
Withdrawal of Life Sustaining Treatment

Eleven Case Summaries

by
DISABILITY RIGHTS MONTANA

April 2009

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PREFACE

As the designated protection and advocacy system for people with disabilities in Montana, Disability Rights Montana investigates when we learn that the withdrawal of life sustaining treatment for a person with a disability is being considered. Since April 2006, Disability Rights Montana has investigated eleven such cases. Those eleven investigations are summarized in this report.

We are alarmed that in only one of the eleven cases the person was in a terminal condition as determined by a physician or an advanced practice nurse as required by Montana law. The other nine patients did not meet the definition of terminally ill, yet someone other than the patient decided to withdraw life sustaining treatment, in violation of Montana law.

Our experience leads us to conclude that in spite of a well written law and the good intentions of people, the law is misunderstood and unlawfully applied leaving people with severe disabilities vulnerable to premature death.

We believe that publishing this report shines the light on the misapplication of the Montana Rights of the Terminally Ill Act, specifically as applied to people with disabilities. We hope to create a dialogue that can lead to changes in the law and the practice so that people with disabilities are protected from premature death.

A special thank you to Steve Heaverlo and Tom Dooling for intervening and investigating these cases and for the collaborative work of the State of Montana's Department of Public Health and Human Services Adult Protection Services and Developmental Disabilities Program. Together we truly are saving lives. I also want to thank Beth Brenneman for her work in writing this report.

Sincerely,

DISABILITY RIGHTS MONTANA

Bernadette Franks-Ongoy
Executive Director

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INTRODUCTION

Since 2006, Disability Rights Montana has received notifications of the following eleven situations where the withdrawal of life sustaining treatment for people with disabilities was being considered. Through this work, we have realized the need for changes to Montana statutory law, which we have worked to accomplish in recent legislative sessions, and the need to educate the public about the reality of the decision making process in cases where patients are people with disabilities.

Disability Rights Montana has generally found that the decision-making process to determine whether to withdraw life sustaining treatment does not always meet the requirements of state law when the patients have significant disabilities. Unfortunately, this has meant that in the majority of these cases, decisions to withdraw life sustaining treatment have been premature.

Our intervention in these cases has been limited to ensuring that state law is followed. In just one of the eleven cases, the patient was in a terminal condition when the withdrawal of treatment was considered. In the first case, life sustaining treatment was withdrawn in compliance with state law. In the second case, the patient died in spite of continued life support. In all of the

remaining nine cases, the patients who had been facing withdrawal of treatment were not in a terminal condition and are still alive.

The women and men described in this summary have one thing in common: they are, or were, developmentally disabled and cognitively challenged. In the majority of these cases, “quality of life” as assessed by health care providers was a significant factor in the initial decisions to let these men and women die.

Eight of the eleven patients in these cases are women and three are men. These eleven patients were treated, and decision making occurred, in hospitals all over the state of Montana. The ages of the individuals ranged from the early 20's to the mid 60's. Information which might reveal the identity of any individual patient has been removed to protect their and their family's privacy.

CURRENT MONTANA LAW

Under current Montana law, a person has the right to enter a declaration that they want to cease life sustaining treatment when they are terminally ill and unable to communicate that decision. This is a model law that was passed in a handful of states, including Montana, in the 1980s. The law is entitled the “Montana Rights of the Terminally Ill Act.” In the

absence of such a declaration, if a physician or advanced practice nurse certifies that a person is in a terminal condition¹ and the patient is unable to communicate their decisions regarding care, the person's relatives are entitled to make the decision to withdraw such treatment by written request, witnessed by two persons. Mont. Code Ann. § 50-9-106 (2007). Palliative, or pain relief care, which can include nutrition and water if it is being used for palliative purposes, cannot be withdrawn. Mont. Code Ann. § 50-9-202 (2007).

Medical guardians cannot make these decisions on behalf of the patient unless: 1) they are family members who are already authorized to do so because of their familial relationship; or 2) a court has specifically granted the guardian the authority to withdraw life-sustaining treatment, after making a determination that this would be consistent with the patient's wishes. Mont. Code Ann. § 72-5-321 (2007).

¹ "Terminal condition" is defined as "an incurable or irreversible condition that, without the administration of life-sustaining treatment, will, in the opinion of the attending physician or attending advanced practice registered nurse, result in death within a relatively short time." Mont. Code Ann. § 50-9-102 (2007). "Life sustaining treatment" is defined as "any medical procedure or intervention that, when administered to a qualified patient, serves only to prolong the dying process." *Id.*

A "Do Not Resuscitate" order ("DNR") is a directive from a physician or advanced practice nurse that "emergency life-sustaining procedures" should not be imposed upon a patient. Mont. Code Ann. § 50-10-101(7) (2007). A "life-sustaining procedure" is defined as "cardiopulmonary resuscitation or a component of cardiopulmonary resuscitation." Mont. Code Ann. § 50-10-101(11) (2007). Although statutory law provides authority for the Montana Department of Public Health and Human Services to promulgate rules to set out a protocol for the use of DNR orders, the department has not done so. The law does not provide a clear basis upon which a physician or advanced practice nurse is to issue a DNR. The law does not require consent of a patient, nor does it require a determination that the patient is in a terminal condition. The only requirement is that "DNR identification" indicate that the patient wearing the identification has entered a declaration and is in a terminal condition, *or* that a physician or advanced practice nurse has issued a DNR and documented the grounds for the order in the patient's medical file. Mont. Code Ann. § 50-10-101(6) (2007).

DISABILITY RIGHTS MONTANA'S EXPERIENCE

Generally in the cases in which we have been involved, there has not been a

determination by a physician or advanced practice nurse that the person is in a terminal condition, yet life-sustaining treatment has been withdrawn or is soon anticipated to be withdrawn. Frequently, this occurred because health care professionals advised family members or guardians that they had the authority to make decisions to withdraw life sustaining treatment prior to formally finding a terminal condition. This is not allowed by Montana law. Although we do not know all of the reasons and motivations driving this phenomenon, in the majority of our cases, health care providers have, without regard to a terminal condition, stated that life-sustaining treatment may be withdrawn because the person, from their perspective, will have a poor quality of life.

Disability Rights Montana is authorized by Federal law to access medical records of persons with disabilities whom it has probable cause to believe have been abused or neglected. (Protection and Advocacy for Individuals with Mental Illness Act of 1986 (PAIMI), 42 U.S.C. 10801 et seq.)

Quality of life is an extraordinarily subjective assessment. Studies have found that this perception is very different for patients with disabilities than for physicians. Physicians typically assess patients' quality of life as much lower than patients assess their own

quality of life.² This is especially so when the patient has a significant disability.³

²P.M. Rothwell, Z. McDowell, C.K. Wong, P.J. Dorman. *British Medical Journal*. (International edition). London: May 31, 1997. Vol. 314, Iss. 7094; pg. 1580, 4 pgs. L. Gething, "Judgments of Health Professionals of Personal Characteristics of People with Visible Disability" *Social Science and Medicine*, 24 (1992), 809-15; E. Ralston, P. Zazove, and D.W. Gorenflo, "Physicians' Attitudes and Beliefs about Deaf Patients," *Journal of the American Board of Family Practice*, 9:3 (1996), 167-73, Roush, "Health Profession as Contributors to Attitudes Towards People with Disabilities: A Special Communication," *Physical Therapy*, 66:10, (1986) 1551-56.

³ Compared with people with disabilities' own assessments of quality of life, physicians consistently underestimate the quality of life of ventilator-assisted polio survivors, and quadriplegic patients using ventilators. J.R. Bach and D.I. Campagnolo, "Psychosocial Adjustment of Post-Polio Ventilator Assisted Individuals," *Archives of Physical Medicine and Rehabilitation*, 73:10 (1992), 934-39; J.R. Bach and M.C. Tilton, "Life Satisfaction and Well-Being Measures in Ventilator-Assisted Individuals With Traumatic Tetraplegia," *Archives of Physical Medicine and Rehabilitation*, 75 (1994), 626-32. In a summary study of emergency care providers, 82% said they preferred death to serious disability. M. Hauswald and D. Tanberg, "Out-of-Hospital Resuscitation Preferences of Emergency Health Care Workers," *American Journal of Emergency Medicine*. 11:3 (1993) 221-24.

Another substantial factor in these cases has been the existence of a DNR. Often in these cases, the DNR was not requested by the patient, most of whom have not been capable of communicating orally. Thus, the DNRs have been in place at the decision of the health care provider or a guardian. Although these DNRs are only for the purpose of withholding cardiopulmonary resuscitation, DNRs have been the basis for denials of a tremendous range of treatments, including the denial of nutrition, water, and antibiotics.

We have engaged in education throughout the state about these issues. However, we are aware that some of the issues involved in these decisions have to do with unspoken judgments of the general quality of life of individuals with disabilities, especially when their health becomes compromised. It is this element of these cases that causes us great concern about the protection of people with disabilities throughout the state when they are hospitalized for serious health conditions.

In conclusion, it bears mentioning that Disability Rights Montana learned of each of these cases informally. Most often we were notified by persons who provide services to the people with disabilities or by staff of the Department of Public Health and Human Services (DPHHS) Developmental Disabilities Program and/or Adult Protective Services, with whom we have

collaborated in the resolution of many of these cases. There is no requirement in law that Disability Rights Montana be notified of situations where withdrawal or withholding of life-sustaining treatment to a person with a disability is being contemplated. As such, we cannot assert that these cases are representative of a substantial number or even a majority of the cases where such decisions are being made. Although we would like to believe that the law is being followed in the majority of cases, our experience causes us great concern that this is not the case.

Case Study 1: Cora (Spring 2006)

In early 2006, Cora, a woman in her early forties who had a traumatic brain injury secondary to surgery for brain cancer as a child, was repeatedly hospitalized. She developed aspiration pneumonia and an antibiotic-resistant staph ("MRSA") infection and a PEG tube was inserted for her feeding. Prior to her hospitalization, she was living independently in her community with supports provided by a local private disability agency.

A regional council formed for the purpose of providing medical guardianships for people with disabilities obtained temporary medical guardianship of Cora in February 2006. According to the medical record, in

March, the attending physician documented that he had changed Cora's "code status" to "DNR/DNI" pursuant to consultation with the guardian council, which the council disputes.

Cora aspirated during a tube feeding on a Friday morning. Consequently, further tube feedings were discontinued temporarily by her treating physician until a consultation could be held the following Monday. Her IV line, which was providing her with hydration and antibiotic treatment, failed the following morning. A so-called PICC line, which delivers hydration and medication directly to a large vein near the heart, was discussed but could not be installed because hospital policy prohibited such procedures on weekends "except in emergencies." Apparently, the failure of Cora's IV line and the discontinuance of her feeding tube did not constitute an emergency. At the time Cora's IV line failed, she was still responsive, conscious, and able to communicate verbally.

The treatment team met on Monday and the guardian representative apparently determined not to try further feeding through the PEG tube or to restart an IV tube, thus effectively discontinuing hydration, nutrition, and antibiotic for the MRSA. No single person determined, stated, or documented that Cora was in a terminal condition. Carl, her brother, was reported to have assented to the discontinued treatment

although not in writing. Another brother, Caspar, who lives in a mid-western city, was not consulted about either the guardianship or this decision to discontinue life support.

Cora was moved to a nursing home about two weeks after her feeding was stopped – ten days after the decision to continue withholding life support – and died the same evening.

Apparently, whether she wanted to be "allowed to die peacefully" or to have efforts expended to keep her alive was never discussed with Cora. She had made no declaration under Montana law. Neither of her brothers were consulted as to any wishes she may have expressed to them or to her own preferences. All involved assumed that the guardianship council had the authority to make end of life decisions in this case. Our review found that under state law at the time, the council did not have that authority.

Case Study 2: Daphne (Winter 2006)

Daphne is a 25 year old woman with developmental disabilities including mental retardation and a seizure disorder. Although she could not communicate verbally, she learned to express her feelings about herself, her life, and those around her by her eating habits. Daphne apparently teased her house-mates over food, expressed happiness by eating

avored goodies such as M&M's and let people know she was unhappy by refusing to eat altogether. Her weight had varied over the last two years from a reported high of 125-130 pounds to a low of 96. She lived in a community group home.

In early winter 2006, Daphne was hospitalized because she had refused to eat for several weeks and had lost a significant amount of weight. A PEG tube – a feeding tube which is surgically installed through the abdominal wall – was put in place. However, her parents, who were also her court-appointed co-guardians, ordered that the PEG tube be used only to administer her anti-seizure medications and enough water to deliver the medications. This meant feeding was to continue by mouth or not at all. Her parents expressed the opinion that they believed Daphne wanted to end her life and they wanted to honor her wishes. Apparently the attending physician believed the parents had power to make this decision and ordered that there be no tube feedings, even though no physician or APRN had made a determination that Daphne was in a terminal condition.

Daphne's weight continued to drop and she was re-admitted to the hospital. A DNR order was entered by the attending physician at the parents' request. Daphne continued not to eat and her weight continued to drop to approximately 75 pounds.

The Hospital's Ethics committee, convened at the request of Disability Rights Montana, considered the legal and ethical ramifications of the situation, reversed the DNR order and ordered that Daphne be fed through the PEG tube.

She rallied and was discharged from the hospital to a nursing home where she continues to be fed through the PEG tube and has steadily improved in body weight and function.

Case Study 3: Elsie (Winter 2006 - 2007)

Elsie, a profoundly retarded woman, lived in a group home. She had become non-responsive and was believed to be nearing the end of her life when she was admitted to a major hospital in early 2007. Elsie's advocates, along with DPHHS and provider representatives, were invited to meet with the hospital ethics committee and discuss the issues which had arisen in the cases involving Cora and Daphne as they might be applied to Elsie.

Elsie's guardian was a DPHHS employee. Elsie never developed the cognitive skills or communications abilities to discuss the end of her life. No one else could be found who had any understanding what Elsie's wishes might have been with respect to the artificial prolongation of her life.

After consultation with the hospital ethics committee, two attending physicians wrote specific notations to the medical file stating that to the best of their professional judgment, Elsie was in a terminal condition and that death was imminent. The hospital requested and received a written request from Elsie's parents that she not be resuscitated and she died within two days.

Case Study 4: Fred (Spring 2007)

Fred was hospitalized with diarrhea, dehydration, and a urinary tract infection. While he was in the hospital it was also learned that he had aspiration pneumonia. Fred had no guardian and his brother is his closest relative. The hospital had temporarily discontinued feeding Fred through his PEG tube, because he was occasionally aspirating stomach contents and exacerbating his pneumonia. A meeting was held at the hospital to consider his course of treatment. Disability Rights Montana staff advised that in the absence of a diagnosis of terminal illness, state law did not allow the hospital or staff to withhold treatment. The hospital changed its decision from withholding feeding him through a PEG tube to actively treating him to get him past his infection. Fred was discharged to a nursing home. A new swallow study later indicated he could swallow normally with help and does not need a

PEG tube. When last heard from, he was doing well.

Case Study 5: Gwen (Summer 2007)

Gwen was living in a group home when she was admitted to a small intermediate care hospital. Gwen has acute, chronic, and progressive scoliosis which, in the absence of orthopedic surgery, will eventually crush her lungs, liver and stomach. The chief of the hospital ethics committee, on consultation with the treating physician, determined that the scoliosis process was "terminal" although neither doctor could predict how many years she could live before death might occur. Neither doctor recommended a surgical alternative or other possibility. One of the two doctors opined, in a letter to Disability Rights Montana, that similar to this scoliosis, ALS or "Lou Gehrig's Disease" is also a terminal disease.

On request, Disability Rights Montana staff wrote an opinion that the patient had not been found to be in a terminal condition within the meaning of state law, that the guardian did not have the legal authority to withhold insertion of a PEG feeding tube, and that the guardian did not have the legal authority to speak for a patient "who cannot speak for herself" with respect to letting her die of starvation. Gwen was released and a PEG tube installed at a different hospital.

She is presently doing well in a nursing home.

Case Study 6: Harry (Fall 2007)

Harry was hospitalized in early fall with aspiration pneumonia. He had no guardian. The hospitalist said that he was in acute danger of further aspiration and worsening of his (probable) Methicillin-resistant *Staphylococcus aureus* or MRSA pneumonia, and requested a DNR/DNI order and permission to withdraw life support. Hospital staff believed that Harry's only relative was a brother in another city who favored termination and had no intimate current contact. Representatives from Adult Protective Services, the state Developmental Disabilities Program, hospital staff, representatives from Disability Rights Montana, members of the hospital's ethics committee, and Harry's brother met regarding his situation. Disability Rights Montana's attorney advised that prior to any decision regarding the withdrawal of treatment, a physician or APRN must determine that Harry is in a terminal condition. This determination did not occur.

Harry's brother, contrary to reports received from the hospital staff, expressed a vital interest in Harry's welfare and did not consent to termination of his brother's life

sustaining treatment. Since this event, Harry's brother has become Harry's guardian.

A suggestion was made that a surgeon in another city could separate Harry's esophagus from his trachea, thus eliminating the danger of aspiration. Harry stayed in the original hospital until antibiotic treatment stabilized his MRSA lung infection. He then transferred to a second hospital, where surgery was successful and he is now living in a nursing home.

Case Study 7: Irene (Late Winter 2007 – 2008)

Irene had been diagnosed with unilateral hydrocephalus as a child and a shunt was inserted into her brain to drain the excess fluid. Unfortunately, this allowed pressure to build up on the other side of her brain. The shunt failed during the winter and the physician treating her determined that the pressure on her brain should be allowed to build up until she suffers a stroke and dies "of natural causes." Irene had no guardian or known next of kin. Disability Rights Montana intervened and during the time that the possibility of reopening the shunt was discussed, they discovered that pressure on her brain was no longer increasing. The DNR order entered by the treating physician was discontinued and Irene

was transferred to a nursing home in stable condition.

Case Study 8: John (Late Summer 2008)

John, a middle aged man with a developmental disability, began refusing to eat while at a local hospital. Staff felt that a PEG tube would resolve his difficulties. John's parents were at odds with the staff of John's group home on many issues. The staff was recommending the tube, the parents opposed it. No physician or APRN had determined that he was in a terminal condition. Disability Rights Montana spoke to John's parents' attorney, persuaded him that a PEG tube is not a "heroic measure" as the parents had called it. The DNR order was then withdrawn and John's parents agreed to surgery to install a PEG tube. When John regained stability, his parents moved him to a nursing home/group home closer to where they live.

Case Study 9: Katie (Early Winter 2008 – 2009)

Katie is a middle aged woman who had grand mal epilepsy and a fall-triggered status epilepticus or continuing *grand mal* seizure. She was sedated at the hospital into an artificial coma.

However, her swallow reflex disappeared and the only way to provide her with the anti-seizure medication that seemed effective was by mouth. Katie's mother was the only known member of her family available. At the time, the hospital questioned her legal authority to give consent for medical treatment because her parental rights had been terminated many years earlier.

Initially, Katie's mother did not want her to "be stuck full of tubes" and thus was in favor of foregoing treatment. However, following discussions of the options with hospital staff, she changed her mind. The hospital accepted Katie's mother's consent to a tracheostomy and later a PEG tube. The anti-seizure medication was resumed through the PEG tube and brought back to therapeutic levels, but Katie's stomach began rejecting everything. Katie died without emerging from the coma.

Case Study 10: Leona (Early Winter 2008 – 2009)

Leona is a young, vivacious woman who has paraplegia and cerebral palsy. She had been cared for most of her life by her father, who was dying of cancer and had been moved from a nursing home to the home of his ex-wife, who with the help of hospice was providing for his last days. Leona came into the nursing home with her father, whose last expressed

wishes were that Leona not be intubated. He had arranged for his former wife to become Leona's temporary guardian and had also set up a trust with one of Leona's brothers as the trustee. Leona appeared depressed, her appetite had disappeared and she had quit eating. Her former stepmother interpreted this as Leona's way of telling the world that she wanted to die and felt that her caregivers should honor this wish.

A meeting was held with nursing home administrators, hospice staff, Leona's former stepmother and her attorney, a Disability Rights Montana representative, and a community caregiver, as well as representatives from DPHHS Adult Protective Services and the Developmental Disabilities Program. All parties agreed that the PEG tube should be an option and that Leona should be moved from the nursing home and transferred to a community group home. Leona was moved and started eating again on her own. As of the writing of this report, it has not been necessary to insert a PEG tube.

After Leona was moved, her father died. Her current caregivers have notified Disability Rights Montana that Leona, whose cerebral palsy significantly interferes with her ability to communicate, may have greater cognitive abilities than had been previously determined and are taking steps to build on this ability for Leona's

long term benefit. She is living in a group home.

Case Study 11: Martha (Midwinter 2008 – 2009)

Martha executed a DNR order while in a Montana hospital several years ago, which is still in her medical record. She now has an Adult Protective Services guardian. Martha was recently found to have a urinary tract infection and was checked into the same hospital where the DNR had been entered. Based upon this DNR order, the hospital staff refused to give Martha antibiotics to treat her infection. After consultation with Disability Rights Montana, the APS guardian ordered the antibiotics resumed and is investigating how the DNR order was created and has survived.