Joseph Mayo

Clerk Emeritus of the Maine House of Representatives

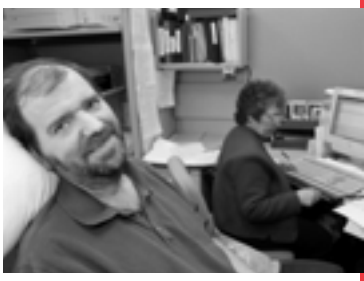
Joe Mayo used his personal experience with ALS to advocate for legislation that has resulted in better access to end-of-life care for Maine people.

All Mainers can anticipate better access to end-of-life care thanks in great measure to a selfless and courageous man named Joe Mayo. Mr. Mayo is Clerk Emeritus of the Maine House of Representatives and a former 10-year state representative who, for the past several years, has suffered with amyotrophic lateral sclerosis (ALS, commonly called Lou Gehrig's disease). He fought for passage of landmark legislation to promote death with dignity. The resulting law is Joe Mayo's legacy to our state.

While the disease has confined him to a wheelchair and compromised his ability to speak, it has not destroyed his spirit. He put his energy into fighting for this comprehensive bill requiring private insurers to cover hospice, palliative, and end-of-life care and promoting education about care options for the terminally ill. The bill was "born" in Joe Mayo's home where he hosted the very first meeting. With characteristic determination, he saw the bill through from start to finish. He worked tirelessly to educate his peers at the State House about the bill and was the only terminally ill person to testify before the Banking and Insurance Committee. As a man in his early 40s facing an incurable disease, he made a

resounding impact. He used his experience with ALS to advocate for every citizen who currently does or will ultimately face a terminal illness.

"There are many people in Maine, also enduring a terminal illness, who do not have the wealth of support I do. I appear here for them," Mr. Mayo testified in a statement read by his wife. "We all have an obligation to ensure that those facing terminal illness do so with our comfort and aid. Most importantly, we must help the healthcare community understand what people enduring terminal illness need. With the advances in modern medicine, no one has to die in pain."



When the bill became law in 2001, it was a tremendous victory for Maine. The bill not only makes coverage of hospice care a required insurance benefit, but it makes people eligible for hospice care when they have a life expectancy of twelve months or less (a change from the preexisting six months or less). In addition, the bill increases the State's Medicaid reimbursement rate for hospice care to more accurately reflect the rising costs of drugs and other treatments.

"A portion of this bill addresses the education of medical professionals who are taught to heal and save lives but, for the most part, have very little training in end-of-life care," says Mr. Mayo. The bill has a provision for a State-established center to educate health professionals and the public about support and care for the terminally ill. The Maine Center for End-of-Life Care will serve

as a clearinghouse for information on issues such as pain management and palliative care. The Center will collect and distribute information on services available to the terminally ill and their families, and maintain a registry of medical providers who specialize in end-of-life treatment. The bill commissions studies to track care for the terminally ill, assess educational requirements related to end-of-life care for licensed healthcare professionals, and overcome barriers to the establishment of inpatient hospice programs in Maine. It also provides funding to support volunteer hospice programs.

"A portion of this bill addresses the education of medical professionals who are taught to heal and save lives but, for the most part, have very little training in end-of-life care," says Mr. Mayo.

Though many supporters share the victory of the bill, Joe Mayo is seen as the catalyst. In recognition of his contributions, he received the Advocate of the Year Award from Maine's Home Care Community, and the Maine Hospice Council created an award in his honor. The first recipient of the Joe Mayo Award was Representative David Madore, primary sponsor of the bill.

Mr. Mayo says his love for his family and his work at the State House are what keep him going. He vows that he will continue this work just as long as he is able. When he and his doctor feel the time is right, Joe Mayo plans on using hospice care. He says, "I want to die with dignity at home. Doctors and nurses can prolong my death for a day or so but what does it matter? What does it cost in terms of comfort, peace, and quality of life in its final days?"

Joe died at his home surrounded by his family and friends on May 23, 2002 with loving support from hospice care.