



A former surgeon at Lankenau has started an unusual business: Helping people decide how they want to die.

## End-of-life pioneer



DAVID SWANSON / Staff Photographer

**Karl Ahlswede, who quit** his surgery practice, discusses living wills with Judy and Jim Snyder at their Lower Gwynedd home.

By Stacey Burling  
INQUIRER STAFF WRITER

**T**his was the sort of situation that made surgeon Karl Ahlswede think there had to be a better way to die and, maybe, a better way to be a doctor:

One of his patients, an elderly woman, had survived cancer and heart surgery, but had landed in the intensive care unit with pneumonia.

She had been on a breathing machine for 10 days, and her family was facing a tough decision. Should it allow doc-

tors to insert a feeding tube and do a procedure that would insert a breathing tube into her neck rather than through her mouth?

Three out of four doctors involved in her care believed the patient would never be able to breathe on her own again.

The woman couldn't speak. One daughter said her mother had told her she never wanted to live on a machine. But nothing had been written down, and another daughter and son wanted all-out care. They fought and cried. In the

See **LIVING WILLS** on E2

### Pa. group homes get new guidance for their residents' end-of-life issues

**A**bigail Sandler has fought for clearer rules on who calls the shots when a group-home resident becomes deathly ill ever since her mentally disabled sister got sick in 2006 in Horsham, setting off a conflict between the home's administrators and her family.

Sandler says her sister Aimee's group home, Lynch Homes, balked at the decision of Aimee's uncle, her legal guardian, not to insert a feeding tube. Aimee had stopped eating, and two doctors said she was terminally ill.

The case was a messy one — Aimee actually had an undiag-  
See **DISABILITIES** on E2



DAVID SWANSON / Staff Photographer  
**Abigail Sandler**, who lobbied for clearer rules. The result was last month's Aimee's Bulletin, named for Sandler's disabled sister.



**Abigail Sandler** with disabled sister Aimee. Sandler says Aimee's case raised questions of whether families or caregivers make end-of-life decisions.

## Making choices for mentally disabled

**DISABILITIES** from E1 nosed, treatable problem — but Sandler says it raised questions of who has the legal upper hand if families disagree with care providers, who often have sought all-out medical care for their intellectually disabled charges.

Last month, the state issued a statement, dubbed Aimee's Bulletin, meant to clarify how Pennsylvania laws affect decision-making for group-home residents near death who can't make choices.

"It's been a controversial issue," said Kevin Casey, deputy secretary for the Office of Developmental Programs at the Pennsylvania Department of Public Welfare.

Casey said that, as care has advanced, people with intellectual disabilities are living longer and presenting the same ethical dilemmas near death as others.

Their situations, though, are further complicated by the fact that they may never have said how much care they would want at the end of life and may no longer have close family members or friends who can help. Plus, people who work with the severely disabled may feel a special need to honor life no matter what, say people involved in such decisions.

Casey said a situation like the Sandler's case was unusual, but "it's a very difficult problem when it does come up."

The bulletin is meant to give more guidance on a law passed after Aimee's illness in 2006. It clarifies that these kinds of decisions "ought to be made between the family and the doctor," Casey said.

In a two-sentence written statement, Lynch Homes declined to discuss the Sandler case and said it "always has the residents' needs and well being as its top priority."

Aimee Sandler died of pneumonia in 2009. Abigail Sandler, of Lafayette Hill, said doctors had failed to detect gallbladder disease. Once it was treated, her sister's appetite returned. She never got the feeding tube. Sandler said Lynch Homes refused to allow her sister to return from the hospital in 2006 without one, so she was put in a hospice, then transferred to a different group home after her condition improved.

Abigail Sandler said the new bulletin was an improvement, but remained too complicated. "This is a beginning," she said, "but it's certainly not the end."

Casey said the state planned to offer training to help family members know their rights in end-of-life situations.

The bulletin says no one can withhold life-preserving care for a group-home resident who has a life-threatening medical problem but is not in an "end-stage" condition or permanently unconscious.

For people reaching that point, there is a hierarchy of decision-makers, starting with those legally appointed as health-care agents and ending with the facility director. Among family, spouses get top priority, followed in order by adult children, parents, siblings, and grandchildren.

The state recommends — but does not require — that facility directors get legal advice if they want to withdraw life-sustaining treatments or establish a do-not-resuscitate (DNR) order. This won't add much cost for group homes, Casey said.

Shirley Walker, president of PAR, Pennsylvania's Service Network for Autism and Intellectual Disabilities, disagreed. The option "would add legal fees," she said, "and it could add time to the process."

Still, she said, providers have been eager for more guidance. The new bulletin, she said, "goes a long way to answering a lot of questions."

Trina Losinno, executive director of SPIN (Special People in the Northeast Inc.), has been dealing since mid-December with the deteriorating health of one resident, a "tiny wisp of a person" in her 80s who goes through periods when she doesn't eat. A hospital where she has been treated has wondered why she is not in hospice and doesn't have a DNR.

The agency hired a lawyer and tried to find someone who knew her well enough to serve as her health-care representative. The woman is too fragile for tube feeding, and the staff has been feeding her painstakingly with a teaspoon. "It's an all-day thing to feed her," Losinno said.

She said things were usually much easier when family members were involved. Even so, deaths are very hard on staff members, who often know residents for years.

Hospice can relieve some of the burden. "You can't really just let a person starve to death," Losinno said, "and expect people who are practically paid minimum wage to just sit there and watch it."

— Stacey Burling