

ACT 60 DNR/COLST Order Informed Consent Committee

Meeting Minutes – September 28, 2011

Attendees:

Dr. Harry Chen, Commissioner VDH
Dixie Henry, Senior Policy Advisor VDH
Bessie Weiss, AAG, VDH
Joyce Brabazon, VDH
Jackie Majoros, Long Term Care Ombudsman
Trinka Kerr, Health Care Ombudsman
Madeleine Mongan, Vermont Medical Society
Peter Cobb Director, VAHHA
Jill Olson, VAHHS
Dr. Robert Macauley, Clinical Ethics FAHC
Sally Bliss RN, Clinical Ethics FAHC
Cindy Bruzzese, Vermont Ethics Network
Laura Pelosi, Vermont Health Care Association
Merle Edwards Orr, DAIL
Tom Paquette, VNA
Avril Cochran, VPQHC

Absent: Christine Scott, Mayo Healthcare, Lori Collins, Deputy Commissioner DVHA, Vicki Loner, Deputy Commissioner DVHA, Angela Means, VNA

Minutes: Joyce Brabazon

Agenda:

Dixie Henry facilitated the meeting and had everyone introduce themselves. Cindy Bruzzese provided a copy of the booklet entitled *Making Medical Decisions for Someone Else* published by the Vermont Ethics Network.

Dixie asked participants if they had any comments or corrections regarding the August 24, 2011 minutes before requesting approval. Jackie Majoros requested a correction to the statement attributed to her on page 3, paragraph 4, second sentence because she was misquoted. The sentence, “nursing homes abide by statute and hierarchy,” will be replaced with: “the hierarchy in statute is too rigid and nursing homes do not follow it.” Dixie then asked whether there was consensus to approve the minutes. All those present agreed, no one was opposed and the minutes were approved.

Dixie told the committee that there is a short timeframe for the committee to conduct its work. This committee is to:

- Make recommendations on criteria for rulemaking concerning individuals who are not the patient, the patient's agent or guardian to give informed consent for a DNR/COLST, including:
 - Which family members or known close friends of the patient shall be authorized under the rule to provide informed consent;
 - Parameters of how decisions shall be made, including protecting the patient's wishes, consistent with § 9711;
 - Access to a hospital's internal ethics protocols if there is a disagreement over the appropriate person to provide informed consent; and
 - An examination of the patient's wishes expressed in an advanced directive and a DNR/COLST order

Dixie stated that our rule must be filed with ICAR by October 31, 2011 leaving one more meeting before filing the rule. Dixie summarized the rule making process to the committee and that due to those requirements the rule will get ahead of the study report. Dixie said that the meeting today was to discuss these elements and what the committee needs to do for drafting a rule. Dixie introduced Bessie Weiss and Madeleine Mongan and their presentation on DNR/COLST Order and Informed Consent across states.

Presentation Surrogate Consent Laws in VT and other States and Group Discussion

Bessie Weiss started the presentation focusing on Vermont Statutes and Surrogate Decision Making. Bessie presented slides on the overriding principles associated with Vermont Statutes pertaining to:

- Guardianship and its hierarchy of consent for medical or dental treatment for wards without capacity
- Guardianship Services for adults with developmental disabilities who are in need of supervision and protection for their own welfare or the public welfare.
- Revised Uniform Anatomical Gift Act and its hierarchy of persons who can make anatomical gift of decedent's body or part
- Right to Disposition of Remains absent written directive of decedent priority of competent adult(s) to determine disposition of the remains of decedent.

Cindy Bruzzese asked whether the scope of determinations a guardian would make was made in court ahead of time?

Dr. Macauley said that it was his understanding that the guardian was required to go back to court if there was a shift of goals or a refusal of treatment.

Madeleine Mongan said that there were four reasons for going to court: (1) patient objects, (2) court orders prior approval for specific treatment, (3) DNR and (4) life sustaining treatment issues.

Cindy Bruzzese asked whether a change in placement was one of the reasons for going back to court as well?

Dixie responded that this was broad information and that the focus of the committee was on surrogate consent for DNR/COLST Orders.

Bessie resumed the presentation with the Right to Anatomical Gift Act slide. If there is a dispute and a person listed in the hierarchy knows of an objection of another member of the class, then the gift may be made only by a majority of the members of the class who are reasonably available. Bessie then presented information on how decisions are made for withholding or providing consent for life sustaining treatment for persons under guardianship. Bessie said that if there is no time to get prior court approval before a decision must be made to withhold or provide life sustaining treatment, the clinician must certify that there is not sufficient time and the court must be called, if the situation is even more critical the guardian makes the decision and then informs the court. The decision must be made using evidence of what the ward would have done or if no evidence exists then the best interests standard with some limitations would control. Bessie then presented the slide on the Advance Directive statute saying this has more substance to how surrogate decisions are to be made and that the abiding principle behind the statute is for a person to be able to direct decisions for themselves and if the individual is incapable, then their agent makes the decision in accordance with the wishes of the person. If there is not sufficient information on what the principal would have wanted it directs that the best interests standard be used. There are limitations on the best interest standard as well.

Bessie then discussed the Uniform Health-Care Decisions Act approved in 1993 by the Uniform Law Commissioners. She said this is a comprehensive model statute relative to adult health care but has only been fully adopted in five states. However, it appears that many states have used it as a guide.

Dr. Macauley stated that it was his opinion there was a big hole in the middle saying that if a patient told you what to do, you did it but if there was no information what steps should be taken. He noted that at least our Advance Directive statute does a better job. Sally Bliss agreed saying that the language in Vermont law encourages gathering of information about a patient's values.

Jackie Majoros said that the model law contains more instructions and that what is contained in the presentation is an abbreviated version.

Dixie said that while we may be able to do some tweaking in the rule, we cannot be inconsistent with the language in the Advance Directives statute.

The statute provides for dispute resolution which comes into play if there are multiple individuals in one particular class. Dr. Chen asked if a class was evenly divided could you go to the next class on the list to make a decision? Bessie answered no, the lower class would be disqualified.

Cindy Bruzzese said it was her opinion that the Uniform Act was broader than what we were talking about for purposes of this committee.

Bessie turned the presentation over to Madeleine Mongan who presented on 2009 Surrogate Consent Laws from the ABA Commission on Law and Aging. She framed her presentation stating that it was designed to be an objective review and not based upon her advocacy position. Madeleine said that patient designation takes priority over informal designations. Alternatives to the default rule, which is a very strict hierarchy, boiled down to three models (1) consensus of interested parties; (2) person on list of interested parties – no priority and (3) physician selects from list of interested parties.

Dixie asked Madeleine if she could flag when there were limits on consenting to DNR/COLST. Bessie said they took this information out of the presentation because a surrogate decision maker for this committee's purposes is just for DNR therefore already limited. Dixie said that she just wanted to know if surrogates can consent to other treatment but not DNR/COLST. Madeleine said she would need to go back and look at that information again. Dixie said this information is general as to surrogates and may not be just for DNR/COLST. Madeleine said she would look at some possible options from other states that would be helpful for Vermont to consider.

Madeleine then presented the slide on the Consensus Model stating that the common theme was that if there was disagreement, any interested person could seek appointment of a guardian.

Dr. Macauley asked what happens in the interim when there is a disagreement since an appointment would not be immediate. Madeleine said that we would have to figure this out for Vermont.

Dr. Chen asked Bob what else could it be? Dr. Macauley said that in his experience when you are in a holding pattern waiting for a judicial decision, the default would be to provide maximal treatment.

Madeleine said that with the Consensus Model the selection of a surrogate as opposed to decision making could have the same effect.

Jill Olson said they are also working on some issues with VSH and delays with the judicial process in these decisions. Jackie Majoros said we would be going to court for deciding the appropriate person. Jill Olson said it has the same effect. Problem is that courts do not operate on clinical time. Jackie Majoros asked how this works regarding picking a surrogate. Madeleine said the committee would need more information on this model if they want to go in this direction. Dixie asked whether if over time or under changing circumstances whether more than one person could be designated as a surrogate? Can this decision change based upon a particular decision being made?

Next, Madeleine talked about the Physician Selection Model. Dixie noted that this model uses a priority list of individuals who could be selected by the physician. Madeleine said physicians generally follow a priority list, but there are options not to follow a list.

Dr. Chen asked what the criteria are for choosing someone from a lower priority class. Madeleine answered that anything she would say would be a guess on her part. Dr. Macauley said this model was not a bad description for what they do at his hospital. He said that while a list is not set, they go down a list. Usually the spouse or adult child is selected unless that person is not able to make a substituted judgment decision or there is strife. He deferred to Sally Bliss to see if she agreed. Sally agreed and said that a priority list may seem too restrictive and that they generally use a consensus model. She clarified that they really use a blend of the consensus and physician selection model. Dixie asked whether they document in the medical record why and how they made a particular decision. Dr. Macauley responded that they do.

Tom Paquette asked whether we are talking about hospitalists or primary care physicians. Dr. Macauley answered it depends on the primary care physician, and that decisions are on a case-by-case basis.

Jackie Majoros wanted to know whether the clinician could look at another category of person on this list or whether there were criteria or a trigger to why you would do this? Madeleine said that only one state went with a lower priority class.

Merle Edwards-Orr provided an example of someone who led a rough life, had been married and had children but that they were no longer an active part of the person's life. DAIL looked to an adult grandchild, age 19, who remained connected to this person.

Dr. Macauley said who decides on what clinician involved deals with a hospitalized patient depends. He said it would be great if he knew the patient, but by talking with everyone else he gets to know the patient and evidence of the patient's wishes. It is not so much his knowledge, but knowledge elicited in conversation with those who know the patient. Sally Bliss said that when they contact the primary care physician they may never have had a discussion about a DNR/COLST because the context of a visit is specific to a particular problem at the time. Dr. Chen said that having made some of these decisions, more often than not he did not call the primary care physician.

Madeleine talked about the slides on the Clinician Selection Model where the physician and surrogate make decisions and Unbefriended Patients.

Lastly, Madeline said that what is in place in Vermont now are common law provisions where physicians turn to family members as described in the Right to Die Treatise in the slide.

Dixie observed that there is a lot of information out there. A lot of states do this in statute. This group was given a limited charge. The focus is to identify which family members or known close friends of the patient should be authorized by the rule to

provide informed consent and parameters for making decisions. Dixie said she anticipates some type of list that may be hierarchical or not.

Sally Bliss asked if a hierarchical list as reflected in the Anatomical Gifts Act and Disposition of Remains statute is based on property law and whether this would be something that translated into the surrogate decisions needing to be made. Dixie said that both statutes seem to start with a spouse and then list other blood relatives. She said they do provide a range of family members.

Jackie Majoros asked whether it could be any family member or friend?

Dr. Macauley responded that a priority is a method whereas a hierarchy indicates you have to take it in this order. He said we should talk about procedure rather than going through a list.

Dixie said we have to describe family members or known close friends who would be authorized to provide consent. Merle Edwards-Orr said we are talking about three parties in a process all of whom need some level of protection, meaning the list is almost secondary; the process is what is important so people can move in the way they need to move.

Cindy Bruzzese asked whether the group was interested in having a priority or an open list? She said an open list creates a practical process problem. Dixie asked the group to stop on the subject of family for a minute asking whether it could be any family member by blood, which could include a third cousin, or other distant relative. Do we want to be that broad about family; just any family member related by blood or law?

Dr. Chen stated that some people in the process would not have a lot of time from a practical point of view and that they need to be accommodated as well. He said we should require some sort of priority not necessarily a hierarchy.

Cindy Bruzzese said that a hierarchy might be needed in some circumstances. Sally Bliss said that usually it is the emergency personnel that say a hierarchy would be nice. Dr. Macauley said he had deep reservations regarding a strict hierarchy. He said it raises some questions in connection with due diligence. How much due diligence is required to get to the first, second or third person in the hierarchy? He stated that he did not think a hierarchy was a good way to go. He suggested that the FAHC process works well. At FAHC they use a combination of the Consensus Model and Priority List combined with caveats for circumstances where the priority list is not appropriate. Sally Bliss said that it is important to note that regardless of the model, it is about the surrogate applying appropriate substituted judgment. If you do not have a patient's first hand information, stick to second person's substituted judgment.

Cindy Bruzzese said that even though this charge is just for DNR/COLST, once we make a rule it will be utilized for other types of decision making. Dixie responded that this rule

cannot authorize broader application. Cindy nonetheless thought it may seep through to other circumstances.

Dixie asked whether there was consensus regarding family members. Do we want to limit family members in any way, such as excluding a legally separated spouse? Trinka Kerr said she did not think we should automatically exclude anyone, for example sometimes a separated spouse comes back. Dixie then asked whether we should allow any family member by blood or law; what about close friends, or adults who show special care or have knowledge about the patient? Bessie asked whether the interested person description in statute could help here? Dixie suggested that to start we make the eligible list big and narrow it from there. Merle Edwards-Orr recommended creating a priority order to make a decision, and then set criteria to jump around on the list. Dixie asked about criteria. Jackie Majoros said she did not think a hierarchy would work and recommended establishing criteria.

Madeleine Mongan reviewed considerations for selection in the Clinician Selection Model that include knowing the wishes or best interests of a patient, regular contact with the patient, demonstrated care and concern for the patient, availability to visit the patient during illness, availability to engage in fact-to-face contact with clinicians.

Cindy Bruzzese said it should be important to explain the concept of substituted judgment that it is about the patient and not about themselves.

Sally Bliss responded that it is the language about substituted judgment that incorporates values.

Cindy Bruzzese said that asking the question who can put aside their own values and beliefs and make a decision for you is not a bad way to start.

Dixie said lets start with criteria and apply the substituted judgment standard, known wishes or best interests of a patient, regular contact with the patient, demonstrated care and concern for the patient, availability to visit the patient during illness, availability to engage in fact-to-face contact with clinicians.

Jackie Majoros said she was not sure about the regular contact with the patient as a criterion.

Merle Edwards-Orr said he liked the regular contact requirement. He said it helps in situations such as where an adult child lives in California.

Cindy Bruzzese said contact does not necessarily mean physical contact.

Dixie Henry said contact includes known wishes and values. Dixie asked if we should tier the criteria?

Dr. Macauley said that this may be good but reachability is a factor. The person needs to be involved in updates and available.

Dixie asked if there were other criteria?

Cindy Bruzzese suggested we include everything from other states and then we can exclude them out as we go.

Madeleine Mongan reviewed the Consensus Model, Priority Model and Clinician Selection Model with the group.

Bessie Weiss said that in the Advance Directive statute there is a presumption that the agent is available. She said the statute defines the term “willingness.”

Cindy Bruzzese asked how it would be divided among clinicians and was the definition consistent across statutes?

Dixie Henry told the committee that she and Bessie were marking up a draft rule and would get it out to the group by the end of the week. Dixie said that a next meeting was planned for October 26 but we would have to get the rule out for signature by then. She asked about another meeting before then to discuss the rule language and then take that feedback and draft a committee report.

Cindy Bruzzese asked about the week of October 10

Sally Bliss asked about nursing homes, long term care facilities, assistants, long term care givers and whether they could be included on the known patient list. She wanted to know in terms of how we look at substituted judgment was there a way to address these individuals as family or known close friends?

Dixie Henry said that no other state has done this by rule and we have limited statutory authority, however, providing this information to the legislature will assist them as they consider other health care decisions.

Cindy Bruzzese said she just wanted to confirm that a personal care assistant would not be included. Dixie responded that the rule will authorize family members and known close friends, so the individual would have to fit into one of those categories..

Dr. Macauley wanted to know if this excluded someone’s nurse. Bessie Weiss referred to the Advance Directive statute definitions.

Next Steps:

Dixie Henry said she would send out a notice for the next meeting.