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Massachusetts Probate and Family
Court Department, Division.

In the Matter of Barbara HOWE

No. 03 P 1255. | March 22, 2004.

Findings of Fact, Conclusions of Law, and Rationale on the Petition of Massachusetts General Hospital for Declaratory Relief in the Matter of Patient Barbara Howe

SMOOT, J.

Procedural History

***1** 1. On June 18, 2003, Massachusetts General Hospital ("the Hospital") filed a petition pursuant to G.L. c. 201D, §§ 14, 15, and 17, for declaratory relief. The Hospital requested a determination as to the appropriate level of care that must be afforded to its patient, Barbara Howe. In its petition, the Hospital stated that an actionable dispute had arisen between itself and Barbara Howe's health care agent, Carol Howe, as to what level of care Barbara Howe, who suffers from Amyotrophic Lateral Sclerosis ("ALS"), must receive.

2. On July 21, 2003, the court (Smoot, J.) assigned Attorney David Aptaker to represent Barbara Howe's interest as her attorney during these proceedings.

3. Attorney Robert R. Hamel, Jr. represented the Hospital. Attorney Gary Zalkin represented Carol Howe.

4. On July 21, 2003, the court (Smoot, J.) assigned Attorney Martin O'Connor to act as a guardian ad litem / next friend for Barbara Howe. In this role, Attorney O'Connor was to investigate and report on the issues raised by the Hospital's complaint.

5. The parties jointly drafted and filed a pre-trial memorandum on September 10, 2003.

6. On September 10, 2003, the guardian ad litem filed his first report.

7. On November 3, 2003, the court (Smoot, J.) held a status conference.

8. On November 5, 2003, the court (Smoot, J.) issued an order after status conference. The order stated, *inter alia*, that, "Counsel and the guardian ad litem shall attempt to reach a stipulation as to the meaning of [the] term 'locked in' as it applies to Barbara so that the term can be used in an efficient and helpful manner."

9. On November 3, 2003, the guardian ad litem filed his second report.

10. On February 9, 2004, the guardian ad litem filed his third report.

11. The guardian ad litem reports were impounded upon motion of the guardian ad litem and by agreement of the parties.

12. The trial was held before Smoot, J. on February 9, 10, and 11, 2004.

Findings of Fact

General Information

1. Barbara A. Howe was born on April 24, 1925, and at the time of trial was seventy-eight (78) years old.

2. Prior to her admittance to the Hospital, Barbara resided at 65 Harbor View Street, Dorchester, Massachusetts.

3. At present, Barbara is a patient at the Hospital, Room No. 2124, Phillips House 21st Floor, 55 Fruit Street, Boston, Massachusetts 02114.

4. Barbara has three adult daughters: Carol A. Howe, Maureen Howe, and Barbara A. Johnson. [1]

5. Carol resides at 723 Pleasant Street in Bridgewater, Massachusetts. She has lived in Bridgewater since October of 2003. Prior to moving in October of 2003,

Carol lived at 65 Harbor View Street in Dorchester, Massachusetts. When Carol was residing in Dorchester, she lived with her mother, Barbara, and her sister, Maureen.

6. Maureen Howe resides at 65 Harbor View Street in Dorchester, Massachusetts. She has lived in this house for her entire life.

7. Barbara owns the house at 65 Harbor View Street, and there is no mortgage encumbering the property. Maureen pays the bills associated with the house.

***2** 8. Barbara does not have a will.

9. Maureen has been employed with the NStar Corporation for twenty-seven years.

10. Barbara's husband, whose name was not introduced into evidence, died from advanced colon cancer on June 29, 2001. He was cared for at the Hospital's Phillips House on the 20th floor.

Diagnosis and Progression of Amyotrophic Lateral Sclerosis 1991 -1997

11. ALS is a disease of the motor nerves characterized by progressive muscle weakness and atrophy.

12. ALS begins with weakness in selected parts of the body, and extends slowly to impact all parts of the body. The muscles of the eyes are the last muscles affected.

13. Symptoms of ALS include tripping, stumbling and falling, loss of muscle control and strength in hands and arms, difficulty speaking, swallowing, and breathing, chronic fatigue, muscle twitching, and cramping.

14. In 1991, Carol noticed that Barbara had a “foot drop” episode. “Foot drop” is a condition in which the foot hangs in a plantar-flexed position due to weakness or paralysis of the muscles of the lower leg.

15. Several months later, in December of 1991, Barbara was diagnosed with ALS.

16. The advancement of ALS is characterized by muscle twitching and slowly progressing paresis of the voluntary muscles along with weak or absent muscle response. When the facial muscles are impacted, the patient experiences speech problems, swallowing problems and drooling.

17. There is no cure for this disease. A treatment regime cannot stop the disease's progression.

18. When Barbara's breathing muscles weakened during the progression of the disease in 1994 and 1995, Barbara's attending physician, Dr. Doug Johnson, started preparing Barbara to consider the use of assisted breathing devices. Between 1995 and 1997, Barbara needed the assistance of a non-invasive ventilator.

19. Much of Barbara's life after 1995 was homebound and involved the assistance of a wheelchair.

20. During the 1990's, while planning for her future treatment, Barbara communicated to her doctors and her family that if a tracheostomy and placement on a permanent ventilator was necessary, she wanted to be allowed to die.

21. In 1997, Barbara experienced a loss of breath and choking, and she changed her mind about her treatment plan. She underwent a surgical tracheostomy and has been completely ventilator dependent since 1997.

Barbara Howe's Health Care Proxy

22. On September 14, 1998, Barbara executed a health care proxy. The document included the following statements:

a. “I, Barbara A. Howe, residing at 65 Harbor View St. Dorchester, MA, appoint as my Health Care Agent: Carol A. Howe of 65 Harbor View St. Dorchester, MA”

b. “My Agent shall have the authority to make all health care decisions for me, including decisions about life-sustaining treatment, subject to any limitations I state below, if I am unable to make health care decisions myself. My Agent's authority

becomes effective if my attending physician determines in writing that I lack the capacity to make or to communicate health care decisions. My Agent is then to have the same authority to make health care decisions as I would if I had the capacity to make them EXCEPT (here list the limitations, if any, you wish to place on your Agent's authority): [This space was left blank.]”

***3** c. “I direct my Agent to make health care decisions based on my Agent's assessment of my personal wishes. If my personal wishes are unknown, my Agent is to make health care decisions based on my Agent's assessment of my best interests.”

23. The health care proxy was signed by Barbara on September 14, 1998. Her sister, Catherine A Lee, and her daughter, Barbara A Johnson witnessed the signing.

24. Barbara's health care proxy is a valid document and meets the requirements of G.L. c. 201D, § 1 et seq. Barbara's attending physician has determined that Barbara lacks the capacity to make or communicate health care decisions. Carol is Barbara's health care agent.

Dr. J. Andrew Billings

25. In 1998, Dr. J. Andrew Billings became Barbara's attending physician.

26. Dr. Billings has been employed in some capacity with the Hospital since 1978. From 1979 to 1983, Dr. Billings was an assistant in medicine at the Hospital. From 1984 to 1988, Dr. Billings was an assistant physician at the Hospital. From 1984 to 2002, Dr. Billings has been an assistant clinical professor of medicine at Harvard University. From 1996 to the present, Dr. Billings has served as a physician and as the director of the Palliative Care Service at the Hospital. From 1997 to the present, Dr. Billings has served as the co-director of the Harvard Medical Center for Palliative Care. From 1999 to the present, Dr. Billings has served as the co-director of the Palliative Care Program-in-Development at the Dana Farber/Harvard Cancer Center.

27. The Palliative Care Service at the Hospital is an interdisciplinary approach to practicing medicine which attempts to address the medical, psychological, social, and spiritual needs of a patient.

28. Dr. Billings met Barbara in July of 1998 when a Palliative Care Service consult was placed.

29. Dr. Billings evaluated Barbara's case. There was some disagreement on his staff about whether he should become Barbara's attending physician, as the staff had concerns over potential conflicts with the family concerning Barbara's treatment. On or about November 2, 1998, Dr. Billings and Dr. Linda A. King sent a letter to the Howe family agreeing to act as Barbara's primary care physicians which included a proviso stating that:

> “The primary care relationship requires building trust and open communication between providers, patient, and family over time. In general, threats of formal complaints, being fired, or legal suits lead to a mutual lack of trust and often to inappropriate medical decision-making. If differences arise between the patient, family, and primary care team, attempts to resolve them in non-threatening manners, such as team and family meetings, should be pursued.”

30. At the beginning of Barbara's care, Dr. Billings carefully reviewed with Barbara the progression her disease would likely take.

31. On November 15, 1999, Barbara was permanently admitted to the Hospital.

Family Commitment

***4** 32. Since her mother entered the hospital, Carol has visited her three to four times per week. During these visits, Carol completes such tasks as:

a. taking and recording Barbara's vital signs;

b. providing medication to Barbara;

c. cleaning Barbara; and

d. suctioning Barbara's tracheostomy.

33. Barbara Johnson and her children visited regularly with Barbara during the first years of Barbara's stay at the hospital. Barbara enjoyed these visits with her grandchildren. Since Barbara's condition deteriorated and two way communication diminished, these visits have become rare.

34. Since her mother entered the hospital, Maureen has visited Barbara every day of the week. Maureen usually arrives at the Hospital at approximately 7:00 p.m. and stays to approximately 11:30 p.m. She does not miss a day of visiting her mother unless there is an inordinate obstacle such as a snow storm.

35. When Maureen visits her mother, she does some or all of the following tasks:

a. cleaning;

b. feeding;

c. massaging muscles;

d. washing Barbara's hair;

e. personal hygiene care.

36. Maureen speaks to Barbara. She is certain that Barbara responds by making a chewing motion. Maureen's view is that Barbara's responses to questions are not random movements, and that her brain is “fine.”

37. Maureen also contacts Barbara's grandchildren by phone and holds up the receiver to Barbara's ear so that the children can speak to their grandmother. Barbara cannot respond to the grandchildren.

Hospitalization 1999-2001

38. Barbara was admitted to the Hospital in 1999. Since then, she has required extensive care to meet her needs. She is ventilator dependent, receives her nutrition and hydration through a feeding tube, and is incontinent.

39. At the time of her admission, Barbara was partially paralyzed. However, she could move her lips and point to a letter board to communicate. Those with the greatest daily contact, Barbara's nurses and family, were more adept at reading her lips than were her doctors.

40. On August 21, 2000, Barbara reported to Doctor Andrew Putnam that, at that time, being alert was more important than eradicating pain.

41. On August 27, 2000, Dr. Putnam had a discussion with Barbara and Carol about Barbara's end of life care. Dr. Putnam's notes from that meeting are as follows:

a. “[illegible character] go Home to Hospice-Not wanted by Pt”

b. “[illegible character] go Home[illegible]-Not wanted”

c. “[illegible character] aggressive Tx to continue-wanted”

42. Barbara often reported to staff that she had headaches, abdominal pain, or other ailments that her health care providers treated with analgesics.

a. On October 24, 2000, a nurse left the following notation on Barbara's medical records: “Patient c/o headache medicated with tylenol ● further c/o pain.”

b. On October 25, 2000, a nurse left the following notation on Barbara's medical records: “Patient c/o headache medicated with tylenol with ● relief, refusing anymore tylenol.”

***5** 43. In 2001, Barbara could “track” with her eyes, i.e., when someone entered the room, she could follow them around the room with her eyes.

44. In 2001, Barbara could move one of her fingers.

45. By April of 2001, Barbara had lost the ability to communicate by mouthing words or by pointing at letters.

46. In a letter dated April 22, 2001, Dr. Billings stated:

a. “One major change has occurred gradually over the past year and particularly the past 6 months: due to ALS and her mental confusion, she [Barbara] is no longer reliably able to communicate nor to indicate her wishes, let alone confirm whether she is comfortable or in pain or suffering in any manner.”

b. “I now feel I can state my firm and best medical judgment that her condition will not improve and that she will not be able to communicate meaningfully with her family, to communicate her wishes to us, nor to tell us when she is suffering. This is the state that she said she did not want to endure.”

47. In response to Dr. Billings letter, Carol reports that she consulted with her terminally ill father who was also a patient at the Hospital, and thereafter, retained an attorney.

48. In a letter to Dr. Billings dated April 25, 2001, Attorney M. David Blake, stated:

a. “They [Carol and Maureen] understand that you believe that their mother would not want to be kept alive at this stage in her illness. As her mother's Agent under her Health Care Proxy, Carol understands her mother's wishes differently. Carol bases her understanding on conversations that she had with her mother in which Barbara discussed criteria for when she would no longer want to be kept alive. Specifically, Barbara reported wanting to be kept alive until she was ‘brain dead’ or ‘semi-comatose.” ’

49. On April 27, 2001, Dr. Billings sent an email to Attorney Blake, stating

a. “I know you and the family want to do what is right by the patient, but keeping her alive by extraordinary means seems only to offer her the opportunity to suffer greatly, and is more like torture than respectful medical care.”

50. On June 6, 2001, a nurse entered the following comments in Barbara's medical records: “Pt eyes closed and a response from 3 -5 p. When daughter Carol in pt awoke + alert + responding to questions eye blinking.”

51. In a memorandum dated August 11, 2001, Dr. Billings wrote that there have been “major discrepancies” between his neurologic examination of Barbara and the reports from the patient's family which were playing a significant role in the “currently intractable conflict between me and the family.” Dr. Billings instituted a protocol to be followed when a physician and Carol were present, whereby Carol would be given specific questions to ask her mother so that Barbara's responsiveness could be assessed. There was no evidence presented concerning the outcome of this directive.

52. On November 24, 2001, a nurse entered the following comments in Barbara's medical records: “Mental state, when asked to close eyes tight in response to questions and blink she did ...”

Optimum Care Committee

***6** 53. The OCC examines cases where ethical concerns are present. The focus of the committee is end of life care provided by the Hospital. The standard procedure for the committee is to have one or two members of the committee evaluate a case and make recommendations to the rest of the body.

54. In May or June of 2001, the OCC was asked to involve itself with Barbara's treatment. At that time, the question to be addressed was whether ongoing life support (primarily ventilatory support) should be continued. Dr. Rae M. Allain and Nurse Ann Quealy represented the OCC in evaluating Barbara's situation, and submitted a report summarizing their investigation on July 26, 2001.

55. Dr. Allain is an anaesthesiologist and a specialist in intensive care medicine at the Hospital. Dr. Allain was a member of the Hospital's OCC from 1991 to 2003.

56. In preparation for an Optimum Care Committee ("OCC") meeting in 2001, Dr. Billings drafted a memo to himself about Barbara's care. In this memo, Dr. Billings made the following statements.

> "She is suffering and she can only be expected to suffer. Her baseline level of physical and emotional distress is high. Since I have known her, Mrs. Howe has regularly expressed physical distress, while everyone around her has considered her also to be in emotional distress (note multiple psychiatric medications). Hardly a day went by when she was more communicative when she or her daughter would not indicate pain in her head, mouth, neck, chest, abdomen, bladder, or feet. I presume that she continues to suffer with these pains. We have no reason to believe that patients with ALS do not feel pain associated with suctioning, sores on her neck, venupuncture, bronchoscopy, etc. At a very minimum, she should be put on a regimen of pain medication that assures her comfort, although it may accelerate her demise. The family recently described prolonged sobbing."
>
> "Do we know her expressed wishes? She was asked repeatedly about whether she wanted to go on living in her current condition and she always indicated yes when she was mentally clear enough to answer the question. She indicated that she wanted to be kept alive as long as she could enjoy her family."
>
> "Did she feel it wrong to let yourself die in the face of a terrible illness or suffering? She never said that she should be kept alive in this sort of situation. I frankly do not believe the construction we now hear from the family. Withdrawing support was an option for her, but she did not chose it at that particular time. As far as I know, she never mentioned anything about staying alive until she experienced 'brain death' or 'semi-coma.' Indeed, we know that she was capable of deciding to forego treatment and did not feel obliged to keep fighting to remain alive: before I assumed responsibility for her care, she had indicated for a considerable period of time that she did not want to be intubated, a decision she reversed at the very last minute."

***7** 57. During the course of their investigation, the OCC consulted neurologists Dr. Robert Brown and Dr. David Caplan. As a result of their examinations, it was determined that Barbara was de-efferented, i.e., it was not possible to determine how much Barbara could understand because her expressive ability is severely limited.

58. On July 18, 2001, representatives from the OCC met with Carol, Maureen, and Carol's attorney. During this meeting, Carol and Maureen stated

that their mother would want continued aggressive treatment. In response to questions about cardiac arrest, Carol stated that at this point, Barbara would want full resuscitative measures, including CPR and intensive care.

59. Carol stated that her mother would want treatment until she was "semi-comatose" which she defined as meaning that Barbara could not spontaneously open an eye in response to a family member's presence or voice.

60. In its July 26, 2001 report, the OCC noted the following:

a. "A study of patient preferences from the Eleanor and Lou Gehrig MDA/ALS Center at Columbia University suggests that between 6% and 12% of patients diagnosed with ALS were committed to tracheostomy."

b. "In addition, of those ALS patients who do request a tracheostomy and mechanical ventilation, only 10% become locked in."

61. In its July 26, 2001 report, the OCC made the following recommendations:

a. "Respecting Mrs. Howe's autonomy involves carrying out her wishes for end of life as expressed when she was competent and capable of expressing those wishes. Currently, it is impossible to determine what Mrs. Howe's wishes are and so we turn to her surrogate, Carol Howe, who as her proxy has been entrusted to represent Mrs. Howe's wishes. Carol is quite certain in her mother's wishes, although 'semi-comatose' is a non-medical term which Carol has somewhat defined as meaning unable to open eyes spontaneously to a family member's voice or presence in the room. Precise definition of this state may prove difficult as Mrs. Howe's condition deteriorates further."

b. "The concept of nonmaleficence in Mrs. Howe's case means avoiding harm with no benefits. At present, continued aggressive treatment, including suctioning for pulminary toilet, venipunctures, and urinary catheterizations does invoke some harm, but based on past experience, none of these procedures seemed to be an undue burden to Mrs. Howe. The treatment of cardiopulmonary resuscitation, however, which Mrs. Howe has not undergone to date, is a brutal therapy which causes pain, may fracture ribs, and may lacerate internal organs. CPR was developed as an attempt to reverse cardiac arrest in patients suffering from an acute, reversible illness which Mrs. Howe does not have. A study of patients with ALS who were receiving long-term mechanical ventilation indicates that *of those who could communicate*, the majority (58%) did not want to undergo CPR. Thus, given the risks and pain associated with CPR with no benefit of reversing disease in this case, it is the recommendation of the OCC that Mrs. Howe be protected from harm with a 'limitation of life-sustaining treatments' order."

***8** c. "Finally, the principle of relative benefit versus burden may be applied to each of Mrs. Howe's treatments. At this point, it is not clear that continued ventilatory support poses an undue burden, although it is questionable because no one is able to definitely assess if Mrs. Howe is in pain. Dr. Billings' concern that Mrs. Howe may be suffering pain is legitimate. An evidence-based review of practice parameters for ALS patients published by the American Academy of Neurology reports that pain is experienced by 40%-73% of patients in the terminal phase of ALS. Additionally, Mrs. Howe may be suffering from anxiety, psychological distress, disorientation, or delirium that we simply cannot appreciate. In this context, Mrs. Howe's physicians might consider a time-limited empiric trial of pain-killers, anxiolytics, antidepressants, neuroleptics, or other medication that might be deemed to be of some benefit. The OCC recognizes the diligent care that has been delivered to Mrs. Howe throughout her hospitalizations and that many of these therapeutic options may have been exhausted in the past. Also, efficacy of any of these treatments may be extremely difficult or impossible to judge. While this issue of whether or not Mrs. Howe is suffering does torment many of her care givers, if we apply past experience with her expressed wishes to continue ventilation, chest PT, and

suctioning, we can only assume that her current level of ventilatory support would not be against her wishes. This assumption may change, however, based on further developments in her condition, especially complications that may alter the balance between burdensome and beneficial therapies. It is the opinion of the OCC that care in a critical unit (or interventions usually performed in a critical care setting), which normally includes painful, invasive procedures, would pose an undue burden to Mrs. Howe with minimal potential benefit. Therefore, the OCC recommends that in the event of complication, Mrs. Howe not be transferred to a critical care unit nor be subjected to the equivalent of 'critical care.' Finally, escalations in the current level of care must be carefully weighed by her physicians with respect to the benefit to burden ratio in this patient with advanced terminal disease."

62. Carol disagreed with the July 26, 2001 findings and report of the OCC. The Hospital attempted to resolve the conflict by convening a meeting on October 17, 2001.

63. On October, 17, 2001, the OCC convened a special meeting to discuss Barbara's care and treatment. The meeting was divided into three phases.

a. Phase one of the meeting consisted of a presentation by representatives of the medical team caring for Barbara.

i. Dr. Billings stated that Barbara did not want to extend her life to the current state, and given her condition, he advocated for a treatment plan that consisted of comfort care only. This would mean withdrawing ventilatory support.

ii. Dr. Brown stated that it was impossible to determine Barbara's mental status. Dr. Brown noted that many of Barbara's actions may be reflexive, but some of her movements may reflect intact cognition.

***9** iii. Dr. Johnson, Barbara's pulmonologist, stated that the goal of ventilation was to provide comfortable breathing. Aggressive bronchoscopy had been abandoned because it had been ineffective at preventing lobar collapse for the past several months.

iv. Dr. Reid of the Palliative Care Service stated that the simple, daily care of Barbara elicited signs of pain.

v. The nurses of Barbara's medical team stated that many aspects of Barbara's daily care are painful to the patient.

vi. Several nurses confirmed Barbara's consent to and desire for aggressive care when she was able to communicate.

b. Phase two of the meeting consisted of a presentation by Carol and her legal representative.

i. Carol and her representative presented their view that Barbara had clearly expressed that she wished to receive aggressive medical care until she was comatose or semi-comatose with a "flat" or "minimal" EEG.

ii. Carol described her mother as a religious woman who was a "war horse" in her ability to manage pain.

iii. Carol shared anecdotes concerning Barbara's thoughts and ideas on death.

iv. Carol presented evidence concerning a 1997 visit to the emergency ward. At that time, Barbara was intubated on an emergency basis and synchronized cardioversion was used successfully to restore Barbara's sinus rhythm.

v. Carol expressed her desire that Barbara be transferred to a different attending physician at the Hospital.

vi. A letter was presented to the OCC from Marjorie O'Leary who is a nurse assigned to provide nursing care to patients on the 21st floor of the Philips House. Ms. O'Leary wrote that "when [Barbara] was more able to communicate ... she indicated that she wanted everything done to maintain her; including CPR, antibiotics, and ICU if needed."

c. Phase three of the meeting consisted of deliberations by the OCC members. Following their discussions the committee unanimously arrived at the following recommendations:

i. “Given Mrs. Howe's advanced, terminal neurologic disease and severe co-existing medical conditions, she should be protected from chest compressions and electrical countershock on the grounds that these treatments are both inappropriate and harmful. As described in the CP & P Manual, ‘treatments are inappropriate when they provide no reasonable possibility of extended life or other benefit for the patient,’ and ‘treatments are harmful when the additional suffering or other harm inflicted is grossly disproportionate to any possibility of benefit.” ’

ii. “Vasopressor and antiarrhythmic medications are inappropriate for Mrs. Howe.”

iii. “Mechanical ventilation should be continued at present.”

iv. “The OCC strongly suggests that comfort care be the main focus of Mrs. Howe's treatment at this stage in her disease, but feels that this decision rests with her daughter, Carol Howe. The committee is disturbed by the notion that Mrs. Howe may endure significant periods of suffering during the day and acknowledged the distress of her care givers over this issue.”

***10** v. “Dr. Billings should be allowed to transfer responsibility for Mrs. Howe's care to another attending physician given the conscientiously untenable position in which he is placed with respect to Mrs. Howe's care. Ideally, a new responsible physician can be found at MGH, but this is not at all certain. The process of finding a physician to accept Mrs. Howe's care may be difficult, and may require the aid and guidance of the Chief Medical Officer. Any new responsible physician must be approved by Carol Howe. If a new responsible physician cannot be found at MGH, transfer to another facility may be entertained only if the accepting physician and institution agree not to provide what the OCC has deemed to be harmful treatments for Mrs. Howe.”

64. On November 13, 2001, the Hospital's Chief Medical Officer, Dr. Britain Nicholson, entered an order to conform Barbara's care with the OCC's recommendations.

65. On January 24, 2002, Carol filed a verified complaint against the Hospital in the Superior Court of Suffolk County and requested a temporary restraining order. The complaint requested that a restraining order be issued ordering the Hospital to stay its execution of the OCC's recommendations. In response to this legal action, the Hospital agreed not enact the OCC's recommendations.

Hospitalization 2002-June 2003

66. While Dr. Billings remained Barbara's primary physician, Dr. Colleen Reid was Barbara's daily care physician from June of 2001 until August of 2002. Dr. Reid reported at trial that although Barbara grimaced in response to nursing care or being touched on the hand, she could not consistently demonstrate when she was in pain. Dr. Reid reasoned that Barbara has a long history of various chronic pains; that the causes of these pains have not diminished; therefore, Barbara is still experiencing these pains, but is no longer able to communicate with her care givers about these pains.

67. Dr. Reid indicated that she always found it difficult to communicate with Barbara.

68. Dr. Reid did observe Barbara respond to a male aide when he greeted Barbara with a “booming affectionate voice.” The aide elicited a smile from Barbara.

69. Dr. Reid has not witnessed Barbara interact with her family since at least June of 2002.

70. Barbara's medical records indicate that in addition to or as a result of ALS, she has been diagnosed with the following conditions:

a. calcium deficiency

b. cardiac hypertension

c. vitamin D deficiency

d. kidney problems

e. bowel problems

f. bladder infections

g. blood clots

h. osteoporosis

i. recurring gastro-intestinal bleeds

j. anemia

k. Graves disease (a thyroid gland disorder)

l. depression

m. anxiety

71. Beginning in the Spring of 2003, Barbara's inability to lubricate her eyes caused abrasions and ulcerations of the cornea on her right eye. These abrasions and ulcerations formed despite the Hospital staff's rigorous administration of medication and artificial lubricants to Barbara's eyes.

***11** 72. On May 23, 2003, the cornea service at the Hospital included an entry on Barbara's medical chart. The entry described: (1) Barbara's corneal ulcer on her right eye; (2) the possibility of a tarsorrhaphy, which is an operation to suture together a portion of or the entire upper and lower eyelids for the purpose of shortening or closing entirely the eyelids; and (3) the need for a conjunctival flap, i.e. a covering for the eye.

73. On May 31, 2003, a tarsorrhaphy was performed on Barbara's right eye.

74. On June 5, 2003, there was a perforation of Barbara's right eye. At this time, Dr. Billings had a conversation with Carol. Dr. Billing's notes of that conversation are as follows:

I explained to her my grave concerns that this current clinical situation requiring removal of [right] eye was, in my mind, a drastic step to take (though, if we were to proceed at current level of care, certainly necessary.) However, given her advanced ALS; inability to communicate or reliably indicate pain or comprehension, and her "locked in state" with questionable cognitive functioning-that in her losing her [right] eye-it was clear to me we had reached the point where we have surpassed Mrs. Howe's expressed wishes to "DO EVERYTHING as long as she can interact or appreciate her family."

Carol agreed that if her Mom were to lose vision altogether, (even though she had hearing intact), it would NOT be a quality of life sufficient to warrant continued life support. Carol also remarked that she would have to choose to let her Mom die with peace, comfort + dignity *IF* this procedure (evisceration) would take away vision from her Mother. Carol feels in favor of this procedure at this point given the patient has not had vision in her [right] eye for the last several months given the tarsorrhapies + taping.

... should rupture of [left] eye occur, "I [Carol] would have to step back, and allow my Mom to pass comfortably in that situation. It would be CRAZY to go ahead with removing her [left] eye too."

75. On June 7, 2003, the Hospital performed a bedside surgery which eviscerated Barbara's right eye.

Optimum Care Committee

76. On the evening of June 5, 2003, the Optimum Care Committee held a regularly scheduled monthly meeting.

77. On June 6, 2003, Dr. Edwin H. Cassem, the OCC chairperson, completed a brief entry on Barbara's medical records, and later provided a full typed note. Dr. Cassem made the following observations, *inter alia:*

a. "We [the OCC] met again last night regularly (1/mo) +, as usual, received the update [of Barbara's status]. There is now 100% unanimous agreement that this inhumane travesty has gone far enough. This is the Massachusetts General Hospital, not Auschwitz."

b. "When, over 3 years ago, this, her terminal hospitalization began, she made it clear to everyone that as long as there was any possibility left to communicate to her beloved family, she wanted every standard resuscitation process employed should she have a cardiac and/or respiratory arrest."

***12** c. "She lies here today, her face fixed in a frozen grimace as though she were a woman now in constant suffering. Through the grimace leaks a constant flow of sputum; absorbed by the routinely changed washcloth placed at the dependent corner of her mouth."

d. "They [the Hospital staff] have lived for two years with the appalling realization that they are under orders to resuscitate her and so guarantee that her gallant life will be wiped out by a senseless act of brutality. The administrative mandate demands that the dimension of emotion in their care be shut out, repressed, stamped on, derogated, or just plain pretended away. It is therefore not only delusional but unfair. It demands that the entire body of caregivers violate their professional oaths, the standards of medical and nursing practice, the standards of the Massachusetts General Hospital, and the standards of ethics, morality, human decency and common sense."

e. "The family has been allowed to dictate medical practice. The resuscitation orders themselves were written by attorneys and make absolutely no medical sense whatsoever."

f. "Today Mrs. Howe is doomed to inevitable endopthalmitis which brings with it excruciating pain. Prior to this, the family has stridently opposed the administration of even Tylenol for pain. This tolerance of deliberately inflicted pain on Mrs. Howe must stop at once."

78. Other than Dr. Cassem's entry on Barbara's medical records, there was no evidence presented concerning the OCC meeting held on June 5, 2003. It is not clear who attended this meeting, and other than Dr. Cassem's notes, no documents were produced as a result of this meeting. There has been no formal change in the OCC recommendations since October of 2001.

Hospitalization June 2003-Present

79. Barbara has a cataract in her left eye. Additionally, there is a corneal abrasion in Barbara's left eye. An optical specialist examined Barbara's left eye in the fall of 2003. The results of this examination could not definitively state whether Barbara retained vision out of her left eye. Barbara's eyelid does open and her pupil is reactive to bright light.

80. Presently, Barbara has her left eye taped shut for a majority of the day. When Carol and Maureen visit Barbara, they un-tape her left eye. Both daughters are aware that by leaving their mother's eye un-taped they are increasing the chances that it will ultimately rupture.

81. Carol's position is that having the eye untaped improves the quality of her mother's life, and that the quality of her mother's life is more important than the length of her mother's life. Carol stated that she would authorize the withdrawal of life-sustaining treatment should the evisceration of Barbara's left eye become necessary.

82. When Maureen visits, she places warm compresses on her mother's left eye and helps place ointments in the eye. Maureen has observed that sometimes Barbara's left eye is swollen, but there is movement in her eye.

***13** 83. Maureen reports that Barbara reveals when she is in pain by grimacing.

84. There has been a long-standing discrepancy in the amount, quality, and complexity of Barbara's communications. This varied ability to perceive communication persists to the present, with the Hospital staff asserting that Barbara can no longer communicate and the Howe family asserting that Barbara is able to communicate.

85. All parties report that one of Barbara's common facial expressions is a grimace. When she is moved in her bed, when her face is touched, or when she is "suctioned," Barbara often grimaces.

86. The parties have interpreted Barbara's grimacing in various manners.

a. Barbara's family asserts that her grimacing is a valid expression of discomfort and/or pain. Therefore, when Barbara is not grimacing, she is likely to be pain free or experiencing low level pain.

b. The Hospital agrees that one of Barbara's natural reflexes is to grimace when she is in pain; however, the Hospital asserts that Barbara could be in pain and not grimace.

87. Presently, Barbara's chart has a PRN order. This means that Barbara is not administered pain medication regularly; instead, Barbara is to receive pain medication on an "as needed" basis. Carol is opposed to having a permanent order of pain medication, given Carol's impression that pain medication results in Barbara becoming non-responsive.

88. On December 28, 2003, it was discovered that Barbara had suffered rib fractures on her right side. On December 29, 2003, it was discovered that Barbara had a break in her left humerus bone. These breaks in Barbara's bones were discovered after exploratory chest films were taken to help diagnose a respiratory illness.

89. In a letter from Dr. Billings to Carol dated January 9, 2004, Dr. Billings noted that the fractures "occurred in the course of usual care, such as turning her on her side or moving her up in the bed."

90. Barbara has weak bones due to among other things her limited mobility and vitamin D deficiency.

91. Presently, Barbara tends to acquire small abrasions and cuts on her face. For example, on January 20, 2004, there was a skin tear in or around Barbara's left ear.

92. In January of 2004, Dr. Reid visited with Barbara. At that time, Dr. Reid noticed that Barbara's left eye could not "track" an individual in the room. Additionally, Dr. Reid concluded that the fractures discovered in December of 2003 reveal that Barbara suffered from osteoporosis.

Nursing Staff

93. Janice Cameron-Calef has been a nurse at the Hospital for approximately sixteen years of her twenty-seven year nursing career. She has cared for Barbara since she first became a patient on the 21 st floor of the Philips House.

94. Ms. Cameron-Calef had the opportunity to build a strong bond with Barbara through gestures, nods, and use of the alphabet board. She found Barbara to be a strong, courageous, and smart woman.

***14** 95. As Barbara's ability to communicate diminished, Ms. Cameron-Calef occasionally observed with amazement as Barbara recognized and tracked her daughter Carol.

96. However, Ms. Cameron-Calef has not seen Barbara give a sign of recognition to anyone including Carol since June of 2002.

97. Barbara grimaces when Ms. Cameron-Calef washes Barbara's face, or suctions the secretions from Barbara's mouth and tracheostomy..

98. Ms. Cameron-Calef has not observed Maureen's interactions with Barbara.

99. Ms. Cameron-Calef could not participate in the evisceration of Barbara's eye. She found the treatment to be "vile", considered it a "disgrace," and was overcome with "disgust."

100. Ms. Cameron-Calef finds it hard to tell if Barbara is feeling pain. She assumes that she is in pain.

101. Ms. Cameron-Calef finds it hard to treat Barbara as "it breaks her heart," but she would never say that she didn't want to take care of her.

102. Betty Ann Britton has been a nurse at the Hospital for all twenty-five years of her nursing career.

103. Since the year 2000, Ms. Britton has been one of Barbara's primary nurses.

104. She has seen Carol and Maureen take excellent care of Barbara since the beginning of her illness. Ms. Britton testified that Carol and Maureen are "... both dedicated daughters showing up nearly every day to help take care of their mom."

105. When Barbara could communicate with Ms. Britton, much of her communication was through her eyes. Presently, Barbara's right eye is eviscerated and her left eye must remain taped shut a majority of the day.

106. Ms. Britton has been unable to communicate with Barbara since June of 2002. She has not seen Barbara communicate with any individual since June of 2002.

107. Ms. Britton feels it is morally and ethically wrong to continue to treat Barbara unless it was absolutely clear that Barbara wanted the treatment.

108. Wendy Renda has been a nurse at the Hospital for approximately twenty-two years.

109. Ms. Renda has been working with Barbara since 1999 or earlier.

110. During her night-shifts, Ms. Renda sees Maureen visiting Barbara.

111. Ms. Renda has not seen Barbara communicate in the past year. She has not seen Barbara alert to anyone's presence in the past year.

112. Ms. Renda finds treating Barbara in her present situation disconcerting but she is able to continue caring for her.

113. Marjorie O'Leary has cared for Barbara since 1999 or earlier. In 2001, she wrote to the OCC that "when [Barbara] was more able to communicate ... she indicated that she wanted everything done to maintain her; including CPR, antibiotics, and ICU if needed."

114. Ms. O'Leary has not seen Barbara communicate for a "long time."

115. Ms. O'Leary is concerned that Barbara could be in pain all the time. She is saddened by the thought that she could be inflicting more pain on Barbara, but she indicated that she could continue treating her.

Dr. Robert Brown, Jr.

***15** 116. Dr. Robert Brown, Jr. is a neurologist at the Hospital. He is also a professor of neurology at Harvard University's medical school. Dr. Brown is the director of the neuromuscular disease clinic at the Hospital.

117. Dr. Brown first met with Barbara as early as 1995.

118. Through his position at the Hospital, Dr. Brown treats many patients who have ALS. Dr. Brown has not seen another ALS patient whose eye ruptured; furthermore, Dr. Brown reported that Barbara's bone fractures in December of 2003 are not expected side-effects of ALS.

119. Between May 4, 1998 and February 4, 2002, the Radiology Department at the Hospital completed at least fifteen (15) reports on Barbara.

120. The radiology reports indicate that Barbara has suffered two small strokes with no known demonstrable effects arising therefrom.

121. The radiology reports and Dr. Robert Brown's testimony present evidence of a continued thinning of Barbara's brain. Dr. Brown called this thinning of the brain a "normal" process for someone Barbara's age.

122. On February 2, 2004, Dr. Brown performed a neurological evaluation of Barbara in the presence of Carol, Attorney Gary Zalkin, Attorney Robert Hammel, and Attorney Martin O'Connor.

123. As a result of the evaluation, Dr. Brown reported the following:

a. "During this evaluation, Ms. Carol Howe asked several questions of her mother-some with a yes answer and some with a no answer. Carol Howe stated that her mother uses mouth movement to

signal 'yes.' To some of the questions, Ms. Howe responded with repetitive mouth / jaw chewing motion, similar to the motion she demonstrated spontaneously. I was not able to see a reproducible, clear pattern of meaningful, appropriate yes or no answers. I also asked Ms. Howe several questions with yes or no answers and again failed to see a consistent pattern of responses that looked different from the random episodes of chewing motions."

b. "Ms. Howe remains in a tragic state in which she lies with the L eye open appearing alert, the R eye enucleated, completely paralyzed except for recurrent facial movements that have a chewing quality and appear to be spontaneous, and distinct facial grimacing when she is in pain."

c. "Under these circumstances it is difficult to describe her mental state with precision, as she is effectively completely de-efferented. By this I mean that she has lost so much of her voluntary control of motor function that she cannot execute movements when she so desires. Another term sometimes employed to describe this state is "locked-in;" the problem with that term is that it is loosely defined to mean different neurological conditions as used by different neurologists."

d. "In my view, if she is fully conscious, Mrs. Howe is therefore unable to communicate with the outside world. I have not been able to see clear evidence of consistently interpretable communication, although Ms. Carol Howe reports this does occur."

***16** e. "Because she is without control of voluntary movements, and because communication is so tenuous if it occurs at all, it is exceedingly difficult to assess Ms. Howe's level of consciousness. Given her overall neurological exam, and her response to pain, one can argue that Ms. Howe is not unconscious. However, whether she always experiences pain when painful stimuli are present is not clear to me, nor can one determine whether she has experienced some alteration of consciousness or any fundamental change in underlying mental function."

124. During the evaluation, Dr. Brown poked a piece of cotton into Barbara's remaining eye. Barbara did not blink or grimace in response to this action. Dr. Brown reported at trial that either it didn't hurt her or it did hurt her and she couldn't express the pain.

125. Dr. Brown reported that based on the information available to him, he could not determine if Barbara is experiencing pain and not expressing it.

126. Dr. Brown reported that Barbara is conscious but he is unable to determine the extent of her consciousness. Her consciousness may range from muted to normal.

127. Dr. Brown reported that the nursing staff and Barbara's family would be in the best position to determine the extent and nature of Barbara's pain because of the length of time these individuals spend with her.

128. On February 1, 2004, Barbara received oxycodone and acetaminophen. Carol asserts that these medications blunted her mother's ability to respond on February 2, 2004 when Dr. Brown examined her.

129. Dr. Brown does not have any ethical concerns in treating Barbara under her current treatment plan.

Guardian Ad Litem

130. On July 21, 2003, the court (Smoot, J.) assigned Attorney Martin O'Connor to act as a guardian ad litem / next friend for Barbara to investigate and report on the issues raised in the Hospital's complaint.

131. Attorney O'Connor made at least four visits to Barbara's Hospital room. Additionally, in his capacity of guardian ad litem, Attorney O'Connor contacted: Carol, Attorney Gary Zalkin, Betty Ann Britton, Janice Cameron-Calef, Dr. Andrew Billings, Attorney Robert Hammel, and Attorney David Aptaker. Attorney O'Connor visited Barbara in the presence of Carol, and when Carol was absent. Attorney O'Connor did not contact Maureen Howe or Barbara Johnson.

132. Attorney O'Connor observed Dr. Brown poke Barbara in the eye with cotton and this action elicited no response from Barbara.

133. Attorney O'Connor did not find Barbara to be capable of cognitive or intelligent communication.

134. Attorney O'Connor reported that Carol is diligent in caring for Barbara, and that Carol is sincere in her belief that Barbara is able to communicate. Attorney O'Connor reported that any "communication" between Barbara and Carol is rooted in Carol's perceptions, as opposed to the reality of their interactions.

135. Attorney O'Connor recommended that "the Court direct both parties to take all necessary steps on behalf of Mrs. Howe to allow her to disengage from her ventilator."

Financial Considerations for the Howe Family and the Hospital

***17** 136. Carol was last employed in 1990. Thereafter, caring for her mother became a full time job.

137. Carol has not had a source of income since 1990. Carol's past employment includes jobs as a kindergarten teacher, a billing clerk at the Hospital, and an administrative assistant.

138. For a monthly income, Barbara receives: (1) approximately $290.00 each month from the Social Security Administration; (2) approximately $433.65 each month from a widow's allowance from the Boston Police Department; and (3) approximately $488.00 each month from her husband's civil service annuity. These three sources of income result in Barbara receiving approximately $1,211.65 each month. When these monies are received, Carol places the monies into a Fleet Bank joint checking account held in Carol and Barbara's name.

139. On May 7, 2003, Carol withdrew $2,919.25 and $6,420.00 from the Fleet Bank savings account held in Barbara and Carol's name. On this date, $6,420.00 was deposited into a Fleet Bank savings account held in Carol's name only. Carol testified that this transfer of $6,420.00 from Barbara and Carol's savings account to Carol's savings account was a "gift" from Barbara to Carol.

140. On June 5, 2003, Carol withdrew $1,768.06 and $6,420.00 from the Fleet Bank savings account held in Barbara and Carol's name. On this date, $6,420.00 was deposited into a Fleet Bank savings account held in Carol's name only. Carol testified that this transfer of $6,420.00 from Barbara and Carol's savings account to Carol's savings account was a "gift" from Barbara to Carol.

141. Carol has paid Attorney Zalkin approximately $42,000.00 in counsel fees out of Barbara's funds. There was no evidence presented at trial as to the amount that Carol paid to Attorney Blake.

142. There was no evidence presented concerning: how Barbara's medical bills are being paid; what type of insurance coverage Barbara has; or, what costs the Hospital has incurred in maintaining Barbara as a patient.

Factual Conclusions

Communication

Dr. Robert Brown, neurologist and director of the neuromuscular disease clinic at the Hospital, has evaluated Barbara several times since 2001, when the issue of Barbara's ability to communicate arose. During his examinations, he has not observed Barbara communicate in an intelligible or reproducible manner.

Dr. David Caplan, who is a neurologist at the Hospital, has also examined Barbara. When he examined her in 2001, she did not respond in a comprehensible way to any of his requests, one such request was to "close your eyes if you have children."

Four nurses testified at the trial. Each one of them has worked with Barbara over the course of her illness and has witnessed the disintegration of her communication skills. Each one communicated with Barbara when she was clearly able to communicate. Each witnessed Barbara communicate with one or more of her family members. One nurse remembered

an occasion when she was amazed that Barbara recognized and tracked Carol which suggests that family members were more likely to elicit a response from Barbara. None of the nurses, however, have seen Barbara recognize or track anyone, including her family members, since June of 2002. None of the nurses have seen Barbara communicate with anyone, including her family members, since June of 2002.

***18** The court appointed guardian ad litem was not able to elicit any communication from Barbara during his four visits with her.

Notwithstanding the testimony of Carol and Maureen, who are closest to Barbara and who have spent the most time with her, the preponderance of the evidence establishes that Barbara is unable to communicate her thoughts, her feeling, or her wishes to others.

Pain

Barbara shows discomfort and communicates that she is in pain through grimacing. For example, the testimony of many of the witnesses established that if you gently raise Barbara's injured arm, she will grimace in obvious pain and that the grimace is directly related to the act of raising her arm.

The Hospital contends that it is likely that Barbara is also in pain at other times and cannot express her discomfort. When she could communicate, Barbara regularly complained of pain such as headache, stomach pain, neck pain, chest pain, and foot pain. The Hospital asserts that since the causes of these pains, namely her underlying illness and her bedridden state among others, have not diminished, Barbara must still be feeling these pains. This assumption prevails among the treating physicians and nursing staff. Accordingly, the Hospital is critical of Carol's directive to administer pain medication as needed rather than on a continuous basis at set intervals every day.

During his most recent evaluation, Dr. Brown gently stuck a pin in Barbara's finger and there was no response. He also poked a piece of cotton in Barbara's remaining eye and Barbara did not grimace in response. Dr. Brown concluded that either the cotton ball did not hurt Barbara or it did hurt her and she was unable to respond. Dr. Brown could not determine whether Barbara was experiencing pain and not expressing it.

Dr. Brown reported that the nursing staff and Barbara's family would be in the best position to determine the extent and nature of Barbara's pain given the length of time these individuals spend with her.

The nursing staff reasonably assumes Barbara is in pain even when she is not grimacing in pain for the reasons given above. Carol and Maureen spend the most time with Barbara. Maureen, in particular is with her mother four to five hours each day. Their observations are that their mother clearly grimaces in obvious pain whenever she is in moderate to high pain. Their observation of their mother is that if she is not grimacing in pain, she is not in pain.

With respect to the Hospital's criticism of Carol's directive to administer pain medication as needed rather than on a continuous basis at set intervals every day, Carol's response is not unreasonable. In essence, she says that Barbara's quality of life is centered on her consciousness. The evidence at trial established that certain pain killers alter and numb the consciousness. In Carol's view, continuous numbing of Barbara's consciousness eliminates Barbara's reason for living. Accordingly, it is her desire to meet her mother's needs concerning pain without a continual numbing of her consciousness.

***19** The preponderance of the evidence establishes that Barbara communicates when she is experiencing moderate or greater pain through a facial grimace indicating obvious pain. It is simply not clear whether Barbara feels the kind of pain that she once routinely complained of.

Consciousness

Barbara is not unconscious. The level of her consciousness falls somewhere on a spectrum, with muted at one end and normal at the other end. She may be fully conscious. The Hospital concedes that what Barbara sees, hears or feels is not known.

Legal Conclusions and Analysis

"The proxy statute ... ensures that a patient's right of autonomy and self-determination with regard to medical care is respected, even after she loses the capacity to make and

communicate her wishes." *Cohen v. Bolduc*, 435 Mass. 608, 618, 760 N.E.2d 714 (2002)

In accordance with Barbara's health care proxy, Carol has the authority to make any and all health care decisions on Barbara's behalf that Barbara could make, including decisions about life-sustaining treatment. See G.L. c. 201D, § 5. Barbara placed no limitations on Carol's authority.

After consultation with health care providers, and after full consideration of acceptable medical alternatives regarding diagnosis, prognosis, treatments and their side effects, Carol must make health care decisions in accordance with Carol's assessment of Barbara's wishes, religious beliefs, and moral beliefs. If Barbara's wishes are unknown, then Carol must make health care decisions in accordance with Carol's assessment of Barbara's best interests. See *id.*

The Hospital must comply with health care decisions made by Carol under a health care proxy to the same extent as if such decisions have been made by Barbara, subject to any limitations in the health care proxy (there are none), or in any specific court order.

The Hospital's complaint is brought pursuant to G.L. c. 201D § 17. This statute permits the Hospital to commence a court action to override Carol's decision about health care treatment on several grounds, of which only two are applicable here:

(a) the decision was made in bad faith; or

(b) the decision has not been made in accordance with the requirement that Carol first consult with health care providers, consider acceptable medical alternatives regarding diagnosis, prognosis, treatments, and their side effects, and then make health care decisions in accordance with Carol's assessment of Barbara's wishes, religious beliefs, and moral beliefs provided that if Barbara's wishes are unknown, then Carol must make health care decisions in accordance with Carol's assessment of Barbara's best interests.

There is no disagreement that Carol has, in fulfilling her obligations as the health care agent for her mother, consulted with health care providers and considered acceptable medical alternatives regarding diagnosis, prognosis, treatments, and their side effects.

There is no disagreement that Carol has made health care decisions in accordance with *Carol's assessment* of Barbara's wishes, religious beliefs, and moral beliefs.

***20** There is significant disagreement over whether Carol's assessment of Barbara's wishes is an accurate assessment. Indeed, the Hospital contends that Carol's assessment has run contrary to Barbara's wishes and Barbara's well-being.

In 2001, the OCC accurately described CPR as "a brutal therapy which causes pain, may fracture ribs, and may lacerate internal organs" and recommended that Barbara "be protected from chest compressions and electrical counter shock on the grounds that these treatments are both inappropriate and harmful." Carol rejected this recommendation in 2001 and filed litigation to prevent its implementation. At that time, Carol's position was supported by a letter from Nurse O'Leary which said that "when [Barbara] was more able to communicate ... she indicated that she wanted everything done to maintain her; including CPR, antibiotics, and ICU if needed."

In his notes and at trial, Dr. Billings reported that before 1997, Barbara made it clear to her doctors and her family that if the time came when she would not be able to live without a permanent ventilator, she was to be allowed to die. Although Barbara changed her mind, her previous position is significant because it suggests that refusing life support was and remains an option for her.

When faced with the decision, Barbara did choose to be placed on a permanent ventilator by tracheostomy, which is a decision rarely made by ALS patients. Later, in August 2000, Dr. Putnam had a discussion with Barbara and Carol about Barbara's end of life care during which Barbara told Dr. Putnam that she wanted aggressive treatment to continue.

There is understandable frustration among the hospital staff and others with Carol's decisions and the reasons she gives to justify them. For example, Carol points to her mother's Roman Catholic religious beliefs as one basis for her decisions concerning continued aggressive treatment. However, the Hospital has explained to her and Carol acknowledged at trial that withdrawing aggressive treatment (i.e.ventilator) from her mother is not inconsistent with the teachings of the Roman Catholic faith.

Like the nursing staff and other hospital personnel, Maureen was also upset by Carol's decision to have Barbara's right eye eviscerated rather than letting Barbara die at that time. Currently, Maureen fully supports continued treatment for her mother.

In December of 2003, the Hospital discovered that Barbara had broken ribs and a broken humerus bone. Carol did not decide to authorize a DNR order until the trial in February and did not have the order placed on Barbara's medical chart until late February. There can be no disagreement over the necessity for the DNR order, and it should have been entered without hesitation.

There are inter-personal dynamics at play in this case that merit discussion because they be may be impacting Carol's decision making. There is no relationship between Carol and Dr. Billings. It is clear from her testimony that she believes that his conclusion in April of 2001 that life sustaining treatment should be withdrawn was wrong. At that time, he described continued treatment as "more like torture than respectful medical care." Carol points out in her written post trial submissions that this was more than a year before June of 2002, the time at which other hospital witnesses mark as the end of two way communication. There is a serious question about whether Carol's anger over this battle is impacting her decisions concerning her mother.

***21** Nevertheless, the evidence is insufficient to warrant court usurpation of Carol's role as her mother's health care agent. The Supreme Judicial Court has said that "[b]y executing a health care proxy, a principal determines in advance that a person of her choice (rather than a judge) will make medical decisions on her behalf. *Cohen,* 435 Mass. at 616, 760 N.E.2d 714.

Up to this point, Carol has tried to adhere to her assessment of her mother's wishes. She has not acted in bad faith. The financial issues raised at trial do not cast a shadow on Carol's motivation. The money that she has spent on attorney fees to advocate for her mother's interests as she understands them is substantial, and eliminates any questions which could be raised concerning her motivation.

However, in order to prevent any future concerns regarding the use of her mother's funds, Carol, or another family member, shall file a petition in this court to become conservator of Barbara's assets. This ensures court oversight of Barbara's estate and a proper accounting of her money. The petition shall be filed within thirty days of the entry of this judgment.

There was no evidence presented at trial to suggest that the Hospital's motivation in this case has been based on anything other than compassion for its patient.

Although Barbara knew she would get progressively sicker, she could not have considered all of the variables in her future. She appointed Carol to speak for her knowing that she had an uncertain future. Up to now, Carol has acted based on Carol's assessment of Barbara's wishes. Barbara could not have foreseen that, in addition to the suffering she would endure as ALS took its course, she would also endure broken bones, the rupture and loss of her right eye, and severe damage to her left eye. It is clear that Barbara's wishes are no longer ascertainable through ambiguous statements and ill-defined directives of years past. Accordingly, as the health care proxy statute requires, henceforth, *Carol shall act based on Carol's assessment of Barbara's best interests.*

In this regard, this court shall not confine Carol, on an issue of life and death, to her one word answer given at trial to a compound question from this judge, which indicated that her assessment of her mother's best interests is that life sustaining treatment should be stopped. [2]

In accordance with the health care proxy statute and this court's order, Carol is to refocus her assessment from Barbara's wishes to Barbara's best interests. See G.L. c. 201D, § 5.

The Hospital's Request Made Pursuant to G.L. c. 201D, § 15

There was no evidence produced by the Hospital that pursuant to G.L. c. 201D, § 15, it informed either Barbara or Carol prior to Barbara's admission as to what its policy was for treating patients in her present condition. Barbara entered the Hospital as an ALS patient attached to mechanical ventilation and, while certain aspects of her condition were not expected, the course of ALS is such that it was foreseeable by the Hospital that she would eventually be conscious but de-efferented and

totally dependent on the Hospital staff and her family to meet her needs.

***22** Carol's decision concerning CPR is now in conformance with the Hospital's position.

The transfer of Barbara's care to a physician other than Dr. Billings is not contested by Carol.

All Citations

Not Reported in N.E.2d, 2004 WL 1446057

Footnotes

1 Throughout the remainder of this document, Barbara Howe will be referred to as “Barbara,” Carol Howe will be referred to as “Carol,” and Maureen Howe will be referred to as “Maureen.” This stylistic choice is for convenience and readability, and is not a sign of disrespect to the parties involved in this litigation.

2 Judge: So, at this point, you believe it is in your mother's best interests, stepping out of your health proxy role, to terminate treatment, but because you believe it is her desire, her wish, to go forward, and stepping back into your health proxy role, you want to honor that desire and wish.
Carol: Exactly.