

COMPASSIONATE CARE ALS MEETS A SEASON OF INCREASED DEMAND AFTER DECADES OF UNRIVALED CARE

The vision of CCALS has developed over two decades based on the vision of our founder and Executive Director, Ron Hoffman. Spring of 2021 has brought a new focus and renewed dedication to providing the programming to support that focus. The unfolding of the next phase of CCALS began as remote work and inspired our staff to meet new challenges in new ways. In addition to visiting families virtually, CCALS has creatively brought new gatherings to our community of more than 850 active ALS families, as well as the thousands of families we have supported in the past twenty three years.

As you will read about in this newsletter, we have introduced a Volunteer Caregiver Program. This program brings trained volunteers into ALS families' homes. We have also reinvigorated our Cultivating Compassion Education Series, providing weekly gatherings and a special speaker series.

The collective grief and ongoing loss of life through this pandemic has exposed our culture-at-large to many of the same burdens carried by our ALS families. Our new programs speak to this reality, and serve to lessen these burdens as we continue to build a resilient community.

PERSPECTIVE FROM BRENDA FOX, CCALS' GRIEF AND BEREAVEMENT CARE LIAISON

One aspect of CCALS' next chapter is providing means for families who have lived through an ALS diagnosis to give back. So many in our community have lived the daily realities of ALS, and we are endlessly grateful for our community's eagerness to share their caregiving skills.

CCALS Grief and Bereavement Care Liaison, Brenda Fox met Ron in January 2010. She describes the need her family experienced after her father was diagnosed with ALS.

"Words cannot convey the hardship and grief that accompany what is not just a death sentence, but largely within the medical community is a proclamation of 'we got nothing for you.' This is the terrifying context into which CCALS steps in with heart and help. The care provided by Ron Hoffman and his outstanding team of folks changed our path!"

Nearly 11 years after the fact, our entire family continues to support and pay the care we received forward. We will run the Falmouth Road Race this year as we did 11 years ago and we regularly attend the other CCALS events throughout the year."

Many of our families have shared this same sentiment; CCALS programs fill the care void, bringing connection, knowledge and resources into their life at a critical time. We have had so many incredible means of support through Falmouth Road Race runners, event attendees, and donors. The future of CCALS incorporates even more opportunities to be involved. We will continue to present our community with different opportunities to give back, all in order to provide the unparalleled level of care CCALS provides to individuals and families living with ALS.

GIVE BACK THROUGH OUR VOLUNTEER CAREGIVER PROGRAM

CCALS has launched an exciting opportunity to give back to the ALS community. Our **Volunteer Caregiver Program** is a new initiative funded by Adira Foundation and Mitsubishi Tanabe Pharma Corporation that trains individuals to serve as more consciously aware and soulful caregivers. This program allows CCALS to better meet the needs of families living with ALS.

Our first cohort of volunteers were introduced to CCALS' end-of-life work, through monthly webinars, handouts, videos and books to complement the training at the end of March. Initial live training was a Zoom weekend intensive which included sessions led by Tom Daly, PhD, of the Living Arts Foundation, Julie Brown Yau, PhD, trauma therapist, and Ron Hoffman, who spoke about end-of-life. CCALS' approach to this program is based on the relational model developed by Ron Hoffman during his 25 years caring for families living with ALS. It is

a model rooted in personal inquiry and growth as essential elements in the ability to show up fully for those in our care.

"I'm pleased that our regular staff also participated in the weekend intensive," Ron adds. "These are skills we can all benefit from learning, even if we've been involved in ALS care for a long time."

Another weekend event put on by the Upaya Zen Center, called "Being with Dying," is based on the work of Upaya Zen Center founder and teacher Roshi Joan Halifax. This particular training is among the core teachings that has inspired Ron's work and the CCALS model of care.

"There is an art to showing up, a level of clarity and inner harmony that can only be achieved by looking at and healing our personal wounds," says Ron. "We've got a great group of volunteers who have the courage to explore their inner landscape so they can really be there for our families."

After completing training, volunteers will shadow staff and/or visit families remotely (dependent on COVID-19 protocols) to gain first-hand experience. The training teaches volunteers how to serve as a source of awareness, understanding, and consistency to individuals living and dying with ALS. They will learn how to support individuals living with a terminal diagnosis and will be equipped with the tools and knowledge to enhance quality of life, all in support of our staff.

We are taking applications for the second cohort of volunteers. Training begins in July of 2021. Please visit ccals.org/caregivertraining to learn more or apply.



CCALS' CHRIS CURTIN VISITS CHRIS THALACKER IN HIS HOME

IN MEMORIAM

Alan Albert, Dedham, MA
Michael Allan, Saugus, MA
Christopher Anderson, Cambridge, MA
Elton Araujo, Stow, MA
John Areias, East Taunton, MA
Angie Argiriou, Summerville, SC
Patrick Asare, Everett, MA/Ghana
Frederick Ayers, Scituate, MA
Thomas Barber, Lynn, MA
Fred 'Chip' Bargetzi, Upper Saddle River, NJ
Hugo Barreto, Plaistow, NH
Jim Berry, Portage, MI
Richard Ross Blackinton, Harwich, MA
Janet Brand, East Falmouth, MA
Randy Brooks, Amesbury, MA
Mark Cardilli, Brunswick, ME
Sharon Caron, Tolland, CT
Christopher Carr, Staten Island, NY
Ron Carreiro, Bristol, RI
Jerry Castleman, Swampscott, MA

Anthony Chaves, Raynham, MA
Lisa Chernow, New York, NY
Joseph Comber, Melrose, MA
Stephen Cook, Attleboro, MA
Sister Helen Colbert, Brighton, MA
Ann Corbett, Brookline, MA
Leo Corey, Saugus, MA
Dan Cote, Southbridge, MA
Tim Coulter, Hudson, NH
Kevin Coyle, North Easton, MA
Patricia (Paddy) Dipadova, Sandown, NH
Christopher DePerrio, Holden, MA
Ann Deruosi, Winthrop, MA
Paul Donovan, Westminister, MA
Gregory Doran, Manchester, MA
William Elfers, Marion, MA
David Elliot, Cambridge, MA
Christine Fairchild, Rockport, WA
Jeanette Fitzgerald, Billerica, MA
Patricia Flaherty, Quincy, MA
Patrick Fontes, Hudson, MA
Nina Galvin, Johnston, RI
James Grimsley, Pittsfield, MA

Adrienne Gunther, Baton Rouge, LA
Pat Harris, North Falmouth, MA
Edward Hill, Salem, NH
Paul Jensen, Nantucket, MA
Amalia Kent, Bedford, MA
Yegya Grigorian, Watertown, MA
Sunshine Grimes, Salem, MA
Jimmy Gerakas, Fremont, NH
Joe Grillo, Armonk, NY
Jose Gutierrez, Fresno, CA
Frank Hammond, Bridgewater, MA
Edward Hill, Salem, NH
Gary Hogg, Concord, NH
Wilfred Hoyt, Portsmouth, NH
Katharine Kadinsky-Cade, Arlington, MA
Annetta Kastner, Urbandale, IA
James King, Uxbridge, MA
Linda Lameiras, Somerville, MA
Grace Laporta, Mashpee, MA
Carmen Laurenza, Lynn, MA
Jane Lauridsen, Newton, MA
Ray Lemoine, Amherst, MA

Cathy Mathes, East Islip, NY
Kathleen McMath, Salem, NH
James Mercer, Mattapoisett, MA
John Minichiello, Providence, RI
William Moore, Winthrop, MA
Timothy Moynihan, Hudson, NH
Sheila Monnat, Barrington, NH
Steve Nakata, Boca Raton, FL
Karen Nielsen, Warwick, RI
Essex Noel, Roxbury, MA
Dario Nunez, Lawrence, MA
Kevin O'Halloran, Middletown, RI
Peter Parseghian, Shrewsbury, MA
Peter Paulousky, Franklin, MA
Kenneth Pearson, Halifax, MA
Carmine Pettinicchio, Jr., Revere, MA
Marshall Pierce, Clinton, MA
Michael Polidoro, Pittsfield, MA
George Price, Greenfield, MA
Maria Psihogios, Danvers, MA
Pat Quinn, Yonkers, NY
Rolando Castillo-Quinones, Boston, MA

Vuyi Radebe, Sandton, South Africa
Bruce Roderick, Plaistow, NH
Matthew Rothwell, Atkinson, NH
Darryl Roy, Clarksburg, MA
Linda Sarkisian, Arlington, MA
Corrine Schultz, Taunton, MA
Barry Seidman, Bedford, MA
Donna Sheehan, Lynnfield, MA
Hildy Smookler, Stoughton, MA
Robin Stacy, Guilford, NH
Carol Stanmore, West Falmouth, MA
Stacey Title, Los Angeles, CA
George Tokatli, Belmont, MA
Suzanne Triggs, Taunton, MA
George Tripp, Tenants Harbor, ME
Ellen Walsh, Wellesley, MA
Joe Walsh, Nashua, NH
Robert Ward, Quincy, MA
Laurie Warren, West Brookfield, MA
Marsha White, Gloucester, MA
Grace Wiencko, Weymouth, MA
Kenneth Wood, Orleans, MA

ALS ONE LICENSE PLATE

Compassionate Care ALS partner ALS One offers the only license plate in the state of Massachusetts to fund ALS research and care. We are proud that the plate debuted on the road in July of 2018, helping to raise critical awareness and much needed funding for CCALS as well as our ALS One research partners. Each plate costs just \$40, of which \$12 goes to the

state and the remaining \$28 goes to ALS One programs. Every time you renew your registration, the entire \$40 supports ALS One. The plate is available to owned or leased cars and can be purchased at any full-service RMV or online at alsonelicenseplate.org.



THOUGHTS FROM RON

I took Madison out for her morning walk the other day and felt the crispness of spring giving way to the warmth of summer. The turning of the seasons made me think about the circle of life, the springtime of youth giving way to the summer of maturity, flowing into the responsibilities of the fall season and circling around to the elder years of witnessing and blessing—the winter of our lives.

For my friends living with ALS, the progression of life has been accelerated. The years associated with the seasons and phases become compressed. Therein lies the mystery of our individual dances here on this earth.

My friends living with ALS sign up for various trials, filled with optimism that this one is “the one” and the nightmare will be over. I’ve been watching this drama unfold for nearly 25 years now, and keep that hope alive as well. There is progress, no doubt, and the search for a cure must continue. And still, the needs of those people whose journey around the hoop of life just got sped way up must still be met in the here and now.

It brings me solace that we restarted our Cultivating Compassion Education Series in March of this year. These weekly gatherings take place under the titles *Caregiver to Caregiver*, *ALS Family and Friends*, *Men of ALS*, *Women of ALS* and *Beyond ALS*. These events—online during the pandemic—are one of the ways CCALS serves our community in the here and now, on a heart and soul basis, with deep listening at the core.

I very specifically do not call these gatherings “support groups” because, in my experience, support groups very quickly devolve into advice-giving and a loss of safety and equanimity. There’s

a lot of interrupting, among the worst of which is the handing of a tissue to somebody who is crying. What happens when that tissue shows up? The person sits up, wipes away their tears, blows their nose and the emotion is pushed away. No time or space for feelings to naturally emerge, be witnessed and become part of healing. At our gatherings, we want to just let it be. Let the person have their feelings. Let it percolate within you. In that way, another person’s emotions freely expressed can be a lens into our own heart, to the wounds and losses of our own that still need tending.

I love it when caregivers and those living with ALS come together at our gatherings. It provides another chance to view our circumstance through someone else’s lens. Speaking or hearing truths between those being tended to and those doing the tending can be hard to come by. Those truths, spoken by another at one of our gatherings can be incredibly illuminating. Then both carers and those being cared for can leave the gathering a little more open hearted and understanding.

I spoke with a woman the other day who attended our Women of ALS gathering. She said it was the best thing she’d done since her husband’s diagnosis.

“What was it about the gathering that had so much meaning for you?” I asked.

“One of the women living with ALS had such a wise perspective about her situation. I had never thought of it in that way. It helped me understand what my husband is going through in a whole new way.”

The other thing we’ve been doing more of—and I think it’s really important—is providing more council time and deep listening to our staff. I call it caring for the carers. It is something sorely lacking in our healthcare system. How can people be expected to show up fully for others when no one is showing up for them?

Someone said to me the other day, “Ron, what you do is not normal.” What we do—working around death and dying every single day—is not normal. It’s a lot to take on for our staff. One of our senior members put it well the other day when he said, “It’s relentless.” Is it ever. All the more so for those families navigating the twists and turns of ALS every day.

We all need tending. I can’t emphasize it enough. We do not have the resources on our own to handle the relentless demands of ALS. We need each other. We need counselors and therapists and faith leaders. We need to gather together in council and simply be together, open our hearts, bear witness, hold space and listen. We need to relieve ourselves of the burden of having to figure it all out, come up with the perfect answer or play the savior.

Come to our gatherings, friends. Relax and be together in our shared humanity. Take advantage of the refuge we are offering. You may find it feels a little bit like coming home.

In Gratitude,

A handwritten signature in black ink, appearing to read "Ron Hoffman".



RON HOFFMAN
FOUNDER

CULTIVATING COMPASSION EDUCATION SERIES

A new regular schedule for the Compassionate Care ALS Cultivating Compassion Education Series is set and now available to all of our CCALS families and friends. Through this program, CCALS provides a safe space to share knowledge, support, and experience caring for and supporting individuals living with ALS, their families and their communities. Cultivating Compassion helps to improve effective communication while shedding light on the realities of living with ALS and when appropriate exploring the reality of one's mortality.



A CULTIVATING COMPASSION GATHERING AT THE HEALD CENTER

This series is designed to provide an honest, open and accepting forum in which to explore various aspects of the ALS experience for everyone involved. Our talented staff will facilitate the discussion and make sure everyone's voice is heard and respected. Most gatherings are offered monthly. Visit ccals.org/gatherings to sign up or learn more.

FAMILY & FRIENDS OF ALS

First Thursday of every month

The gathering brings together a variety of family configurations and provides a wonderful interactive opportunity to share our unique experiences on the ALS journey.

BEYOND ALS: AN INTIMATE GATHERING FOR THOSE WHO HAVE BEGUN NEW LIVES AFTER LOSS

2nd Thursday of each month

Join a welcoming group of men and women who are living on the other side of an ALS experience. This interactive gathering highlights where we are now and what may feel different: our identity, our values, our approach to spirituality, and more.

CAREGIVER TO CAREGIVER

Third Thursday of each month

This informal gathering is designed to offer genuine support for those engaged in ALS caregiving.

WOMEN OF ALS

Fourth Thursday of each month

Women of ALS provides connection and unique perspective of other women living with ALS, female caregivers of persons living with ALS, daughters of those with ALS, or any woman touched by the disease.

MEN OF ALS

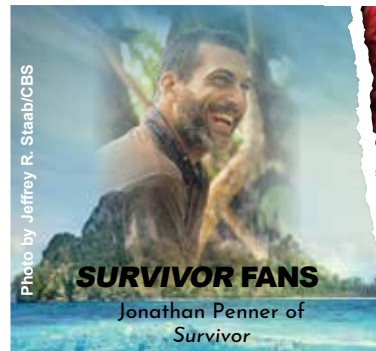
Fourth Thursday of each month

Men of ALS provides connection and unique perspective of other men living with ALS, male caregivers of persons living with ALS, sons of those with ALS, or any man touched by the disease.

CCALS 2021 FALMOUTH ROAD RACE

You don't have to be in Massachusetts to support CCALS at the Falmouth Road Race. As of now a limited number of runners will be on the course August 15 and everyone will be able to run Falmouth virtually. Either way, we have a great event full of fun, fundraising, and competition planned!

You can help support our goal of raising \$250,000 for Compassionate Care ALS in so many ways this year! Either compete individually or raise money as a team and join one of our two competing sides, either *Survivor* or *The Bachelor*. *Survivor* is led by Jonathan Penner, a three-time returning player on *Survivor*, whose wife Stacy recently passed with ALS, while *The Bachelor* is headed by Chris Lambton, a Bachelor runner-up, star of the new Discovery+ show *Clipped* with Martha Stewart and local selectman, who lost his mom in 2008. Individual participants' fundraising totals will be added to whichever side they choose. Do you seek to be the Sole Survivor or to get the Final Rose?



Whichever side you choose, we are still all one team with common goals: compassionate care, positive change, and honoring loved ones. So, lace up your sneakers and form a team or donate to a side! We will see you on August 15th, however we decide to come together (depending on what is safest for everyone), to compete, support our community, and make change.

Visit falmouth.ccals.org to sign up or support a runner.