



RICHARD BURDELL

A trumpeter's elegy

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Portland jazz trumpeter Richard Burdell was diagnosed with amyotrophic lateral sclerosis - commonly known as Lou Gehrig's disease - in 1984. He was only 34. The popular, charismatic musician understood the diagnosis was a death sentence; his mother had died of the disease in 1973. A gifted athlete, an outspoken organizer of political and charitable fund-raisers, a teacher, a man who loved women, Richard knew that within months he would lose his ability to play sports, then to make music, to walk, to talk, ultimately to swallow and then to breathe. Doctors told him he'd be dead in two years.

That's not what happened. In spite of the total paralysis that set in, Richard Burdell found a way to celebrate his life. He made new friends - among them, some of the world's most well-known performing artists. His life was sustained by food supplied through a tube to his stomach, a ventilator attached to a device implanted in his throat, and a group of loving round-the-clock caregivers. Richard communicated by moving his eyes, as his friends and caregivers slowly said the letters of the alphabet. He still told stories. He made jokes. He followed professional sports, he saw movies, he hung out in nightclubs with musician friends. Incredibly, he used portable medical equipment and traveled across the United States, visiting friends Wynton Marsalis, Harry Connick Jr., Herbie Hancock and Ben Wolfe, who once studied jazz with Richard at Mt. Hood Community College.



**Burdell
performs
in 1979**

But it was the friends closer to home who really provided sustenance. Even in bad times, when Richard struggled with pain or infections, there were friends willing to come to Richard's tiny house near the Hollywood District, to sit by his bed and give him a reason to open his eyes. Nearly all were men, nearly all musicians. To the end, they could make Richard smile - even when a smile was nothing more than a tiny movement in the left corner of his mouth.

Because Richard voluntarily went on life support in March 1988, he was free at any time after that to choose to end his life. All he had to do was ask to have his ventilator shut off; his chest muscles had long ago become so weak they could not produce a single breath.

And there were times in the last decade Richard talked about wanting to die. But he always found new things to look forward to, new reasons to keep living. He'd spell to his friends that he wanted to end his life "after the NBA Finals," or "after my camping trip on the Oregon coast."

But recently, after 10 years in which every breath was delivered to the gentle beat of a ventilator, Richard's quality of life began to drop. His hearing worsened, and hearing aids didn't seem to help. His eyes - his only means of communication - became strained too quickly. He stopped watching TV. He was diagnosed with diabetes. Worse, he began to experience pain beneath his skin that felt like "parasites eating my body." And then, in early May, Richard fell from his bed. He broke a hip and an arm.



Richard Burdell succumbs to ALS, surrounded by his friends and family (from left), Tom Grant, Paula Foat, Dr. Lou Libby, Linda Quillin and Shirley Nanette.

On June 5 Richard told his counselor he'd made the decision to end his life. The counselor called Richard's sister, Cindy Burdell. "Richard was steadfast," says Cindy. "He wanted to do it on June 21, summer solstice, at sundown. Richard is not religious, but he believes in the beauty of nature. It seemed good to end his life at the end of the day." Cindy called Richard's older brother Charlie, in Seattle. "Ever since then we've been doing whatever Richard asked," says Cindy. "This has been his show, from beginning to end."

On Saturday, June 13, a half-dozen men who'd once played softball with Richard got phone calls, asking them to come to Richard's house the following night at 9 p.m. Richard had something he wanted to tell them.

Sunday, June 14, 9 p.m.

Richard Burdell's hospital bed sits in the middle of his living room like a throne, which everything else faces. There is a large clock on the wall above the mantel of a fireplace that is never used; a cabinet of medical equipment covers the firebox. Atop a bookshelf sit two trumpets. They are badly tarnished. The wall is covered with photos of Richard and his famous friends, concert posters, newspaper articles about Richard. There is a framed photo of Richard as a small boy in a Little League uniform: He holds his glove; he's crouched, smiling, ready to pick off that grounder. There is a big-screen TV, and a sound system with large speakers, all pointed at Richard's head, in Richard's bed. To his right sits the ventilator. Its long plastic tube gives a gentle kick as it fills and empties with air in transit between machine and lungs.

Hanging from the ceiling, angled so Richard can read them easily, are three large charts on white boards. They are covered with lists of words and directions. "Hot/cold," says one. "Look for sports on TV," says another. "You're holding my eyelid too hard, idiot," says a third. Richard and his caregivers have the charts memorized. They know chart 1, item 10, column A means Richard needs medication now. Caregivers count down the lists; when Richard looks at them, it means "yes." When he looks away, it means "no."



**Ella,
Richard's 20-
year-old cat,
sits on her
master's legs
on the day
Richard died.**

Beneath the charts, beneath the mobiles of shells and fishes and birds, beneath the two skylights through which you can see the sky growing darker, forty- and fifty-something men cluster around Richard Burdell's bed and tell stories about the old days, when they all played on the slow-pitch softball team Richard helped found, called the Oregon Rock 'n' Roll All-Stars. "Richard's team always had class," says one former jock. "Other teams drank Budweiser. We drank specialty beers." They had the best-looking girls, designer uniforms, the most talented players. They won everything.

Then Richard begins spelling: He will end his life one week from this evening, he says.

"We were confused," says Ross Hamilton, a friend and a photographer at The Oregonian who occasionally played softball against Richard. "We asked if there was anything anyone could say that could change his mind. He said no."

Monday, June 15

Word has spread rapidly. The phone rings every 10 minutes. People want to come say goodbye. Linda Quillin usually answers. Linda was a caregiver from 1990 to early 1997; she has come from her new home in Louisiana to organize Richard's last week. Everyone is welcome, she tells the people who call.

Richard is explaining why he has decided to end his life. A sentence can take 20 minutes to spell, but he wants to be understood.

He wants people to know he's sure. "I'm happy and doing the right thing," he spells. He says he felt his health would continue to deteriorate. He is in constant pain, even when he's given morphine. And he has had some bad experiences with caretakers. He says two neglected him; one stole his possessions, including a Pentax camera he'd spent years saving for. "Not only was she taking his things," says Linda Quillin, "she was stealing his medications and selling them. She'd chart that she was giving him meds and not give them."

Tears run from Richard's eyes when he is asked what emotions he feels when he thinks about Sunday. "It is time to stop singing this song," he spells, finally.

An ancient, bony black cat stands on Richard's chest, staring at his face. "Ella is one of the most important things in Richard's life," says Linda. "He got her before he got sick. He told me many times he never wanted to outlive Ella." Last year Ella got thyroid cancer, but after radiation treatment she recovered. She looks weak and sick, though. Richard and Ella stare at each other

for long minutes. "Nobody has ever seen her do that before," says Linda. "She's been acting weird for days."

Tuesday, June 16

Linda sits on Richard's bed, holding his eyelid open so she can better see his eye movement. She is spelling. "Q-R-S. Is it S, Richard? S? First half? A? Is it S-A?" With agonizing slowness, Richard dictates his wishes for the last two days of his life. He wants to enter Providence Portland Medical Center on Saturday morning at 10. He wants people to visit him in the hospital. He wants Ella with him at the end.

Richard looks healthy. His face is ruddy. He's not emaciated. His graying hair is combed, his clothing impeccably clean.

9 p.m.

Three close friends, all musicians, all Buddhists, have come to chant for Richard. Percussionist Obo Addy promises he will play for Richard on the donno ("white people call it the talking drum") after the prayers are over. He kneels beside John Smith, guitarist from the band Nu Shooz, and William Thomas, a jazz drummer who's known Richard for 30 years. The men place the palms of their hands together and bow their heads. Their chanting is deep, soothing, the monotonous tune a gentle wave of sound. Richard's ventilator whooshes a steady backbeat; his chest rises and falls beneath his gaze. He watches his friends pray for his soul. Heart. Beat. Heart. Beat.

The men rise, and Obo, a native of Ghana, tells a story. "When I first came here, when I first started my group, Richard took all the songs and rearranged them the way it was supposed to be. He was the first who understood what I was trying to do." Richard is smiling. William tells of the time Richard was taking a college class in jazz. "The instructor says, 'Who in this class wants to be a pop star?' And Richard raises his hand."

Richard loved the spotlight, and he sought it. He wanted to be the first. The best. The star. And he was, as a trumpet player who nailed the double-E's, as an athlete, as a ringleader.

Even as an ALS patient, Richard was a trailblazer. In 1992 he was the first person ever to have electrodes implanted in his skull and a transmitter in his chest, part of an experiment to see if paralyzed people could communicate by looking at computer screens as their brain waves were being monitored. Richard's surgery failed, but doctors studied his response and created better equipment that now allows other ALS patients to write and speak via computer. By the time the technique was perfected, Richard was too fragile to have more brain surgery.

So he spells. He directs his caregiver to chart 1, item 17, column A. "I love you," it says. "We love you too, man," says John Smith.

Obo Addy plays the donno for a long time.

Wednesday, June 17

Richard's day progresses in an alphabetical swirl.

His nieces Sarah and K.T. Burdell, his brother's daughters, sit in the kitchen just off the living room. They've come down from Seattle. "He's always been such a presence, a motivation in our lives," says K.T. She was a small girl when Richard went on life support. "He used to come and play piano and entertain us. But it was so long ago.

"I had a dream my freshman year in college that I was with Richard, and he put his arm around me. I said, 'How can you speak now?' He said, 'My new ventilator lets me sit up and talk.' I felt so warm and happy for him. He asked me for some tea. I left him sitting there, reading the paper. When I told Richard about the dream, he cried a little."



The Lions of Batacuda perform on the front lawn of Richard Burdell's home.

K.T. has done reports and papers on ALS. "Richard told me stories, and one really struck me. He told me about the time he went to a Christian cafe, back when he was losing control of his muscles. They accused him of being drunk. He left. Getting into his car, he kept falling. He said it was a battle in his mind. He was thinking, 'I'm fine. I'm a normal person. I'm not a drunk.' But they're treating him like he was a transient. But he continued to be positive, to go out alone as long as he could."

People have been visiting all day, to say goodbye. "Some keep coming," says Cindy Burdell. "Tom Grant has come every day." Cindy has not said goodbye to her brother. She can't even think of what Monday will be like; she's spent the past 10 years of her life coordinating his care. "When our parents died in 1973, people didn't understand about grieving," she says. "This will be different. We know more now about how to keep a person in your heart. Richard will always be with me, and with a lot of people, because of his strength and his presence. And presence is an important word. Lots of people were afraid to see Richard, but when they did they'd leave almost exhilarated. Everyone who meets him feels something big."

Richard's neighbor Missy Parker comes to visit, with her two young daughters. Missy and her husband, Mike, have been good neighbors and good friends. Richard's caretakers could call at any hour for help getting Richard in or out of bed, or the wheelchair, or his van. "Lydia wanted to say something to you before you die," says Missy. Four-year-old Lydia is lifted to Richard's eye level. "Bye-bye Richard," she says. "I'm gonna miss you. I love you." She curls up in a corner of the sofa, near the front window, while her mother lifts her 2-year-old sister to kiss Richard goodbye. "In heaven Richard's going to stand up and kiss us," says Lydia.

Thursday, June 18

Buck Munger, publisher of a music-industry trade paper, *Two Louies*, arrives with a mock-up of next month's issue. Richard's picture is on the front. He's playing his trumpet. "Richard Burdell," it says. "Artist. Musician. Athlete. Leader." Richard smiles. A cover boy.

Buck has brought Bud Palmer with him, and Bud has brought a young man named Chris. Bud hasn't seen Richard in a very long time; he has a story to tell. It seems Richard had a gig in Beaverton 22 years ago, and Bud met him to watch a game in the bar before the music began. Suddenly, Richard turned to Bud and asked a favor. There were one too many of Richard's girlfriends in the room at the time; would Bud divert the brunette, while Richard talked to the blonde? Bud and the brunette fell in love and got married, happily. Chris is their 20-year-old son. "He's a musician," says Bud. "He's heard about you all his life. He wants to thank you."

Friday, June 19: 6:30 p.m.

Forty men and women have sprung up on Richard's tiny front lawn, like overgrown, noisy weeds. They play drums. The beat quickens the steps of neighbors who stream from their houses to watch the performance. It's a Brazilian drum band called Lions of Batucada, playing for Richard. His bed has been wheeled close to the front door. Drummers are crying, laughing, shouting as they play.

"This is the perfect send-off," says Paula Foat, Richard's head caregiver. She has been working for Richard for nine years. She met her husband, Mark, at Richard's house; he was a neighbor who would help her get Richard in and out of the bathtub. "I finally got up the nerve to ask her if she was single," says Mark. Today they have two sons, both of whom spell with Richard. Mark and Paula stand in Richard's kitchen, as the drums play. "We've broken all the rules this week," says Paula. "For one thing, we're celebrating. And now we're even disturbing the peace. It feels good to make noise, though. This is not a dirge."

When the drums quiet, band leader Brian Davis enters the house and says goodbye to Richard. As he leaves, he turns and salutes.

Richard asks for his brother. Charlie Burdell sits at his bedside. Richard spells. "I remember football on the lawn." "So do I," says Charlie. "Did you score any touchdowns?" Richard indicates yes. "Of course," says Charlie. "All the touchdowns."

"Your wife looks like Hillary Clinton," spells Richard. Someone rushes to the back patio, to tell her. "But more beautiful," Richard spells. Too late.

Doors open, people come and go. Neighbors, former caregivers, relatives, childhood friends stop by. A filmmaker records Richard's last night at home. "For 14 years I imagined today," spells Richard. "This is better than I imagined." Over and over, he tells people he is happy. Chart 17A: "I love you." Over and over, all night long. 17A. 17A. The ventilator pumps along, quiet, steady. Heart. Beat. Heart. Beat.

At midnight, only Linda and friend Ross Hamilton are left, reminiscing with Richard. He doesn't want to sleep. He wants to make a toast. Ross opens a bottle of white wine and pours two glasses. Then Linda draws a tiny amount of wine into a syringe, and puts it in Richard's mouth. He can't swallow, but he might be able to taste a little. Linda and Ross click their glasses over Richard's smile.

Saturday, June 20: 9 a.m.

Linda awakens Richard. Ella sleeps curled at his side. Paula is in the kitchen with Richard's nieces K.T., Sarah, and their sister Laura. She is studying the Yellow Pages. "Richard wants a nice ambulance," she says. "Not the usual transportation." There is talk about a limousine; there is joking about hijacking an ambulance, painting it black, and forcing the paramedics to wear tuxedos. A very nice, white ambulance is arranged for. The paramedics will wear blue uniforms.

Before they arrive, Richard answers the important questions again. Are you comfortable with this? "I am happy," he spells. "Very happy."

The ambulance arrives. It's time for Richard to leave the bed from which he watched the world for the past 10 years. He is asked if he wants his head moved, so he can look at the room one last time. He smiles. Tears flow from his eyes to the pillow. Paula switches the ventilator to battery power. Linda kisses Richard's forehead. He is lifted onto a stretcher. Someone puts on his sunglasses. Ella sits on his lap. He leaves his home.

Noon

In Providence Medical Center's Wing 2R, Room 203, Sheri McPherson pins large photographs to a bulletin board across from Richard's bed. In one, Richard is on water skis. He leans deeply into a turn, the water spray creating an enormous peacock fan behind him.



Mark Foat and Linda Quillin comfort each other after Richard's death. At his bedside, neighbor Missy Parker says goodbye.

Sheri is Richard's ex-wife. They married in 1987 and divorced in the mid-'90s. Sheri has flown down from Alaska to say goodbye. "On a scale of one to 10," she asks, "if 10 is full speed ahead, and one is I want to go home, where are you?" Richard spells "ten."

There are two phones in the room; both ring every few minutes with calls from Japan, from New York, from New Orleans. Goodbye calls. On the table next to Richard's bed is a small paper cup of violets, a bottle of hydrogen peroxide and a bottle of champagne.

9 p.m.

Richard has asked to see three women he has not seen in a decade. Lana Dimeo, Janet Fisher-Welsh and Sarah Stevens talk on top of one another, finish one another's-RT> sentences. "We were Richard's groupies in the early '80s," says one. They laugh. "We were all underage, with fake ID." "We were single and carefree."

"After the bars closed, the musicians were just getting revved up," says Sarah. "They'd all go back to Richard's house." She turns to Richard. "Remember those awful recording sessions at your house? Remember that time you called me at 4 a.m. and woke me up? You said, 'You've got to come over right now. You have to do the claptrack for 'On Broadway.' So we came, in our pajamas, in our sweats. Somebody brought champagne. We hit two-by-fours together in Richard's shower. We sucked."

Richard is smiling. He is very happy. The women are still beautiful, their laughs high and musical. "Richard has always loved women," says Lana.

Peter Mott arrives. Once he owned the Last Hurrah nightclub. "Richard played center field on the Last Hurrah softball team when his band was Cruise Control," says Peter. "I was pitcher. One time, a guy hit a ball into left center. I thought it was gone. Richard got there, held out his glove and pulled it in. He saved my butt. Those were good times." Richard spells 17A on chart 1. "I love you."

The 17As are flying like fastballs.

Sunday, June 21

Curtis Salgado, Calvin Walker, Joe Heinemann. Nearly every famous name in Portland music has leaned over the hospital bed in Room 203 today. And then the national names check in. Harry Connick Jr. calls to thank Richard for being an inspiration. Herbie Hancock calls from New York to say goodbye. Richard spells out a question for him: "What was it like to play with Miles Davis?" As Herbie starts his answer, the other phone rings. It's Wynton Marsalis. Wynton must wait.

At 5 p.m. Richard's doctor arrives. Lou Libby is a pulmonary and critical care physician. He is the same age as Richard. In high school, Lou played the trumpet. After he met Richard the doctor pulled out his old horn, polished it up and started to play again.

"This is not doctor-assisted suicide," Dr. Libby explains. "When Richard went on the ventilator in March 1988, I told him then that he didn't need to be on it forever. It's his choice. It's not (legally) necessary to continue to live using extraordinary means. And this is extraordinary means. Even the pope agrees. It's perfectly appropriate to do this with a doctor."

Dr. Libby explains that he will give Richard medication until he can't indicate he wants more. "And then I'll give him a little more." The drugs will relax Richard, make him less conscious. And then the doctor will turn off the ventilator. "He won't breathe at all when we turn it off. His breathing muscles stopped working 10 years ago." Without oxygen, Richard will live five to 10 minutes. His cause of death will be ALS.

Richard spells out a message he wants to be given to his friends. It takes 30 minutes. "I would appreciate anything you can do to help victims of ALS. Concentrate on a concert. My musician friends. Please."

And then he is smiling at friends, spelling to each as fast as his slow eyes will move. "I have loved you since we met," to one. "We will be dancing later tonight," to another. Nurse Verna Grave remembers the time Richard told her she reminded him of his mother. "That meant the

most to me," she says. Singer Shirley Nanette brings an old photo of the two of them, in a band called Overtime. "Overtime and underpaid," she says. Shirley calls Richard "Burdie."

Close friend Tom Grant does not hide his feelings as he says goodbye. "I'll never forget you," says Tom. "You damn well better not," spells Richard. Pianist Glenn Holstrom is disconsolate. "I can't even talk," he says. "That's OK," says Cindy Burdell. "Richard can't talk, either."

Richard says he's at peace, he's comfortable with his decision, he's sure. Over and over he reassures his friends. "No fear," he spells. There are 28 people in the room. Richard is the only one smiling.

It is close to 9 p.m. Hospital medical personnel bring in Richard's medication and hang it from his IV. But there are dozens of people who haven't had a chance to say goodbye. Paula directs them to pass by his bed, let him see their faces, kiss him goodbye.

Finally, at 9:45, the room is empty except for the few people he has asked to remain. His brother, his sister, his nieces. Linda and Paula. A few friends. They cluster around the bed. Richard begins to spell.

"I want everyone here ..." People have always reached to help Richard communicate. They leap to guess the words that lie ahead, to spare him the effort of spelling each letter. Now they begin to guess the rest of his message. "You want us to love each other?" Richard indicates no. "To take care of each other?" No. He spells: ". . . T-O L-E-A-R-N . . ." They jump in again. "You want us to learn patience?" No. "Learn about ALS?" No. Richard continues: ". . . L-E-A-R-N T-O W-A-T . . ." "Watch out for one another?"

More spelling. "W-A-T-E-R-S-K-I." Richard wants everyone present to learn to water-ski. The crying stops for a moment; everyone's laughing too hard. To Linda he spells "Even you." "I'm a grandmother," protests Linda. Richard smiles.

It is 10:06. Linda asks if he wants to spell. For the first time all day, he indicates no. "Are you ready?" Yes. "Would you like me to put your hand on Ella?" Yes. She lifts his hand from beneath the sheet and gently rests it on Ella's scruffy black back. "Will you come see me in my dreams?" Linda asks. Richard's eyes look directly at hers. "I love you," she says.

Dr. Libby sends the medication through Richard's IV line. Shirley Nanette and Tom Grant and a few others begin to sing. "When you're down, and troubled . . . you've got a friend." Richard's eyes are open; he is still present, but he's beginning to float. "Oh happy day," people sing. "Oh, happy day . . ." And then, "Amazing grace . . ." When the song ends, Dr. Libby asks Richard to look at him. Richard's eyes move to the doctor, who says, "I'm going to give you more medication." The ventilator's soft rhythm continues.

Someone says, "Until we meet again, Richard." Someone else says, "Write us a bunch of new songs to sing." It's time. Quietly, quickly, Dr. Libby turns off the ventilator. Silence. Richard's chest does not move. Paula and Linda and Cindy begin to sob. Someone says, "17A, Richard." And then everyone is calling, shouting, "17A! 17A, Richard!"

The door to the hall is opened, and the crowd pushes in. Some are singing "Happy Birthday." Richard's eyes are open. Dr. Libby listens to his chest with a stethoscope. "There is still a heartbeat." Heart. Beat.

The beat of a new song fills the room: "Swing Low, Sweet Chariot." At its end, someone starts "When the Saints Go Marching In." The singing grows louder, reckless, rowdy. Dr. Libby checks the pupils of Richard's eyes, listens again to his chest. His heart has stopped. It is 30 seconds past 10:38 p.m., June 21, 1998.

In the uproar, frightened by the shouts and the singing, Ella has jumped from the bed. Someone finds her beneath a chair and carefully places the fragile, raggedy cat on Richard's chest. She curls up and closes her eyes.

It is quiet now. There is no more singing.

Margie Boulé and photographer Ross William Hamilton were invited to spend Richard Burdell's final days with him.