These minutes contain materials which paraphrase and/or summarize statements made during this session. Only text enclosed in quotation marks

report a speaker's exact words. For complete contents of the proceedings, please refer to the tapes.

HOUSE COMMITTEE ON JUDICIARY FAMILY JUSTICE

May 13, 1991Hearing Room 357 3:00 p.m.Tapes 121 - 125

MEMBERS PRESENT:Rep. Kelly Clark, Chair Rep. Judy Bauman Rep. Marie Bell Rep. Jim Edmunson Rep. Kevin Mannix Rep. Tom Mason Rep. Del Parks Rep. Ron Sunseri

MEMBERS EXCUSED:

STAFF PRESENT: Holly Robinson, Committee Counsel Kathy Neely, Committee Assistant

MEASURES CONSIDERED: SB 494 PH (Health Care)

These minutes contain materials which paraphrase and/or summarize statements made during this session. Only text enclosed in quotation marks report a speaker's exact words. For complete contents of the proceedings, please refer to the tapes.

TAPE 121, SIDE A

003 CHAIR CLARK: Calls the meeting to order at 3:15 p.m.

SB 494 - PUBLIC HEARING Witnesses: Senator Bob Shoemaker, District 3 Bob Smith, AARP Joan Mahler, Sisters of Providence Hospital Dr. Susan Toll, Oregon Health Sciences University Janet Hamilton Maureen Lore Dr. Tina Kitchens, Mental Health & Developmental Disabilities Brian DeLashmutt, Oregon Nurses Association Ian Timms, Oregon Health Decisions Karen Creason, Oregon Association of Hospitals Rollie Smith, Citizen Dr. Eric Chevlen Lyndia Harrington Davit Mohler Robert Castagna, Oregon Catholic Conference Ted Falk Shirley Barnard Jane Marnchianes

019 HOLLY ROBINSON, COMMITTEE COUNSEL: Defers to Senator Shoemaker.

022 SENATOR BOB SHOEMAKER, DISTRICT 3: SB 494 had extended hearings in the Senate Committee. *Deals with handling end of life decisions to preserve the dignity of the patient and to do what is ethically appropriate. *This is not unlike estate planning. *Comments on current laws: The Directive to Physicians statute, or the living will, authorizes a competent person to sign a document indicating desire for life sustaining procedures if terminal. Not widely used because it is complicated to execute. The other law is the Power of Attorney for Health Care which allows individuals to select a trusted person to make health care decisions including decisions to withhold life sustaining procedure. These two do not "mesh" very well. *SB 494 brings these two laws together into a single law and improves the forms that are in the Living will and power of attorney statute. *This allows for a power of attorney and a directive to physician. The directive will serve as a

set of instructions. Power of attorney is a delegation of authority. *"Alzheimer" provision is on page 13, line 9 of the bill. This contains a set of instructions in the "new form of directive". Comments on Janet Atkin's case regarding assisted suicide and this provision.

152 CHAIR CLARK: Asks for elaboration on definition of life sustaining procedure as compared to 1989 session bill SB 523.

159 SENATOR BOB SHOEMAKER: Definition of life sustaining procedures does not include feeding tubes. Separated that into "artificial nutrition and hydration". *Terminal is defined "when death is imminent irrespective of treatment".

186 CHAIR CLARK: Asks about the relationship between the phrase "fatal disease" and "terminal illness".

191 SHOEMAKER: Fatal disease is not defined separately. Means a disease that will cause death. *These provisions allow the person some "autonomy" while they can still make decisions. *Cruzan case impacts on Oregon. Discusses the case about a young woman in a terrible auto accident resulting in a permanent vegetative state for 8 years. Guardians petitioned court to take her off tubes. In the appeal, the Missouri Supreme Court reversed the trial court's ruling and imposed a standard that in order to allow removal of tubes there needs to be clear and convincing evidence shown that the patient would not have wanted to stay on the feeding tubes. The question to the US Supreme court was could Missouri impose such a limitation on her right to die. They held that she did have a right to die and that each state could decide the limits set on the exercise of that right. Upheld the Missouri Supreme Court. *This relates to Oregon because of the current presumption that everyone would consent to tubes absent a clear and specific statement to the contrary.

245 CHAIR CLARK: Asks about the Missouri standard.

SHOEMAKER: That standard is clear and convincing evidence of desire to have or not have feeding tubes.

CHAIR CLARK: What is current law in Oregon, SB 523, would satisfy clear and convincing but not go the other way.

SHOEMAKER: Believes Oregon's standard of clear and specific statement goes further. *SB 494 gets rid of the presumption but does not impose the "opposite presumption", just no presumption. It sets up a procedure for withdrawal of feeding tubes. *Under SB 494, the guardian would be the one to decide what was appropriate with regard to the feeding tubes. *Need to confirm "permanently unconscious" by a neurological specialist.

289 REP. MASON: That is a concern regarding SB 494. *It would take a neurology specialist to do this. Which in the long run could create an "expertise" and an area of medicine created for this. This could develop into a medical specialty over the years.

SHOEMAKER: This would be a pretty narrow specialty with not much call for it.

318 REP. MASON: Would this group "evolve into a profession expert witness group"?

321 SHOEMAKER: If decision by guardian to take a permanently

unconscious person off tubes were referred to a court for review, which is provided for under the bill, expect the specialties that made the determination would be called as a witness, not necessarily an expert one but factual.

REP. MASON: Under Section 21, without the health care power of attorney, the same determination needs to be made. Before a petition were brought to the court about a "permanently unconscious" patient, the guardian would want to have a professional witness examine the patient.

SHOEMAKER: Yes. Medical specialists are bound by ethical rules and would not suspect them of "selling their services to the highest bidder" to give them the opinion they want.

357 REP. MASON: Correlates the "shopping for witness" example with that of attorneys and being expert in their field. *Is there anything in the ethical considerations of the law stating when someone comes to hire an attorney to bring a legal action, that the lawyer taking the case must be examined regarding this being the "right thing to do"?

388 SHOEMAKER: Court is there for that purpose, to hear both sides.

396 REP. MASON: Point is the lawyer hired has the professional duty to obtain a successful petition. The lawyer would try to find the best witness.

SHOEMAKER: There is no immunity from a doctor's liability if they give a fraudulent diagnosis.

REP. MASON: In a criminal defense, the lawyer would try to find the best expert witness possible.

TAPE 122, SIDE A

SHOEMAKER: Concludes testimony.

016 CHAIR CLARK: Asks the Senator to come back to rebut testimony and answer questions.

025 REP. EDMUNSON: This is not limiting the scope of the health problem the patient suffers.

SHOEMAKER: The intent was for any and all health problems.

REP. EDMUNSON: This is talking about "diseases, injuries, or conditions which affect health".

037 REP. PARKS: Asks about Section 21.

SHOEMAKER: Section 21 is existing law that allows a person who is terminal and permanently unconscious to have life sustaining procedures, not including feeding tubes, removed.

REP. PARKS: Who would advocate in opposition of a person seeking the appointment of a guardian?

053 SHOEMAKER: Probably another member of the family. A judge will normally conduct investigation on the petition for guardian. The court actually makes the appointment.

063 REP. MASON: There is someone bringing a petition with a hired attorney and an expert witness. Is there an automatic appointment of a guardian ad litem?

SHOEMAKER: It would have to be sought.

REP. MASON: What if no one does and there is a proceeding. The patient will not have an advocate. Is there anything in the bill that compels a court to appoint a guardian without someone seeking it?

SHOEMAKER: No. If a guardian is not appointed, then no decision is made.

REP. MASON: Compares this situation to a person in a death penalty situation that will have a lot of rights granted. There is nothing as far as rights for the patient.

079 SHOEMAKER: Expects a member of the family would seek the appointment of a guardian.

085 REP. MASON: Nothing in the bill compels that.

CHAIR CLARK: This is what happens currently.

SHOEMAKER: Exactly. It is left to the family to petition.

087 REP. MANNIX: Under current law a physician can discuss options with the family. *If there were enacted, would it create a situation where people must look at the legalities of the process when they did not have to before?

102 SHOEMAKER: Does not believe that will happen.

114 CHAIR CLARK: Will invite back at conclusion of public hearing.

118 BOB SMITH, AMERICAN ASSOCIATION OF RETIRED PERSONS, COUNCIL OF SENIOR CITIZEN: (EXHIBIT A and B) Supports SB 494, it will help guarantee seniors the right to make own medical decisions. *Present Oregon law takes the position that if a person is in a terminal condition, their right to medical decision is severely curtailed. *Power Attorney for Health Care is popular with senior citizen. Gives ability to appoint someone they trust to make the health care decision when the senior is not able to and it provides a means whereby the attorney in fact knows the wishes.

165 REP. MANNIX: Shouldn't the Power of Attorney for Health Care law be left alone to see how it works?

SMITH: It is not as encompassing as seniors would like: *Must have someone who is trusted, usually a spouse or family member. Some have none that can be used in this capacity. *Another disadvantage is that some don't want to give a "loved one" the "burden" of making these decisions. Would prefer a comprehensive living will to allow the senior to make their wishes known.

186 REP. MANNIX: Should this apply to people other than those headed "towards death", the non- terminally ill situation?

SMITH: Yes. A lot of people, in nursing homes, who are "permanently unconscious" are being kept alive through artificial feedings with death

the clear end. *SB 494 would allow people to be relieved about these sorts of things. *Believes younger people are also concerned with permanent unconsciousness. *SB 494 allows the person to state what they want and what they don't want. *The current directive is restrictive. The new form will be more flexible.

231 CHAIR CLARK: Have received a tremendous amount of mail from United Seniors and AARP. Comments on committees feelings on this subject.

250 MAUREEN LORE, CITIZEN: Comments on personal experience of son after a drowning accident. He was in a coma for 12 1/2 years. He was on a feeding tube and was in a permanent vegetative state. *Explains a "permanent vegetative state" as never having any voluntary movements, everything is done for them, being feed, and being turned every 2 hours. *Time to allow a person to die with dignity. Hopes SB 494 will end the tragedy of this.

310 JOAN MAHLER, SISTERS OF PROVIDENCE HOSPITAL: (EXHIBIT C) Supports SB 494 in its present form. *Sisters of Providence are strongly opposed to euthanasia including physician assisted suicide. Opposes SB 1141 which will legalize aid in dying from physicians. *Support SB 494 because it consolidates and simplifies the existent Oregon statutes on "directives to physicians" and "power of attorney for health care".

362 REP. MASON: Perplexed regarding the Sisters of Providence being opposed to euthanasia including physician assisted suicide. *Discusses ways to "kill someone". Correlates killing someone with starvation and removal of feeding tubes. *Asks for distinction between affirmative act of physician assisted suicide and the affirmative act of starving someone to death.

MAHLER: Physician assisted suicide is active euthanasia in which an action is taken to cause death, one which nature would not take on that person's life. *Removal of feeding tubes is not starving someone to death because they are an artificial means of feeding.

REP. MASON: Bring someone a tray with food and water is not starvation where the person can physically take and eat the food but if the person cannot physical feed themselves, is that artificial or natural?

TAPE 121, SIDE B

012 MAHLER: It is somewhat artificial.

REP. MASON: Discusses the difference between feeding tubes, being able to eat on their own and having to be fed with regard to "starvation".

CHAIR CLARK: Asks Senator Shoemaker to discuss this differentiation.

SHOEMAKER: Discussing the difference between SB 494 which allows for the removal of feeding tubes from the permanently unconscious patient and SB 1141 which is physician assisted suicide by lethal injection. *The problem with the physician assisted suicide is that it makes death too easy. *Withdrawing a feeding tube is not easy to do. The person is "not really alive in any real sense". It is not subject to the kind of abuse the assisted suicide could have. *Comments on the Catholic Church's position on this subject. *Discusses the "dying process" where the body does not want food any more.

083 JANET HAMILTON, LEAD NURSING SUPERVISOR AND CO-CHAIR OF MCKENZIE-

WILLAMETTE HOSPITAL: Testifies in favor of SB 494. *SB 494 consolidates power of attorney for health care and the directive to physicians. It will reduce the confusion of dealing with these provisions. It will remove the presumptive clause which mandates application of artificially administered fluids and food unless the person has specifically stated they do not want them. *The presumptive clause in current law has removed the autonomy of patient's family to make the medical decision on whether or not to have feeding tubes. *Urges to have the medical decision be given back to the patient, families, and physicians.

138 BRIAN DELASHMUTT, OREGON NURSES ASSOCIATION: Reiterates what Janet Hamilton stated. *Nurses are the closest health care provider to the families and the patients and witness the pain and suffering they go through in making the decision. *Discusses personal feelings about the bill regarding illness of father and his passing away. *Comments on the decision process the family went through on whether life support should be withheld or not. *The new form in SB 494 specifically spells out what the patient wants and does not want and will be very valuable to the family at the time of decision making in life sustaining procedures.

209 DR. SUSAN TOLLE, OREGON HEALTH SCIENCES UNIVERSITY: (EXHIBIT D) *Discusses the artificial nutrition and hydration by tube. There are three ways: intravenous which is not an issue of the bill. *Explains the other methods: short term method of tubal feeding through a tube from the nose to the stomach; and long term feeding, over 4 weeks, would be with the gastrostomy.

261 REP. MASON: Fails to find any mention of these forms in the bill. Asks how testimony is relevant to the bill.

268 CHAIR CLARK: Asks to explain the connection between the bill and testimony.

TOLLE: These are the only ways to administer tube feeding, the subject that has been discussed in the hearing. *This answers question on how tube feeding is different from use of a cup, spoon or bottle.

288 REP. MANNIX: There is a description in the written testimony on page 3.

300 CHAIR CLARK: There is no time for the display.

306 TOLLE: The tube and the goal in medical treatment is to sustain life and reduce suffering. There are medical complications with this treatment. *Comments on concerns expressed by patients regarding being sustained or not.

352 REP. MANNIX: What the committee has to deal with is the additional opportunities to intervene with life regarding the medical advancements made. Have to make policy decisions regarding when a person has the right to determine that no further life support methods need to be used.

TOLLE: Discusses known facts about persistent vegetative state regarding neural cells dying. *It usually takes about 3 months to determine where the doctors are going with a patient. There was not the technology years ago to allow people to be in the vegetative state.

393 REP. MANNIX: Comments on the case in Florida regarding the person who came out of a coma after 8 years. Was that a persistent vegetative state?

TOLLE: That person was in a persistent-like vegetative state. "Like" is very important medically because they were not in a persistent-like vegetative state.

417 REP. MASON: Asks about the Nancy Cruzan case regarding voluntary functions.

TOLLE: She had classical symptoms of persistent vegetative state such as roving eye movement and wake sleep cycle but had no meaningful interaction with environment. *Discusses misunderstanding roving eye movement as being more meaningful under careful observation.

TAPE 122, SIDE B

024 REP. MASON: How many days did Nancy Cruzan survive after feeding was withdrawn? Would the process of dying the way she did, for an alert person, be pleasant? *Asks for discussion regarding hypothetical on person bringing another person food and starving them.

030 TOLLE: Approximately 10. Discusses the process of dying from the removal of a feeding tube. *The pleasantness of dying depends on the circumstances of the patient. *Terminal patients with cancer are more uncomfortable with the hydration because the lungs are more full of fluid and breathing is a struggle. *Regarding the hypothetical, the key question is if the doctors are withdrawing a medical treatment which the patient does not want and does not meet medical needs. *Starvation would imply suffering. *Would use "negative nitrogen balance" to describe what happened to Nancy Cruzan.

058 CHAIR CLARK: Recesses at 4:45 p.m. Convenes at 6:07 p.m.

083 TINA KITCHENS, MD, MENTAL HEALTH AND DEVELOPMENT DISABILITIES HUMAN RESOURCES DIVISION: (EXHIBIT E) The division was originally opposed to the bill because there were too many loop holes. After working with it, it is currently stronger than the current law on the books. *It is stronger in protection of people's rights, insures that people with developmental disabilities do not have feeding tubes or life support systems removed in a manner detrimental to their desires. Position of HRD: *Everyone should have the right to make end of life decisions; individuals with developmental disabilities need safeguards so that their rights are not trampled on. *Under current law the definition of terminal is too broad. *Discusses the hypothetical that Rep. Mason has posed on other witnesses: both examples will die by the same psychological mechaniSMbut there is a difference in choice. A choice to refuse the treatment. *SB 494 Gives doctors better ability to make life support decisions and protects patients with developmental disabilities.

177 REP. SUNSERI: How can people conclusively know what an unconscious person wants or not?

181 KITCHENS: You can't. This bill allows the chance to make a choice before they're in the unconscious state and allows for a guardian. Another safeguard built in is the ability of others to take the determination to court.

194 CHAIR CLARK: Asks who Dr. Kitchens works for.

196 KITCHENS: Works for the Office of Developmental Disabilities Services under the Mental Health and Developmental Disabilities

Division, part of the Department of Human Resources.

198 CHAIR CLARK: Then is the "current administration supporting SB 494"?

202 KITCHENS: The Division is supporting SB 494 and whether it has been cleared with the Dept. of Human Resources, am not aware.

204 CHAIR CLARK: The Dept. is supporting SB 494 on its own?

205 KITCHENS: The Division is supporting.

208 CHAIR CLARK: The Division reports to the Department of Human Resources which reports to the Governor. Does the Governor support SB 494?

211 KITCHENS: Does not know.

215 CHAIR CLARK: Frustrated because this committee is hearing from different agencies in the administration all the time but cannot find out "on who's authority they are speaking". Believes these divisions and department are held accountable to the Governor. The Chair of this Subcommittee would like to know if the Governor of the State of Oregon support SB 494 or not. Would like an answer to that question.

223 KITCHENS: We can ask.

224 REP. MASON: Asks witness if she would like to "recant the position that the Division supports the bill?"

229 KITCHENS: The Division believes that all individuals, including those with developmental disabilities, have the right to make end-of-life decisions; we believe this bill is the proper mechaniSMfor that.

232 REP. MASON and KITCHENS again discuss who is speaking for whom. REP. MASON asks again "Who is we?" KITCHENS responds that testimony is signed by Dr. Lippencott who is the administrator for Mental Health and Developmental Disabilities Services Division. Lippencott is appointed by the Governor. Lippencott's superior supports this bill. No written verification that he approves of this testimony.

266 CHAIR CLARK: Assures that questioning not directed personally at Dr. Kitchens. The frustration comes from indirect testimony. Need guidance, definite yes/no answer from the Governor.

277 REP. BAUMAN: Appreciates informative testimony. Division has come out with a real position. Confusion by committee's position. What's the purpose of browbeating witness about her representation?

295 REP. BELL: Concurs with Rep. Bauman. We're making a judgement call; doesn't make any difference how Governor feels about bill but it makes a big difference how professionals deal with developmental disability patients--they're giving their professional opinion.

305 CHAIR CLARK: The chair is entitled to know whether Governor will sign legislation once it makes it to the floor.

314 IAN TIMMS, OREGON HEALTH DECISIONS: (exhibit F and G). One of our missions is to support the autonomy and dignity of our patients; inform people of their options. Support SB 494 and provisions--consider it

an improvement on current law.

378 REP. MASON: Wants clarification of what Timms considers protection in the bill. Is the protection listed under Section 12?

391 TIMMS: Replies that he is not an attorney, can't speak with authority on how protections would play out.

397 REP. MASON and TIMMS continue discussing aspect of protections stated in the bill. TIMMS states that effort is required for getting guardian appointed and explains that the purpose of the bill is for people who are not attorneys to have a process to appoint someone to speak for them or make a directive to a physician. MASON argues that Section 21 does not have provision for permanently unconscious with respect to guardianship authority. Why wouldn't you want an attorney to represent you if you were permanently unconscious? TIMMS states that permanently unconscious patients would not care and stresses that the bill's purpose is to prevent these cases from getting hung up in court.

TAPE 123, SIDE A

003 REP. MASON and TIMMS continue discussing permanently unconscious patients' rights with respect to SB 494.

052 REP. PARKS: The answer might be that the courts recognize the right to refuse an attorney in any one of those situations. Is that the point of this bill?

062 TIMMS: Point is for people to be able to control their own health care. Issue arises when they cannot speak for themselves.

078 LYNDIA HARRINGTON, EXECUTIVE DIRECTOR, OREGON RIGHT TO LIFE: Introduces Dr. Eric Chevlen, 12 years of experience with oncology medicine (cancer medicine), is Board Certified. Expresses serious concerns with SB 494. Oppose the non-voluntary withdrawal of hydration and nutrition with comatose and permanently vegetative (PVS) patients in Section 21.

095 DR. ERIC CHEVLEN: (EXHIBIT H) Gives personal background--takes care of dying daily. Concerned that patients' rights to decline therapy be secured and that no one should purposely be put to death by withdrawal of sustenance without explicit consent. Balance is difficult. Appointing an agent (guardian) is important but it is equally important to support the principal that person may not be killed by whatever means. *Important to distinguish difference between sustenance and medical care. Sustenance is universally necessary for life, nobody lives without it. Medical care can be done without. No particular medical care that all humans need but all humans need sustenance. Withdrawal of medical care does not automatically mean death but it does with withdrawing sustenance. *Patients should be able to refuse medical care at any time for any reason. A person may refuse sustenance but must be explicitly refused. *Refusal of sustenance is suicide--can only be done for yourself, cannot be done by agent--if so, considered homicide. SB 494 must make distinction perfectly clear the highest evidentiary standards. *Section 25 may apply to medical care but not sustenance.

Cites faults with SB 494, even in what proponents want to achieve. For example, Nancy Cruzan would not be covered by this bill because she was not terminally ill.

197 CHAIR CLARK and CHEVLEN clarify CHEVLEN's position--not that a person would never be able to say they wanted nutrition and hydration withdrawn. It is a patient's right to refuse with specific instructions. It is wise to have safeguard and safeguard is lost with Section 21 of SB 494.

215 CHEVLEN: The reason he opposes non-voluntary removal of sustenance is because it's painful. Assumption made that comatose person doesn't care but they are able to experience thirst--a suffering happens that cannot be measured.

228 CHAIR CLARK: Dr. Tolle said that you would keep some sort of moisture/comfort assistance on the tongue, which is different from artificial hydration?

234 CHEVLEN: Yes. Two different situations: (1) terminally ill patient--many argue continued nutrition/hydration is burdensome to the patient. (2) permanently disabled patients who are no longer able to swallow--the potential victims of this bill. Suffering for them not diminished significantly by putting wet sponge to the lips. We shouldn't presume that people want that.

255 REP. BAUMAN and CHEVLEN briefly discuss CHEVLEN's background and experience with comatose patients. BAUMAN questions CHEVLEN on his assumptions of their preferences and frustrations.

284 CHEVLEN: "I'm not sure that they can be that alert to know frustration. That assumes a certain level of alertness."

285 REP. BAUMAN: "But aren't you assuming that they have a level of alertness in your assumption?"

288 CHEVLEN: "No. When I speak to comatose patients, there are two reasons why I do so. One is, some patients who have recovered from coma tell me they remember things that were said to them--"

292 REP. BAUMAN: "That's not my question. My point is that you are making an assumption. The bill makes an assumption. The bill assumes that people want to make choices before the become comatose, that will apply to your decisions about them as their treating physician after they become comatose."

299 REP. BAUMAN and CHEVLEN continue, CHEVLEN saying he supports that part of the bill. Basis for assumptions are experimental data. CHEVLEN explains that data supports that patients lose ability to localize pain but do not lose ability to experience it.

351 REP. SUNSERI: When people are allowed continued nourishment and lie for years, what do they normally die from?

356 CHEVLEN: Common cause of death is pneumonia.

364 ROBERT CASTAGNA, GENERAL COUNSEL, EXECUTIVE DIRECTOR, OREGON CATHOLIC CONFERENCE: (EXHIBIT I) The Catholic Church has no objection to people being able to declare their health care preferences in a form in advance. Their issue is that they would prefer careful amendments to existing statutory law rather than repealing everything there and writing an entirely new law.

414 CHAIR CLARK: Asks for clarification of Castagna's representation of the Oregon Catholic Conference.

430 CASTAGNA: Explains that he represents the Archdiocese of Portland and the diocese of Baker, in service to the Catholic population of Oregon (300,000). He is on the Board and the Bishops reviewed the bill. He continues with the issue of artificially administered nutrition and hydration. Bishops of different states have taken different positions.

TAPE 124, SIDE A

018 CASTAGNA: Continues. We are willing to address the persistent vegetative state and the irreversible comatose state in terms of withholding or withdrawing artificial nutrition and hydration.

034 REP. EDMUNSON: Senator Shoemaker referred to position; are you in agreement with that position that was taken.

038 CASTAGNA: *Board is in agreement--to have legislation address this. Position of the board is: *To suggest truth-and-law approach. Terms on forms are confusing as to context. When forms are printed, the statutes should accompany the printed form. He continued to address specific comments on SB 494: -Board objects to the language in SB 494 that creates a 4th legal person--the health care representative, appointed to the court to make health care decisions--not subject to judicial oversight and not regulated by statutory law.

097 REP. MASON: The bill is not written very well, especially Section 12 and 21. It makes no reference to how one becomes a health care representative. Assuming that you still have to go to court.

116 CASTAGNA: Have to go to court to be appointed. But if it says "shall be the patient's guardian," the guardian statutes are being invoked. Because this says "health care representative," this person may be literally that 4th legal person, not subject to the guardianship laws, attorney-in-fact laws or the conservative laws.

122 REP. MASON: These are old terms. Under this bill, they may not necessarily have to have the patient's best interest. Is there any language that addresses this?

132 CASTAGNA: Definitions are intricate and weaved. Definition of "principal" on p. 2, line 34, is a person of any age who has a health care representative. The court can appoint the representative who may not be the guardian, that patient then becomes the principal which, throughout the bill applies to that person who may not have ever filled out a power of attorney for health care.

145 REP. MASON: Under SB 494 then who is representing the interests of the patient?

150 CASTAGNA: The first person in priority may be named. If the attending physician is named as health care representative, there may be conflict of interests not covered judicially.

162 REP. MASON: Is there any guidance to the courts under SB 494 regarding economic interests?

168 CASTAGNA: Looking at Section 10. *Basically looking at continuing/discontinuing the life support. *There is potential conflict

of interest and there is no judicial oversight.

180 CHAIR CLARK: Could we take the language "or other person appointed by the courts" out?

181 CASTAGNA: I think we should leave it as a guardian. Highlighting problems with bill: *Page 2, points out in Subsection 10, "health care provider" definition is expansion from existing statutory provisions. With the addition of "and includes a health care facility," this becomes critical when getting into the conscience clause in Section 20. *Section 4, line 15, expansion to non-residents of the state being able to fill out the forms. This is an expansion from existing law. Has concerns over merging of SB 494 with Hemlock Society's additions in SB 1141.

218 CHAIR CLARK: Chair shares concern over SB 1141 but wants to keep discussion solely on SB 494 .

220 REP. MASON: Is there anything keeping Hemlock Society from getting their legislation into SB 494 ?

225 CASTAGNA: We don't want Oregon to become a "death haven". He continues on. *Wants to look at creating one form instead of two forms for people to express their wishes. *Needs to be disclaimer on the forms that says that you do not have to fill out the form if you don't want to.

264 CHAIR CLARK: Would patient run risk of not being admitted to a hospital if they had not filled out this form.

268 CASTAGNA: May not be admissions problem but there may be a problem. Continues on with proposed changes for SB 494 (See also EXHIBIT I): *If Hemlock Society files initiative to amend existing law to permit a lethal injection as part of one of these forms, Catholic hospitals may have problems of conscience with people who check that off. Doctors too may have ethical qualms. *Provision in Section 20, page 14, Subsection 2D. If there is no health care representative for incapable patient and instructions not in dispute, health care provider shall make reasonable effort to locate different health care provider and authorize transfer of patient to that provider. Suggest deletion of Subsection 2D. *We do want presumptive language to remain.

431 CHAIR CLARK: So you feel that existing law could be approved upon and amended without starting all over again.

435 CASTAGNA: Yes. That would be our preference.

TAPE 123, SIDE B

012 TED FALK, AN AUTHOR OF SB 494: (EXHIBIT J) Explains that the current Oregon forms are confusing.

046 REP. MASON: Argues that people out there are making life and death decisions and are confused. Suggests considering a repeal.

062 CHAIR CLARK: What would happen if there were no law on the books under the current situations covered by SB 523?

066 FALK: Prior to enactment of SB 523, every Oregonian had the Common Law right to execute power of attorney. The only difficulty with Common Law is that no one knew what power was and health care providers might

not be willing to act on it. Need statute for power of attorney to survive disability in Oregon.

074 REP. MASON: Asks about constitutional rights, Section 21 provisions.

083 FALK: The bill is confusing on that score. Section 21 is existing law.

087 CHAIR CLARK: Would like Mr. Falk to walk through comments.

091 FALK: Comments on written testimony. *SB 494 has substantial continuities with existing Oregon law. Many provisions debated today are provisions of current Oregon law. Agrees that this should be drafted as an amendment to the existing law.

108 CHAIR CLARK: You would feel comfortable with that approach?

109 FALK: That is not a basic issue in the way of drafting. Legislative Counsel did it that way to make the bill easier to read for the consumer.

112 CHAIR CLARK: Done this way as a way to make it easier to see what the bill was before and after changes.

118 FALK: There are provisions in the bill that I don't support. (I think it's a bad idea to put a warning on a power of attorney form but left in bill at committee's request--since it's not hurting anything I left it in). *Should change those things that were not working correctly, for instance, check-off box language. *SB 494 does not change in any regard what medical procedures are legal or illegal in the State. They would remain the same.

146 CHAIR CLARK: You say Cruzan was a Constitutional case. Declaring a right to die is a liberty interest, not a privacy interest. What significance do you see in that?

150 FALK: My understanding is that a privacy interest is more unqualified. Cannot balance it against a nexus of state interests as with liberty interests. *Corrects the misconception about SB 494 which is making it easier to withhold life-sustaining procedures. The effect of the bill is that many decisions currently without statute protection would come under the protection of this statute. *SB 494 would create new standards to guide the guardian making these decisions where they do not exist.

181 CHAIR CLARK: Asks about Section 22, amending the definition of professional archeologist and Indian tribe.

184 FALK: It's a renumbering step. Two important points: *Nothing that says guardian procedure is exclusive under current Oregon law. *Purpose of this bill is to keep people out of court.

206 REP. MASON: Section 21 is not existing law.

210 FALK: It is a rewording of ORS 127.635.

212 REP. MASON: The bill repeals ORS 127.635--has it ever gone to the Supreme Court?

215 FALK: Does not believe any of this has.

217 REP. MASON: Would you maintain that a person's life can be maintained/taken in a judicial hearing where no one is there to advocate for that person?

233 FALK: I don't believe this a judicial procedure.

235 REP. MASON: That's why it's unconstitutional. Assuming there is a judicial procedure, would a person have fundamental rights of due process if there were judicial proceedings that could take their life with no one there to represent them?

242 FALK: Assumes the court would be appointed in an appropriate case.

246 REP. MASON and FALK further discuss ORS 127.635 and provisions to withdraw life support and the definition of killing and allowing a person to die.

265 REP. BAUMAN: There is an ethical discussion/tenor with this bill that has superseded the tenor of other bills we've discussed. Is it suicide if my doctor tells me my drinking will kill me and I continue to drink?

278 FALK: Would not call it suicide, maybe self-destructive behavior.

281 REP. BAUMAN: Is it suicide if I am so ill that nothing I eat feels good, tastes good, and I stop.

286 FALK: No. I would assume person would desire to be free of that disability.

288 REP. BAUMAN and FALK continue discussing peoples' personal decisions regarding death.

295 REP. BAUMAN: Terms such as "killing" and "murder" don't really belong in this setting.

302 FALK: There are reported cases of people who are mentally capable but who have declined nutrition and hydration.

305 KAREN CREASON, ATTORNEY, OREGON ASSOCIATION OF HOSPITALS: (EXHIBIT K)

TAPE 124, SIDE B

032 ROLLIE SMITH, CORVALLIS (EXHIBIT L)

142 JEFF BRANDON: Acted as a professional guardian for a public agency for 13 years. Job is to make health care decisions for others. *Oppose this bill but if it has to be, would like to keep it as "clean as possible". *Regarding Section 21, I'm quite sure there is no court proceeding; still oppose this notion. There should be a process. Many people don't have the guardian choices on the list and the physician would end up in that position. Appreciate due process as a surrogate. *Keep integrity as a pre-planning bill. Don't let there be other ways of appointing an agency or attorney in fact.

232 REP. BAUMAN: This is the most encouraging testimony in favor of having a "pre-planning tool." The condition of people in Section 21 is

hopeless.

250 DAVID MOHLER, MENTAL HEALTH PROFESSIONAL: Wanted to stress BRANDON's points. Bill is confusing. No provisions made for health care representative appointed either by the court or by physician. We're switching from a judicial model to a medical model that is avoided in civil hearings and guardianship hearings. If a guardianship is petitioned, there has to be a visitor who goes out and assesses the definition of incapacity and makes a recommendation. There's no authorization for that, which is a real concern with this bill.

277 REP. EDMUNSON: Mentions other side of all of this--guardianship making decisions that cost a tremendous amount. When a patient wakes up ten years from now, they're handed a bill for $4 million.

301 SHIRLEY BARNARD: (EXHIBIT M)

358 JANE MARCHIANES, DIRECTOR, OREGONIANS FOR PATIENTS' RIGHTS: Opposed to SB 494. *Growing financial and social pressures--legislation needed to protect vulnerable people who can't speak for themselves. *Minorities and poor detrimentally effected. *Abused by nursing homes and elderly care facilities. Marchianes' own mother labelled as persistent vegetative state when she was not. *Infants and children now included, in violation of 1984 child abuse amendments.

TAPE 125, SIDE A

022 MARNCHIANES: Continues testimony. *Starvation and dehydration the same as lethal injection. This is a painful way to die.

071 REP. SUNSERI and MARNCHIANES briefly discuss Castagna's testimony. SUNSERI distinguishes between Castagna's testimony and the arcHB ishops he represents.

083 CHAIR CLARK: Thanks committee and witnesses. Adjourns at 8:30 p.m.

Transcribed by: Reviewed by:

Darcie Jackson Office Manager

EXHIBIT LOG:

A -Testimony on SB 494 - Robert W. Smith - 2 pages B -Articles pertaining to SB 494 - Bob Smith - 2 pages C -Testimony on SB 494 - Joan Mahler - 2 pages D -Testimony on SB 494 - Dr. Susan Tolle - 6 pages E -Letter from Lippincott, Human Services - Dr. Tina Kitchens - 3 pages F - Testimony on SB 494 - Ian Timm - 3 pages G -Oregon Health Decisions booklet - Ian Timm - 20 pages H -Testimony on SB 494 - Dr. Eric Chevlen - 2 pages I - Testimony on SB 494 - Robert Castagna - 10 pages J -Testimony and book for SB 494 - Ted Falk - 122 pages K -Testimony on SB 494 - Karen Creason - 4 pages L -Testimony on SB 494 - Rollie Smith - 3 pages M -Testimony on SB 494 - Shirley Barnard - 3 pages N -Resolution from National Right to Life - 1 page O -Testimony on SB 494 - Vicky J. Maurseth - 4 pages P -Letter from Campbell Groner with proposed amendments on SB 494 - Staff Submitted - 2 pages Q -Teresa Bright letter submitted for the record - 2 pages