## State Advisory Council on Palliative Care and Quality of Life Quarterly Meeting

February 19, 2016 - 10:00 a.m.

## Members Present:

Beth Caine - AL Hospital Association
Peter Czapla - AL Durable Medical Equipment 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
Tom Geary, M.D. - Alabama Department of Public Health
Jim Williams - Baptist Medical Center South
John G. Beard, M.B.A., J.D., President - Alacare Home Health & Hospice

## Department Staff:

Dennis Blair, Deputy 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

The meeting was called to order by the Council Chairman, Dr. Rodney Tucker. Dr. Tucker introduced himself to the members and for the benefit of those who were unable to attend the first meeting in November, self-introductions of each member were made around the table. Dr. Tucker reminded the members to appoint a proxy to attend meetings in their absence and to give the name of appointee to Dr. Geary and Rosemary so we can have that documented for each member.

Dr. Geary brought attention to the draft minutes from the last meeting held on November 20, 2015, and they were reviewed. The main subjects were reiterated which included: the decision to hold quarterly meetings, with teleconferencing being allowed if you are unable to attend but it was emphasized that members would have to be present to vote and proxies would not be allowed to vote. Also, subject of assigning a proxy was included in minutes as well as the website to be created and a report of the CAPC was reviewed. A motion was made to approve the minutes and was seconded. At this time Dr. Geary had Dr. Tucker sign his approval of the minutes.

Dr. Geary presented a "mock" web page on the projector screen. He described how to access the webpage and explained each section. In his review of the new webpage, in particular the page listing the Council members, Dr. Geary added that the council is still seeking out new members. New members sought should include caregivers and patients that have been through an extended illness, mixture of urban and rural people as well as racial diversity and add people who come from different cultures and backgrounds to sit on this committee. Dr. Geary moved on to describe the web page. Dr. Geary told the Council that, as a working group, the next step be to decide where we want to go with this website, what we want to put on the website, how we want to access information for palliative care in Alabama. Questions we need to answer would be, "How do you get in touch with someone, how do you get into the system, what's available." He went on to say, the other thing is the educational component of the statute. With that, what do we want to put on the website that informs about people about palliative care, what's going on in palliative care, the resources for education, meetings conferences, guidelines,

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etc. Dr. Geary then asked if there were any questions or suggestions and told the council that he'd like for them to look at it. Dr. Tucker asked Dr. Geary to send the group the link.

Dr. Geary asked if they should have more contact information the Council members. Kristi Acker said she thought that would be helpful in case there were people in the community that might want to give a presentation they would have a way to contact someone. Dr. Tucker asked if anyone would be opposed to that because the initial purpose of the Advisory Council was to present palliative care but sometimes when the issue becomes end of life or they become related to suicide bans, etc. there may be some folks that really stretch what we may be comfortable at so are you all comfortable having your emails? Dr. Geary suggested that instead that only his information could be put on the website as the contact and he could distribute any questions or information to the Council member best suited to assist with a particular subject. Everyone agreed that would be a better way and Dr. Tucker said we will add that to the page.

John Beard asked the group if they would want to put a banner up to advertise for new members and allow people to self-nominate. Jim Williams stated they would have to be careful with that because there could be individuals self nominating that we might want to vet. Dr. Tucker suggested the group give it another opportunity among us to see so that we can think about that and then if we see we need to do that we can come back to it. John Beard asked, "If we are looking for a patient, is it someone who is receiving palliative care now." Dr. Geary answered that the statute asks that, in addition to the members that are designated in the bill, they have representation from patients, caregivers in a variety of geographic settings and in racial mixtures. So we don't necessarily have to have a patient. John Beard reaffirmed that it does not have to be a palliative care patient but maybe someone who has been a patient potentially within the last "X" amount of time. Dr. Tucker said that he thought they would want someone who has had experience with advanced illness or palliative care because we all have a connection with and we shouldn't be shy about patients and family members are added to council to have a couple and instead of having proxies for them we could have two that we select. If we could just get the folks in, because they do have a tendency to not make it, so we could get another one to come.

Dr. Tucker asked if there were any other categories we need to designate. All the organizations now have representatives? Dr. Geary confirmed that and read what is written in the statute regarding what categories they have requested. Dr. Tucker stated that all the Council need to look in their area for potential delegates.

As the meeting moved on Dr. Tucker went back to "what more information do we need for website?" He touched on several subjects that can be put on the website. Among those were the 16 hospitals that are reporting to have palliative care and the investigation to see who of those that claim to have palliative care are actually using it. Also, which facilities actually have it and are using it that may not have been reported as having it. One of the main objectives is to try to educate the patients, family members, the public and even the medical community. The website can serve to make them aware of what palliative care is as well as how and where to get access to it. Also, it is imperative that a disclaimer included on the website so as not to look as if the Council is endorsing some of the websites. Also discussed was to assist the above listed groups in establishing when to start palliative care. So it was decided that once

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the resource sites are established the next step would be to promote education of the Medical community and get the word out there, but first we need to unify our resource on the website. Many ideas were discussed and what was decided was that all would search out websites regarding Palliative and were asked to share what they find with other council members so they can be reviewed and discussed.

Dr. Tucker asked if the Council thought it might be beneficial to us to have someone from one of the national organizations to come and present what they are aware of other states and councils and what other legislative things are happening. He said the he believed it would be possible to bring someone here to do that because we have about a million dollar budget now and Dr. Geary confirmed that. So it would only take a small amount out of that budget and Dr. Tucker said that he thought if the Council could link it with something that his organization would do at UAB he could possibly get the executive director of legislative affairs for The American Academy of Hospice and Palliative Medicine to come and give us the national and regional scene of how other states are establishing advisory councils and some of these states are very far ahead in terms of what they are doing with palliative care. Dr. Tucker went on to say that he thought the state of Virginia and the legislature designated funds for Virginia Common Wealth University to be the curricular site to develop mandatory curriculum for the physicians in the state on pain management, advanced care planning and palliative care vs. hospice. John Beard said that we desperately need that and Dr. Tucker agreed. He asked if the Council thought it would be beneficial, he was able, to bring someone from the American Academy to come here to give a presentation and answer some questions to help us find out what's happening with other councils. Dr. Tucker said he would extend an invitation to the director he spoke of earlier.

The date for the next meeting was discussed. It was decided at the first meeting that the quarterly meetings would be held on the 3<sup>rd</sup> Friday of the month but Beth Caine asked if that could be changed to the second Friday instead because of conflicting mandatory meetings she attends. It was then decided that the Council would meet every 2<sup>nd</sup> Friday of the month. Karen asked if there was any objection to could go ahead and schedule the next two upcoming meetings. So it was decided that the next meeting will be May 13, and the one after that will be August 12, both at 10:00am.

Dr. Tucker asked if there were any additional items to be discussed. Dr. Geary said the bill that would amend the "Natural Death Act" to allow a do not resuscitate or a transfer from facility to facility has made it out of committee but that is all I know at this time. I understand it is in a short stack to be voted on. Peter asked if he knew what the number was on that bill but no one knew for sure. John asked if the same committee that worked on that bill last year were still involved and Dr. Geary told him it is.

At that time, Dr. Tucker excused himself early to attend to other obligations and Karen as co-chair, made a brief overview of all that had been discussed and reminded all to bring websites they find that might be helpful to the next meeting for discussion.

Karen made motion to adjourn, motion was seconded meeting was adjourned.

Rodney . 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