

State Advisory Council on Palliative Care and Quality of Life
Formative Meeting

November 20, 2015 - 10:00 a.m.

Members Present:

Beth Cain - AL Hospital Association
Peter Czapla - AL Durable Medical Equipment Association
Stormy Dismuke, C.N.O. - AL Hospice and Palliative Care Association
Karen Marlowe, Pharm. D., B.C.P.S., C.P.E - AL Pharmacy Association
Rodney Tucker, M.D., M.M.M. - UAB Center for Palliative and Supportive Care
Kristi Acker, D.N.P., A.C.H.P.N. - University of Alabama DCH Cancer Center

Department Staff:

Tom Miller, M.D. - Acting State Health Officer
WT Geary, M.D. - Director/Medical Director, Bureau of Health Provider Standards
Dennis Blair, Deputy Director - Bureau of Health Provider Standards
Mia Sadler, State Program Director - Bureau of Health Provider Standards
Carter Sims, Supervisor M. O. Unit - Bureau of Health Provider Standards

Other Representatives and Guests:

Angie Cameron-Smith, (Proxy for Richard Brockman) - AL Nursing Home Association
Samika Williams, (Proxy for John G. Beard, M.B.A./J.D., President) - Alacare Home Health & Hospice
Ginny Campbell - American Cancer Society, Cancer Action Network

The meeting was called to order by the Acting State Health Officer, Dr. Tom Miller who introduced himself to the members and gave an overview of his past practice and experience with the Department. He articulated how excited he is about this initial meeting and moving forward to exploring a very important issue. He feels that in the past palliative care has not gotten the attention it deserves so he is excited to see what this group is going to do to move this agenda forward.

Dr. Miller requested that each member introduce him or herself and state what each one brings to the table and how they are affiliated with palliative care. Introductions were made around the table.

Dr. Miller then turned the meeting over to Dr. Geary for a review of the Act authorizing the creation of the council. Dr. Geary emphasized that he wanted the meeting to be informal and encouraged all attendees to interrupt at anytime if there were comments or questions.

Dr. Geary stated that he succeeded in getting a member appointed for each of the required organizations listed in the Act but pointed out that the Act also mentions various individuals which have not yet been identified for appointment such as a patient, a family caregiver, an advocate and other relevant appointees. He asked that if members know specific people in these categories, especially patients and caregivers, who are involved with palliative care and are willing and able to contribute to this Council to please let him know. Dr. Miller will send a letter to them explaining the situation and asking for their participation. If they agree to serve, he will appoint them to this Council.

The next topic for action mentioned was the election of a Chairperson and Vice-Chairperson. However, before getting to the actual election, Dr. Geary informed the attendees that he had taken it upon himself to allow any of the appointed representatives to designate a replacement if they were unable to attend this meeting. This authorization is not included in the Act, but he strongly suggested that after the election of Chair and Vice-Chair that the Council considers a motion to allow a designated proxy and to consider the possibility of allowing members to attend and participate by phone or videoconference as opposed to requiring attendance in person. Those were just a couple of issues that he wanted to bring up right away before the members actually got to the point of electing a Chair and Vice-Chair.

Since this is a formative meeting, Dr. Geary at this point opened the election process by asking for a nomination or a volunteer for the position of Chairperson for this Council. Kristi Acker nominated Dr. Tucker and Peter Czapla seconded that. Dr. Geary asked if there were any other nominations, and hearing none, asked if there were a motion for the nominations to be closed. There being no discussion and a motion being made without opposition the nominations were closed. A vote was taken and Dr. Tucker was elected as Chairperson.

Dr. Tucker thanked the members. He mentioned that, with respect to his position with UAB, he wanted to make clear that for him it is very important that everyone know that he only has one agenda and that is to improve the lives of citizens of Alabama. He does not favor this council getting mired in controversy. His intention is that the council maintains a unified voice about everything that we do across the continuum of needs and benefits to patients and families throughout the entire state. He is happy to serve but his only agenda is how to benefit the patient.

Dr. Tucker continued on with the next point, that of electing a Vice-Chair. His assessment of the duties of the Vice-Chair would be to serve as proxy for the Chairperson; to conduct the meetings and advise the members in the absence of the chair; and to be an additional liaison to the Department as needed. He opened the nomination for Vice-Chairperson but there were no nomination forthcoming. After discussion of the extent of the work likely to be required by the officers, Karen Marlowe volunteered to serve as Vice Chair. She then asked about the duration of appointment and rotating appointments – whether the tenure lasts a year or whether it is a three year commitment. Dr. Geary mentioned that this is another issue that needs to be discussed and decided upon after a Vice-Chairperson is appointed. A motion was made that nominations be closed and it was seconded. Dr. Tucker asked if there were any other nominations for Vice-Chair, none made and Karen Marlowe was unanimously selected as Vice-Chair.

Regarding the duration of office the initial appointees are to serve, Dr. Tucker stated that he would prefer a three year term. A motion was made and seconded that three years will be the length of time served. This was approved by voice vote. Dr. Geary did point out that the Act does not preclude a member from resigning and another person being appointed or elected by the organization to fill that position. In case of the resignation or inability to serve of a representative of a nominating organization mentioned in the Act, the Department staff will keep track of Council members and be responsible for notifying the organization and asking them to designate a new representative to replace the one who had resigned.

Dr. Tucker brought up the issue of appointment of a proxy. He noted that organizations allowing a designated proxy to participate are able to engage in more robust conversations and discussions when the primary member is unable to attend. He recommended designating a standard proxy and compiling an alternate proxy list in the event that both are unable to attend. Dr. Tucker asked for a motion to

designate a standard proxy and name that proxy. The motion was made and seconded. The motion was opened for discussion. Peter Czapl recommended the Council reach out to the Department's legal office to assure it is something that is allowed. Dr. Tucker agreed that this issue as well as the other issues will need to be reviewed by legal counsel before proceeding with it. Kristi Acker stated that she will need some time to find and select someone as her proxy and all agreed that this will need to be done by each Council member after this meeting. Motion was called to vote on whether or not to have a pre-identified alternate proxy. Results were in favor of the appointment of a named alternate member as proxy.

Dr. Tucker addressed the issue of invited guests attending and speaking at the Council meetings. Extensive discussion was held on this topic. Dr. Geary summarized to accepted protocol for guest attendees and speakers. If a Council member or a guest speaker would like to make a presentation or have an item placed on the agenda, they are to contact Dr. Geary. If it is something from an outside group/guest it would have to be sent to the Chairperson and Vice-Chairperson for approval before it is added to the agenda. The guest or outside group would be given a 10 minute limit for any presentation. Dr. Tucker requested that any guest speaker send a paragraph summarizing what they are going to present along with their request to speak. Both should be sent at least one month in advance of the next scheduled meeting.

At this time Dr. Miller introduced Brian Hale, Departmental General Council, and asked about the questions the Council had entertained regarding attendance at meetings by electronic means, and the designation of a proxy and voting by a proxy. Mr. Hale said he was not sure about the designation of a proxy, but he thought that the Council could approve this if so desired. In regards to the phone attendance or teleconferencing, according to the state's Open Meetings Act, everyone has to be physically present to participate unless specifically allowed by the Council's authorizing Act. He stated that he did not read any sort of allowance in the Act for such distance participation. Dr. Miller asked if there is no business to be conducted, can members still call in rather than not being able to participate at all. Mr. Hale said that if there is not going to be any voting or deliberation or business to be conducted, that should not be an issue. Dr. Tucker asked if there is official business to be voted on, should votes be limited to the primary appointees present? Put another way, does this Council allow other people to participate but the vote of a proxy member or member attending by telecommunication would not be counted. Thus, only the persons physically present will be the ones allowed to vote. Dr. Tucker asked Mr. Hale if a motion could be made stating that the items of business that require voting must be done by the regular membership and in person. Mr. Hale said that would be fine. A motion to that effect was made and seconded; a vote was taken and this motion passed.

Dr. Geary asked about the travel reimbursement for the members, and Mr. Hale affirmed that it is not allowed. Dr. Miller asked if there is anything that could be done or other options that would allow for such reimbursement. Mr. Hale responded that there is not.

Dr. Tucker asked Dr. Geary about the topic of information collection that was listed on the agenda. Dr. Geary explained that the goal of this Council is to gather information that is pertinent and useful for the public as well as professionals and to establish a section of the Department's website to house such information and make it available to the public. The Department, as the administrative branch working for this Council, asks that each person on the Council send their information to Dr. Geary so that it can put together an Alabama specific informational website that would also have links to national websites. This website needs to have detail information that informs the public and professionals what palliative

care is, where this is currently available in Alabama, and who to contact and how an individual can connect with this type of care.

Dr. Tucker asked Dr. Geary if he would like to have this before the next meeting. Dr. Geary said yes, he would hope by the next meeting that the Department has something to show on the website. The department will gather some information and plan to send things out and get everybody's ideas and put together a website and get it going so the Council can discuss the content at the next and subsequent meetings so that the Department has a framework that it can add to, modify, reorganize, rearrange and improve so that by each meeting a better presentation for the public and to the professionals is developed about palliative care. Dr. Miller stated that there is already a lot of this information out there such as pamphlets or fact sheets that are handed to families and information from the Cancer Society that can be used. However, there is a need to be careful on this type of platform about not promoting proprietary products, but the Department has examples and there may be developmental pieces we can use.

Karen Marlow brought up issues seen in her practice, those of illiteracy and reading level. Often, medical information on line is not addressed to the illiterate populations and Hispanic population. She pointed out this issue as something that needs to be considered. The council needs to understand the population being targeted and why. And to be specific in the sense of which counties are being targeted. The Council needs to make sure the literature it promotes is meeting the needs of the population.

Peter Czapla addressed the members to bring attention to the guest in attendance representing the American Cancer Society, Ginny Campbell. He pointed out that she and her organization introduced this legislative effort and worked very hard to create this Council. He offered her the platform to address the Council at this time.

Ms. Campbell thanked the group for this opportunity. She noted that while working with the legislature on this initiative, it was shocking to see how little most people know about palliative care. They automatically think of it as end of life care. But with chronic disease, not everybody is immediately terminal; rather many people do suffer for a long time. So the Cancer Society's biggest concern is to find what barriers are out there to palliative care for all who would benefit. Once these are known, this Council can work on solutions, as Dr. Geary said. If there is a legislative solution or other policy solution, which doesn't have to be a legislative policy, it could be a hospital policy or changes in other areas, the Council could embrace and support these. It may take time to get to that point but the Cancer Society would like to see this group of experts determine what problems are out there, if there are problems, and who else may already know about a solution. For example, there may be physician education that needs to be done. The Cancer Society nationally is currently pushing a bill through Congress to provide money for research and to advance palliative care education in medical schools beyond what is already taught. This Council is an initiative that was heartfelt by the Cancer Society and it is delighted to see this assembly come together. This is what it had in mind.

Dr. Tucker noted that discussion about information collection will be the primary agenda topic for the Council's next meeting. The task between now and the next meeting is to gather and review information from many organizations including the Cancer Society and anyone else that has information to offer that seems to be helpful.

At this time Dr. Tucker gave a power point presentation entitled: "The Palliative Care Report Card 2015". This report provides an update of the data from the 2011 report on state by state and region by region **benchmark for access to palliative care.**

Dr. Tucker then recognized Mr. Carter Sims, a Departmental staff member who had also attended the national CAPC conference several months ago. Dr. Tucker asked if he had any comment about what he had learned in the state coalition session.

Mr. Sims remarked that the primary message conveyed at the CAPC general sessions and at all the breakout sessions was that of putting the patient in charge of their healthcare and not deferring this to a provider or a physician. The goal is to work together to achieve common ends. The largest barrier for everyone at the conference was the financial side of it. Dr. Tucker noted that it is important to educate not just the public, but also the providers and the insurance companies which are going to pay for this at some point. They are either going to pay for their patients to be in acute care facilities or they are going to pay for palliative support and care services somewhere down the line. One member commented that this approach raises a great point. The Council should endeavor to segment out the education by audience. So that it addresses the payers, as well as the practicing physicians, but also the hospital. Dr Tucker said that he has been directing conversations about palliative care right back to the CAPC website because it has so much helpful information that it helps one make the case for palliative care.

Dr. Geary commented on the demographic problems of dementia care and mental health care and the need for increased resources in the United States over the next 30 years. He recommended that the members consider expanding the Council membership to include a mental health representative, patient advocates, family caregivers and people involved with dementia care.

Three issues tangentially related to the stated purpose of this Council were discussed for informational purposes only. The first is an amendment to the Alabama Natural Death Act which will be introduced in the next session allowing for a portable DNAR order when such an order is duly entered in compliance with a form to be developed by the Department. The second issue discussed was that of advanced directives for end of life care for persons who are not competent adults or those below the age of 19 as stipulated in the act. Dr. Monica Murphy in north Alabama has been in contact with several members of this Council regarding this ongoing issue. There has also been press coverage about a family's desire to have a DNAR order consistent with their teenage child's wishes honored at school. The third issue discussed was the development of a POLST type order form that would encompass a patient's transferrable DNAR order but would also be an order for the scope and level of other treatment that a person wants in any extreme circumstance. This type of document seems to be controversial in Alabama and conflated by some with physician assisted suicide legislation in Washington State.

Dr. Geary reminded the members that according the Act the Council should meet not less than two times a year. Karen Marlowe, Vice-Chair, suggested the Council meet quarterly for the time being. A motion was made and seconded that the Council meet quarterly until a different schedule was approved. There was no discussion; a vote was taken and this motion passed. It was decided that the next meeting will be held at 10:00 a.m., on Friday, February 19, 2016.

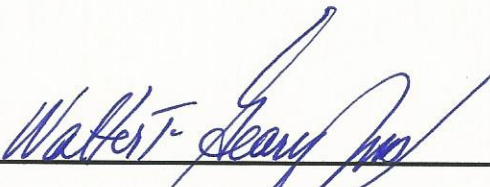
Dr. Tucker then entertained a motion that the meeting be adjourned. This was made and seconded and passed unanimously.

Minutes Approved by:



Rodney O. Tucker, M.D., Chairman

State Advisory Council on Palliative Care and Quality of Life



Walter T. Geary, Jr., M.D.

Bureau Director and Medical Director of Health Provider Standards

Alabama Department of Public Health