I was at a fundraiser recently when I felt a gentle tap on my shoulder. I turned to find two tall young men standing there. When they told me who they were, I was taken aback. I had met them more than ten years prior, after their father had been diagnosed with ALS and didn’t know when or how to tell his boys about it. They were so young and innocent then. Now here they were, grown up, one of them a college baseball pitcher, the other working in his chosen field. They were thankful for what CCALS had done for their family. I cannot imagine how proud their dad would be of them, were he alive to see what they had become.

What we have become...my, my. I ponder this myself, having reached the age this month of what many would consider a true elder, a man of 70. I can still see and feel the boy I once was—like those young men at the fundraiser—who would have never imagined what would turn out to be his calling when he grew up. He would never have guessed that an offer to become the driver of his boss at the catering company where he worked would turn into an international organization devoted to caring for individuals and families living with ALS. If I could go back in time and tell that boy what was to be, I think he would have looked at me and said, ‘What’s ALS?’

Good question, Ronnie! What the heck is ALS? In the 84 years that have passed since Lou Gehrig was diagnosed with the disease that would take his name, we still don’t really know what it is—but we’re getting closer. But do we have a clue about the why?

So, what we do at CCALS is wade into this unsolvable mystery of a disease that has a name but very little else. Research continues at a furious pace. More breakthroughs appear to be on the not-too-distant horizon, and we put all of our hopes and prayers into slowing it further, and eventually finding a cure. Until that day comes, though, somebody has to wade into the unsolvable mystery that is the here and now of that fateful day when a person leaves the neurologist’s office with the shocking and traumatic diagnosis—it’s ALS. What do you do now? My hope is that you find us. Without delay you turn toward someone who will walk along beside you without hesitation, someone who cares in a gentle way. In a way that feels more like hanging out with a new friend who has some helpful information and a medicine bag of useful tools, and a bit of useful wisdom than being cared for.

That’s what I’ve tried to do in the 26 years since I became Gordon Heald’s driver, and then moved in as his full-time caregiver. That’s what I learned to do the first time I assisted Gordon up the stairs to go to the bathroom during a party at his home. You walk along with your friend. You don’t pull him along or push him this way or that. You get close and tune in. You listen with every fiber of your being. You listen without an agenda, without a selfish need to have the answer or provide the perfect fix.

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COMPASSIONATE CARE ALS: A LOOK BACK THROUGH THE YEARS

1998
CCALS is founded
Gordon Hoffman passes with ALS and his caregivers Ron Hoffman and wife Betsy Heald co-founded The Gordon T. Heald ALS Fund based on his wishes.

2002
CCALS is incorporated in Massachusetts
The Gordon T. Heald ALS Fund grows into Compassionate Care ALS, a care organization with Ron Hoffman serving 85 families. CCALS currently supports 1,049 active families.

2003
CCALS Van Program launched
The CCALS Van Program which loans out handicapped accessible vans, began with one donated van in 2003. It has grown into a fleet of 13 vans plus many others which have been donated to families.

2005
Cultivating Compassion Workshop Series launched
Introduction of the Cultivating Compassion Workshop Series offering support to ALS patients and their communities.

2008
ALS Patient Family Caregiver Program grows
CCALS expands, adding three new staff members; Erin LaQueens, Travis Schneider, and Shannon Carey. They all continue to be integral parts of the organization today.

2011
Garber Swim
After his ALS diagnosis in 2009, longtime Falmouth resident and avid swimmer Dr. David Garber supports CCALS by holding a swim on Old Silver Beach going on to raise over $1 million in 13 years.

2012
ALS Patient Family Caregiver Program grows
CCALS expands, adding three new staff members; Erin LaQueens, Travis Schneider, and Shannon Carey. They all continue to be integral parts of the organization today.

2013-2018
Building of the CCALS Heald Education & Retreat Center
CCALS launched our $3.4 million capital campaign to build the CCALS Heald Education & Retreat Center in 2013. Construction was completed and opened in 2018. Since then, CCALS has hosted approximately 200 families annually as well as groups from other organizations for conferences and special events.

2014
The CCALS Van Program grew to 13 vans.

2015
OCTOBER 30
CCALS hosts its first gala
Three hundred people attend the first CCALS Gala at the Fairmont Copley Plaza and raise $138,000. Our biannual galas have continued to support our ALS Patient and Caregiver Program, with our 2022 gala raising more than $420,000.

2016
New York regional office opens
CCALS hires Chris Curtin as our Senior Care Liaison for the New York regional Office to allow us to grow regionally. We currently employ three people in the tri-state area.

2017
MGH, ALS One and CCALS partnership
CCALS and Massachusetts General Hospital (MGH) developed a mutual release form through ALS One. This form is signed by ALS patients to allow the organizations to share information to facilitate better care.

2018
House Calls Program
MGH Medical staff and CCALS staff visit ALS patients together in their homes to provide comprehensive care.

2019
CCALS Staff expands
CCALS hired our 10th employee in 2019. As of 2023, we currently have 26 employees on staff providing exceptional care to ALS families across the country and the world.

2020
Speakers Series
CCALS added a monthly series to our Cultivating Compassion workshops featuring prominent individuals speaking on a variety of topics of interest to people living with ALS and their communities.

2021
Volunteer Caregiver Program
CCALS developed a Volunteer Caregiver Program led by James Churches that trains volunteers in the CCALS model of caregiving. We then match caregivers with our current clients to assist in day to day activities.

2022
Opening of Colorado Office
CCALS staff expanded into Colorado with two employees to handle increased demand in the midwest. We now have a vehicle and storage facility for equipment in the region.

2023
Steve’s Way Partnership communication
CCALS has partnered with Tom Meadows, co-founder of Steve’s Way, to bring education around their groundbreaking methods to use the Apple OS for people with ALS who are losing the ability to communicate verbally.

2024
Trauma Healing
Trauma Healing is a new monthly gathering developed by Dr. Julie Brown You for our community. This workshop will address how traumatic an ALS diagnosis is, and the continuing challenges and trauma that can arise while living with all the complexities of ALS.

2025
CCALS Gala
The 2024 CCALS Gala will be held on May 17, 2024 at the Park Plaza Hotel in Boston.
THOUGHTS FROM RON, FALL OF 2023

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Helping is one thing but being truly compassionate is quite another. Helping implies they need something that only I can provide. Compassion is listening carefully, patiently letting the tale unfold, taking in the intangibles—body language, setting. Compassion is letting the message reach the soul level where intuition resides, noticing if there is a hunch, and sometime later, if time proves the hunch to be true, sharing it with your friend. Compassion is wondering what will truly serve. So often, the most useful caring is to simply bear witness and hold space. That shouldn’t be so hard to do, but for many, it is.

I call this the art of showing up. What we choose to say, how and when we say it, I call the art of language. This is what my 70 years has taught me about care...it is not a science. It is an art. Doing it well requires more than anything a great depth of curiosity. Preparing to care is a deep and continual inquiry. If we cannot face our own wounds, our pain, our mortality, those experiences we avoid from our past, then it will be very difficult for us to show up with an open heart and no agenda for others. To be a healer we’ve got to heal.

These past 26 years, as you can see in the timeline, have been a continual path of change, growth and finding new ways to bring improved programs to the families we serve. It’s been a commitment to learning, an eye towards getting better and better at what we do. I continue to be incredibly grateful to Gordon and Betsy Heald for being the catalyst of all that we do, the unfolding of what has come to be my life’s purpose. I am deeply grateful for the profound impact CCALS has had on the thousands and thousands of individuals and families we have served. Thank you, always, Gordon and Betsy. You live close to my heart and will never be forgotten.

I hope I can continue to be a calm and healing presence in the lives of those that I serve. To be of service is the greatest blessing one can receive. All of you, my friends, my families, my staff, my board, my dog Maddie—you are my teachers and give meaning to my life. I love you and bow to you.

Sincerely,

IN MEMORIAM

Angelo Cotoni, Westbrook, MA
Ann Coloner, Northborough, MA
Anthony Ferlito, Walhalla, MA
Anthony DiBartolomeo, Sandwich, MA
Atif Ali, Denver, CO
Bob Majeau, Chelmsford, MA
Chad McClung, Alliance, OH
Carol Garey, Chatham, MA
Candis Hewitt, Jupiter, FL
Brian Foderaro, Sterling, VA
Bobby Forster, Middletown, RI
Bob Majeau, Chelmsford, MA
Atif Ali, Denver, CO
Edward Dole, Abington, MA
Dianne Salcedo, Orange, MA
Diane Anas, Auburn, MA
Deborah Doktor, Waban, MA
Dale Melanson, Plymouth, MA
David Doran, Robbinsville, NJ
David Pompliano, Marshfield, MA
David Galin, Portland, ME
David Beach, Brooklyn, NY
Deborah Boldsuc, Laconia, NH
Deborah Doktor, Waban, MA
Denise Asmus, Manhattan, NH
Denise Rondinelli, North Andover, MA
Diane Anas, Auburn, MA
Dianne Salcedo, Orange, MA
Doris Gionet, Ashland, MA
Edward Dole, Abington, MA
Edward Mercado, North Kingstown, RI
Edward Mercado, North Kingstown, RI
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Ellen Alires-Trujillo, Broomfield, CO
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Mariene Ormundo, Danbury, CT
Mary McCarthy, Wakefield, MA
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William Kendrick, Roslindale, MA
William McGovern, Manchester, CT
Xiaozhu ‘Jane’ Zheng, Canton, MA
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