Cape-based nonprofit seeks to improve the quality of life of people who have ALS. This degenerative and irreversible nerve decay was made famous by Lou Gehrig and then Stephen Hawking. Doctors can do little to treat it or slow its progressive destruction, even as the mind and senses remain.

Treatments revolve mostly around symptomatic relief, making the patient as comfortable as possible. Though drugs often help with specific physical symptoms, the damage done by ALS is not limited to muscle spasms and weakness.

Stranded and isolated, without proper care, ALS patients often lose the will to continue and lapse into clinical depression. This is where Compassionate Care ALS steps in: this Cape-based nonprofit provides care for the health of people with ALS and enables them to live with dignity as long as they can and without denying the reality of disability and approaching death.

The organization assigns each new patient to a specific counselor, who will facilitate dealings with the organization and the world at large. It's a tall order, but one well-filled. Vineyard seasonal resident Dilly Walsh, diagnosed in 2007, describes his helper, Ron, as "ALS Santa."

Such Santas have years of experience and education dealing with ALS, and they know what kind of help is available and where to get it. Their regular visits bring patients emotional support and advice and often practical help such as waterproof wheelchairs. They, and the organization's other trained counselors, can reassure that a symptom is normal, urge a patient or caretaker to get help, or suggest where to obtain a needed service that is beyond their own scope. Whether you need a wheelchair ramp or a craniosacral therapist, Compassionate Care's prodigious Rolodex is a one-stop shop for victims of ALS.

One of the most useful services of CCALS is the loaner library. Its wide range of

adaptive equipment allows patients to remain active for as long as possible, exchanging a cane for a walker for a wheelchair as the disease progresses. This saves them from purchasing expensive supplies that are only needed for a few months.

Large-scale mobility is also provided: patients can request a lift-equipped van to take them to social and medical appointments, to visit friends, exchange library books or get a massage. Caring for the health of ALS patients is spread across the community. Compassionate Care's help is literally priceless: all of their services are provided free. Well, free to the patient. Someone still has to gas up that van and pay off that counselor's student loans. That's where Islanders can help.

On July 23, Dilly Walsh will be holding a fund-raising dinner at his house on Middle Road. Details are handled by his friend John Verret. There will be music by Johnny Hoy and the Bluefish, fine cuisine from the Oyster Bar and Grill, an open bar and a live auction. You can bid on Island standbys like a fishing charter with Buddy Vanderhoop (read all about him in the most recent Martha's Vineyard Magazine). Or pick up some of an assortment of Vineyard art that ranges from the eclectic to the essential. There'll be Red Sox tickets, yoga classes and honey from Katama Apiary.

And through the whole party, from 5 to 11 p.m., there is babysitting. Dinner and a show for a good cause at \$100 per person. Everything at the fundraiser is either donated or heavily discounted. For more information, directions and to volunteer, call John Verret 508-645-3623, e-mail jverret@bu.edu or go to CCALS.org and click on Vineyard Night.