

STATE ADVISORY COUNCIL ON PALLIATIVE CARE AND QUALITY OF LIFE

QUARTERLY MEETING

**MAY 13, 2016
10 A.M.**

**RSA Tower
Board Room 1586
Montgomery, AL**

Members Present:

Kristi A. Acker, D.N.P., A.C.H.P.N. - University of Alabama DCH Cancer Center
John G. Beard, M.B.A., J.D., President - Home Care Association of Alabama
Richard J. Brockman, J.D. - Alabama Nursing Home Association
Beth Cain - Alabama Hospital Association
Stormy Dismuke, C.N.O. - Alabama Hospice and Palliative Care Association
Karen Marlowe, Pharm.D., B.C.P.S., C.P.E., Co-Chair - Alabama Pharmacy Association
Rodney O. Tucker, M.D., M.M.M., Chairman - UAB Center for Palliative and Supportive Care
James R. Williams, D., Min., B.C.C. - Baptist Medical Center South

Bureau of Health Provider Standards Staff:

Walter T. Geary, Jr., M.D., Bureau Director/Medical Director
Mia Sadler, State Program Director
Diane Mann, HR Director/Project Liaison
Carter Sims, Medicare Other Unit Supervisor
LaKeshia E. Hopkins, Assistant to HR Director

Other Representatives and Guests:

Meka Astin, M.P.H., Graduate Research Assistant - University of Alabama at Birmingham
Marie Bakitas, DNSc, Associate Director - UAB Center for Palliative and Supportive Care
Jacqueline M. Kocinski, M.P.P., Director, Health Policy & Government Relations

Proxy Representatives Present:

Angie Cameron-Smith, Proxy for Richard Brockman, J.D. - Alabama Nursing Home Association
Lisa Wells, Proxy for Peter Czaplak - Alabama Durable Medical Equipment Association

Dr. Tucker called the meeting to order. He thanked everyone for coming and asked each member and guest to introduce themselves and state the field they represent. Marie Bakitas, DNSc, Associate Director, UAB Center for Palliative and Supportive Care, Meka Astin, MPH,

Graduate Research Assistant working with Ms. Bakitas, and Jacqueline M. Kocinski, MPP, Director, Health Policy & Government Relations, to introduce themselves as the guest speakers for today. Dr. Tucker made reference to the last meeting's minutes and said that he hoped everyone had a chance to read them. He asked for a motion to have them approved. The minutes were approved and there were no additions or corrections necessary.

Dr. Tucker pointed out that in the attendee's packet, there was a document that is a vote/tally in regards to linking the State Palliative Care website to the National Palliative Care website. He stated this will be discussed later in today's meeting. The vote is a simple circling of "yes or no" if you agree/disagree that the websites should be linked. The other document Dr. Tucker referenced was about naming each member's proxy. Dr. Tucker encouraged everyone to do so if they haven't already. He also explained that full members are the ones that can vote on the issue. It is very important to name a proxy so they can vote in your absence. Proxies are also able to report information from the meeting back to the members.

At this time, Dr. Tucker again introduced Marie Bakitas, DNSc. Ms. Bakitas has been in Alabama for about three years and has already won four national awards this year in Research and Nursing. We are very proud of Ms. Bakitas and are so fortunate to have her in Alabama. Dr. Tucker made reference to the first meeting where "The Palliative Care Report Card 2015" was discussed and that Alabama had a poor score. Ms. Bakitas, along with her assistant Meka Astin, MPH, has taken a deeper dive into this subject regarding hospitals. Dr. Tucker asked that questions be held until the end of the meeting to be discussed.

Ms. Bakitas began by reporting the 2015 State-by-State Report Card which shows the inconsistent Palliative Care uptake. The East South Central states averaged a "C" grade. Alabama received a "D" in 2013. There were over 50 hospitals in Alabama that qualified for analysis and of those 50, 16 reported having Palliative Care services. The 2014 National Palliative Care Registry is the nation's only repository of data on hospital-based Palliative Care team characteristics and best practices. Meka Astin, MPH, introduced a new app called Heart Care CHF. This app offers comprehensive information for community-based resources available to patients with heart failure and their family caregivers located throughout Alabama.

Dr. Tucker then shifted the meeting to Jacqueline Kocinski, MPP, to discuss the American Academy of Hospice and Palliative Medicine, AAHPM. Ms. Kocinski discussed that the AAHPM has been the home and only national medical specialty society for hospice and palliative medicine professionals. AAHPM's core purpose is to improve the care of patients with life-threatening or serious conditions through the advancement of hospice and palliative medicine. Their core mission is to expand the accessibility of patients and families to high-quality Palliative Care and advance the discipline of hospice and palliative medicine through professional education and training, development of a specialist workforce, support for clinical practice standards, research, and public policy. There are nearly 5,000 members in AAHPM and 81 percent of them are physicians. Thousands of members participate online via Twitter, Facebook and LinkedIn. Also, there have been several bills endorsed by AAHPM. However, no one from Alabama has been a part of this support. Alabama did establish a State Palliative Care Council in 2015.

Dr. Tucker thanked the presenters and asked members if they had any questions for them.

Dr. Geary asked if the VA System had Palliative Care established. Ms. Bakitas stated that there were none in 2013 but could have been added at a later date. Dr. Geary also wanted to know if the University has a plan to look at data outside of hospitals in Alabama. Ms. Bakitas responded there is a more extensive survey that looks into what the needs and resources are in areas which will allow us to get beyond the hospital data. She pointed out there are only three Critical Care Access Hospitals in Alabama and a lot of times they are used as a hub for rural areas.

Richard Brockman interjected asking: "Why isn't the data collected in nursing facilities part of the equation?" Every nursing home has a Palliative Care program with actively enrolled patients. Dr. Tucker commented that Mr. Brockman made an interesting point and he would like to see the same Palliative Care information captured for hospices as it is in hospitals. Also, there needs to be a way to measure if the availability of Palliative Care in nursing homes is a truly comprehensive assessment. Ms. Bakitas said she thought it was an excellent idea to do a survey for a sample of the nursing homes, however, it would require funding. Mr. Brockman stated that they have an education foundation that can look toward contributing a grant. Dr. Tucker added that Mr. Brockman was describing the dilemma of what Palliative Care is. Ms. Stormy Dismuke added her company has contracts with five local nursing homes and her assessment is that the nursing homes will say they have Palliative Care when it is actually through a contract with hospice. She has not seen an active Palliative Care program in a nursing home and because of that, patients are returning to hospitals more frequently.

Dr. Tucker agreed that not every county in Alabama will have specialty levels of Palliative Care. The question then is: "What is the best way to partner so that the palliative model of care is generally available?" Mr. Brockman added that we need to educate on a scale to make sure the families know what is going on with their loved ones. Dr. Tucker added that there is work being done all over the nation regarding Palliative Care. He suggested that maybe at the next meeting the nursing home linkage would be our next effort to obtain a speaker. Dr. Tucker asked Kristi Acker and James Williams for their input. Ms. Acker agreed that it was an excellent idea. She commented that you have to have a balance between education and standard of practice, because they work together. Dr. Tucker stated this will probably be added to the agenda for the next meeting.

Dr. Tucker asked all members to vote "yes or no" beside each listed option to provide formal approval to link the preferred national websites to the state Palliative Care website on the Department's page. He asked that the completed forms be given to him before exiting the meeting.

Dr. Tucker asked Dr. Geary if he would like to talk about the mission statement. Dr. Geary mentioned that it would be useful and helpful to have a mission statement on the Palliative Care website. He commented that the bill has two segments; the first is to provide information and the second is to provide education. The original mission statement, as included in the Act, is not warmhearted and Dr. Geary thinks the statement should reach out and touch people out in the community. Dr. Tucker agreed with Dr. Geary that the mission statement should have a more personal touch. Dr. Tucker would like for himself, Dr. Geary, and Ms. Karen Marlowe to craft a statement and send it out for comments and/or approval.

Dr. Tucker distributed a book entitled *I'll Have It My Way: Taking Control of End of Life Decisions: a Book about Freedom & Peace* by Hattie Bryant. It is about the end of life journey for Hattie and her mom. Ms. Bryant is passionate about getting her book in the hands of providers. Dr. Tucker stated that Ms. Bryant has agreed to come and speak to the Council about her and her mom's life experiences. He encouraged the Council members to review the book for discussion at the next meeting and to decide whether they would like her to attend a future meeting.

Dr. Geary added that Mr. Beard wanted to discuss whether the website should educate people on the differences between hospice care and Palliative Care. Mr. Beard said that Palliative Care is the process of improving the quality of life and making better choices regardless of the provider. There should be some type of Palliative Care component in their system. Dr. Geary asked if this is an issue that the Council should address and generate understanding through our website.

Dr. Tucker interjected that he agreed the Council should work on this to promote continuum of care. Ms. Angie Cameron-Smith agreed that it is important to educate people on Palliative Care, especially individuals that do not have a medical background. Mr. Brockman pointed out that one of the things they have going on is the Integrated Care Network. He stated it is all about placing the right person in the right setting. The mission of this Council is to set the tone.

Dr. Tucker again agreed that there is a place for definitions for Palliative Care, supportive care, and hospice care. However, he also added that the mission statement may be more generic so that it follows our goals to provide resources to patients with serious illnesses across all settings that improve their quality of care. Jacqueline Kocinski said she would like to touch on two things. She referenced the packet that she distributed. In the packet, there is an example of how they have previously worked on definitions. Also, she suggested taking a look at the National Consensus Guidelines for quality Palliative Care which are available online.

Dr. Tucker encouraged everyone to note their proxies on the form before they leave the meeting. The meeting was adjourned and the next meeting will be on August 12, 2016, at 10 a.m., at the RSA Tower, in Board Room 1586 located at 201 Monroe St., Montgomery, AL 36104.