

# The Newport Daily News

## LIVING WITH ALS

Three Newport County men afflicted with Lou Gehrig's disease are making the best of their situations

*Published Sunday, August 10, 2014*



*Jacqueline Marque | Staff photographer*



*Jacqueline Marque | Staff photographer*

*Kevin Waters of Tiverton talks with Ronald G. Hoffman, not shown, founder and executive director of Compassionate Care ALS, about his experience of coming back to life after flatlining during a recent stay at Charlton Memorial Hospital in Fall River, Mass., from complications with ALS. Looking on, from left, are Waters' mother, Janet Waters, his girlfriend Debbie Silvia, his CNA caregiver Amina Baye and Silvia's daughter Natalie, 8.*

*Ronald Hoffman, founder and executive director of Compassionate Care ALS, visits with Ray and Donna Woisbek in their Portsmouth home earlier this week.*

Kevin Waters, 48, of Tiverton was hospitalized at Charlton Memorial Hospital in Fall River, Mass., less than three weeks ago with pneumonia — a critical disease for anyone living with amyotrophic lateral sclerosis, or Lou Gehrig's disease, which has no cure.

"They put me to sleep and cleaned out my lungs," he said. "To do that, they put a tube up my nose and down my throat into my lungs."

His girlfriend, Debbie Silvia, was in the

room with him as he rested afterwards. Something began going wrong.

"I saw the numbers going down," she said. "He was gray."

His pulse had stopped, showing no activity on the heart monitor.

"I wasn't ready for him to pass," Silvia said. "I did everything I could to wake him."

A hospital nurse, who Waters knows only

as Christine, jumped into action and put a tube down his throat to remove fluid from his lungs.

"I just saw blue as I passed out," Waters said. He then slowly regained consciousness.

"I remember moving my hand and thinking, 'How can I be dead if I'm moving my hand?'"

"He had a great fear of suffocation," said his mother, Janet Waters. "But he suffo-

## COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND  
LEADING A NEW VISION IN ALS CARE SINCE 1998

P.O. BOX 1052 · WEST FALMOUTH, MA 02574 · (508) 444-6775 · WWW.CCALS.ORG

LEADING A NEW VISION IN ALS CARE SINCE 1998

# The Newport Daily News



Ray Woishek, who has ALS, uses his eyes to communicate through this computer.

Jacqueline Marqu | Staff photographer

Ronald Hoffman, founder and executive director of Compassionate Care ALS, talks with David Leys and his sister Beth Leys, visiting from Steamboat Springs, Colo., for the summer, during a visit to Leys' Middletown home earlier this week. David Leys was diagnosed with ALS in September 2012

cated and flatlined in the hospital. He said there was no great pain.”

“It wasn’t as bad as I thought,” Waters said. “Why I came back, I don’t know. It’s only a matter of time before I suffocate on my mucus.”

He is not morose or downbeat about his situation, though, and instead is determined to pack in as much living as possible with Silvia, her three daughters — Marisa, 14, Arianne, 12, and Natalie, 8 — and his mother and siblings in the time he has left.

Ray Woishek, 65, of Portsmouth is fully aware of the people and everything going on around him, but is trapped in a body made almost completely motionless by ALS, a disorder that causes muscle weakness and atrophy throughout the body because of the degeneration of the upper and lower motor neurons. Individuals af-

ected by the disorder ultimately may lose the ability to initiate and control voluntary movement, although bladder and bowel function and the muscles responsible for eye movement usually are spared until the final stages of the disease.

A feeding tube was inserted into Woishek’s stomach in January 2013 and he was using a BiPAP, which stands for “bilevel positive airway pressure.” This is a device in which the person struggling to breathe wears a mask and a mechanical ventilator assists with respiration by using pressure to pump air into the lungs.

There were complications; his lungs filled with fluid and he contracted pneumonia.

“We went to the emergency room,” said his wife, Donna Woishek. “He could not come home without a tracheotomy.”

A tracheotomy involves making an inci-

sion into the neck and opening a direct airway into the trachea, which is the windpipe. A mechanical respirator allows people to breathe through the opening.

It is a difficult decision, because having a tracheotomy almost always means losing your voice.

The Woisheks were at the hospital with their three children — Ray III, a teacher in the art department and assistant hockey coach at St. George’s School in Middletown, Carolyn who lives in Carbondale, Colo., where she works as a nurse, and Dan, who lives in Tyngsboro, Mass. The family talked to a respiratory therapist.

“We were lucky that Ray was conscious enough to make decisions,” Donna said.

“We all hoped he would get the trach,” she said. “He got the trach on Feb. 1, 2013. We were very happy. As soon as he

## COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND  
LEADING A NEW VISION IN ALS CARE SINCE 1998

P.O. BOX 1052 · WEST FALMOUTH, MA 02574 · (508) 444-6775 · WWW.CCALS.ORG

LEADING A NEW VISION IN ALS CARE SINCE 1998

# The Newport Daily News

got the trach, he was a different person. We are just so thankful.”

After the tracheotomy, Woishek went to a New Bedford, Mass., rehabilitation clinic for four months.

Not everyone makes the same decision. Waters, for example, has decided for now that he will not get a tracheotomy when his disease progresses to that stage.

The Woishek and Waters families did not have to make their life-and-death decisions alone. Both families had close contact with Ronald G. Hoffman, founder and executive director of Compassionate Care ALS, a nonprofit organization based in West Falmouth, Mass. The organization provides multiple medical devices, all kinds of non-medical equipment, such as specialized chairs, body lifts and mattresses, and even vans with lifts to ease the lives of people with ALS.

Hoffman provided Woishek with a DynaVox, which he operates by focusing his eye gaze onto a computer screen. He can spell messages with his eyes, or select pre-programmed sentences. These messages are then spoken by a computerized voice. He also can call up various television channels on the screen, and select and change channels, by moving his eyes.

More than providing all the mechanical and technological resources, however, Hoffman listens deeply to the families and discusses how they are coping. He calls it “tending.”

Since 1998, Hoffman said he personally has worked with more than 950 families throughout southern New England.

When Ray Woishek was considering a tracheotomy, Hoffman put Donna in contact with another woman whose husband was going through the same thing.

Hoffman said everyone with ALS and their families face these continual challenges: “What do we do when you can’t walk?” “What do you do when you can’t feed yourself?”

“Stuff happens,” Hoffman said. “There is no right way or wrong way of dealing with what comes up. We have to honor what each individual chooses for herself or himself. But they should be aware there are consequences for every choice that is made.”

Ray Woishek met recently with a priest and asked if it was against the teaching of the Catholic Church if he decides he has had enough and just stops the apparatus operating through the tracheotomy opening. The priest said that would be OK, if that was what he wanted.

“People are forced to make end-of-life choices like this all the time,” Hoffman said.

That is not a path the family wants.

“If you could take the ALS out of his body, he is so friggin’ healthy in every other way,” Donna Woishek said.

David Leys, 56, who lives off Purgatory Road in Middletown, was diagnosed with ALS in September 2012. Two weeks before the diagnosis, he participated in a triathlon that involved a quarter-mile swim, 12-mile bike ride and 3-mile run.

“It was a cold, rainy day and I could not

tie my shoes for the run,” he said.

To get assistance from someone would have violated the rules, so he ran the 3 miles barefoot.

ALS first affected his upper body, his arms and voice, before it moved to his legs, he said.

ALS starts in the lower body for some people, for others, it first affects the upper body.

Leys had a feeding tube put into his stomach on June 17. He can swallow with difficulty and said he uses the feeding tube about once a day.

“I can still eat out,” he said.

He said he enjoys going to the Atlantic Grille, owned by his childhood friend Bill Armstrong. The restaurant is not far from his home and he uses his motorized wheelchair to get there. He sometimes uses the wheelchair to travel farther, to the Ida Lewis Yacht Club off Wellington Avenue in Newport, for example.

Although his speech has been affected, he still can make himself understood by speaking.

“I have been working with the DynaVox, but the eye gaze is hard to use when you still have movement in your head,” he said. Hoffman provided him with the DynaVox.

Leys has been practicing with a nurse speech pathologist from the Visiting Nurse Services of Newport and Bristol Counties, who is familiar with the device and trains people to use it.

## COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND  
LEADING A NEW VISION IN ALS CARE SINCE 1998

# The Newport Daily News

The onset of ALS can start with a dysfunction in the body that seems minor at first, an inconvenience that will pass. Ray Woishek first noticed something was wrong with his right hand in the summer of 2009, when he was having trouble lifting a golf bag.

“For us, we went through the whole route of ruling out everything else,” Donna Woishek said. “For a while, we thought it was Lyme disease. He had a pinched nerve in 2010. That led us to Mass General Hospital and he received the diagnosis.”

Woishek was working at the time for Carey, Richmond & Viking Insurance Co., which has an office in Middletown. He had partial use of his right hand and the use of his left hand, but the disease progressed. Hoffman provided him with a scooter that allowed him to get around, and met with the insurance office staff about what other accommodations could be made.

He continued going into the office on a regular basis until Labor Day in 2012. That was the weekend he collapsed on floor of the bathroom because his legs were so weakened. His pulmonary functions also had started to decline.

The Woisheks were living on Park Avenue in Portsmouth. The home was constructed with narrow corridors and doorways that would have been difficult to make accessible. Ray twice fell down the stairs at home.

“The home wasn’t going to work,” Donna Woishek said.

They sold the Park Avenue home and found a single-story home in Oakland

Farm in Portsmouth, where they could widen doorways that led into open, wide corridors.

Donna was working as an assistant to Head of School Eric Peterson at St. George’s School.

“I had to leave my job,” she said. “Somebody has to be with Ray 24 hours a day, seven days a week.”

Hoffman provided a metal-framed structure that fits over the bed, with a motorized lift the Woisheks use to put Ray to bed and lift him out.

In the morning, they go through a three-hour routine of getting Ron out of bed, into a mobile chair and then to the bathroom for showering, dressing and finally to the large mechanical chair that is attached to the DynaVox.

“It’s not easy,” Donna said. “I get really tired and sometimes I get grumpy.”

“That’s human,” Hoffman said.

Using his Dynavox, Ray said, “I miss drinking and eating.”

“Ray was the cook; he loved to do that,” Donna said.

“The biggest shock is to find yourself living a life like this and doing things you never expected to be doing in retirement,” Donna said. “We planned to be doing things like visiting Carolyn in Colorado, going golfing and enjoying life.

“We both had to leave jobs we loved and now collect Social Security.”

Hoffman said the ALS literature generally says that it costs about \$200,000 a year to take care of someone with the disease.

“Most people don’t have those resources,” he said.

The cost estimate includes the cost of paying for caregivers around the clock, which most people cannot afford. Instead, family and friends step in to take on that role.

Donna said the family would not have been able to deal with ALS as well as they have without the help of friends and acquaintances, in addition to the equipment lent by Compassionate Care ALS.

Friends at the Green Valley Country Club in Portsmouth held a fundraiser for the Woisheks.

“People have been generous beyond belief,” Donna said.

“It’s hard to receive,” Hoffman said. “Ray and Donna are always adapting to the profound changes in their lives. Ray does not want to spend his days at home and in a chair, and Donna does not want to spend her days just tending care.”

Kevin Waters first had trouble moving his right foot in 2009.

“It got worse,” he said. “I called it my tail because I had to drag it everywhere.”

A neurologist diagnosed Waters later that year with ALS.

“ALS slowly takes everything you have,” he said. “One leg, the other leg, one arm, the other arm, the eating, the drinking. It’s fast, but it’s also slow.

## COMPASSIONATE CARE ALS

GORDON T. HEALD ALS FUND  
LEADING A NEW VISION IN ALS CARE SINCE 1998

# The Newport Daily News

“I had to close my business down.”

That was in August 2009. The business was Workstation Installations Plus, based in Portsmouth. He created office spaces in locations around the state.

“He was a workaholic,” said his mother, Janet Waters.

He had to sell his home in Portsmouth and moved to a single-story home off Bulgarmarsh Drive in Tiverton. It was there that he met his girlfriend and her daughters.

“Kevin never got married and never had children, but this girl came into his life with her children,” Janet Waters said. “It’s God-given.”

“If it weren’t for Debbie and the kids, my life would be pretty bad,” Kevin said. “They have helped me so much. They didn’t have to deal with this.”

Compassionate Care ALS provided the family with a van that is wheelchair accessible with a lift.

The van has allowed Kevin to go to school functions, malls, stores and fun spots with the family.

“We could not do it without the van,” Silvia said.

“When Kevin no longer needs it, we’ll pass it on to the next family,” Hoffman

said.

David Leys, one of seven children of David and Judy Leys, worked at the family-owned Leys Century Store in downtown Newport for years. He later embarked on a career as a Realtor and became known as an active member of the community, always busy and fit, competing in triathlons and other athletic events.

He is the father of three children — Bowen, 21, Ryan, 19, and Annie, 14.

To assist his breathing, he is now using a BiPAP in the afternoon on most days and before he goes to bed at night.

“It gives my blood more oxygen,” Leys said.

“It’s also good exercise for your lungs,” Hoffman said.

Leys said he is appreciative of all the support he has received from his wide circle of friends and the community. He recently celebrated his 56th birthday with 50 people who came to his house on Easton’s Point.

“It was a good time,” he said.

He is thinking he would like to spend the coming winter in Florida.

“When it’s cold and you have ALS, it’s hard on your body,” Leys said.

“Body sensations are different because of the atrophy,” Hoffman said. “You want to lift your hand and you can’t.”

Leys’ sister, Beth Leys, a teacher living in Steamboat Springs, Colo., spent the summer with him. This week, she, David and Hoffman talked about what David could use next from Compassionate Care ALS, with a Molift and a special recliner chair at the top of the list.

Hoffman thinks of his mission as “tending” to friends with ALS; he never refers to them as “patients” or “clients.”

“We offer guidance and hopefulness and work with them and their families,” he said. “We help them access resources and help them find some sense of wholeness.”

Talking with Woishek, Waters and Leys, one is amazed by how good their dispositions seem to be — free of anger, bitterness or self-pity that would be understandable to so many people given their circumstances.

People have pointed out how unfair it seems that some people come down with such a terrible affliction like ALS and have asked Woishek, “Why you?”

“What not me?” he has asked in return. “It’s God’s plan.”

“He hates it, but he is in an OK place,” Donna Woishek said.

COMPASSIONATE  
CARE ALS

GORDON T. HEALD ALS FUND  
LEADING A NEW VISION IN ALS CARE SINCE 1998