

**MINUTES OF THE MEETING OF THE STATE ADVISORY COUNCIL ON PALLIATIVE CARE
AND QUALITY OF LIFE
December 2, 2016**

Alabama Department of Public Health
The RSA Tower, Suite 1586
Montgomery, Alabama

Members Present

Rodney O. Tucker, M.D., M.M.M., Chairman
Karen Marlowe, Pharm.D., B.C.P.S., C.P.E., Co-Chair
Kristi A. Acker, D.N.P., A.C.H.P.N.
John G. Beard, M.B.A., J.D.
Richard J. Brockman, J.D.
Beth Caine
Stormy Dismuke, R.N., M.S.N., C.R.N.P.
Mary Ann Somers
James R. Williams, D., Min., B.C.C.

Members Absent

Peter Czapla

Staff Present

Walter T. Geary, Jr., MD, Assistant State Health Officer for Regulatory Affairs
Dennis Blair, Health Provider Standards
Mia Sadler, Health Provider Standards
Carter Sims, Health Provider Standards
LaKesha Hopkins, Health Provider Standards
Ryan Easterling, Information Technology
Chris Randolph, Information Technology

Guests

Marie Bakitas, D.N.S.c, A.P.R.N., N.P.- C., A.O.C.N., A.C.H.P.N., F.A.A.N.
Amy Beasley
Hattie Bryant
Jennifer Clark
Kristy Johnson-Pich
Tim Mayhall
Carey McRae
Deborah Walker

CONSIDERATION OF THE MINUTES OF AUGUST 12, 2016 (EXHIBIT “A”):

The Council recommended approval of the Minutes of August 12, 2016, as distributed; the motion carried unanimously.

INTRODUCTION OF NEW MEMBER:

Dr. Geary welcomed Mary Ann Somers as a new Council member. Ms. Somers is a Patient and Family Caregiver Representative.

REVIEW OF MISSION STATEMENT (EXHIBIT “B”):

Dr. Geary informed the Council that the mission statement, which was approved at the last meeting, is now located on the ADPH website under Health Provider Standards, Palliative Care.

ADPH VIDEO/WEBINAR EDUCATION DISCUSSION (EXHIBIT “C”):

Ryan Easterling from the ADPH Information Technology unit gave a presentation on how the unit can assist with any telecommunication needs the Council may have, including training videos. He also described the different options the Council has for webinars, video broadcasting both live and on demand, program marketing, and creating teaching tools to educate people on palliative care. Mr. Easterling explained that once the material is created, it can be viewed on YouTube and on the ADPH page through “on demand”. Dr. Tucker suggested a narrative training video be made on the new *Do Not Attempt Resuscitation (DNAR) Order* form. Mr. Easterling agreed to work with Dr. Geary to get it created.

REVIEW OF PC APP (EXHIBIT “D”):

Dr. Tucker introduced Deborah Walker who discussed her Cancer Resources App, which provides helpful information for community cancer resources located within Alabama. The Cancer Resources App is geared towards the five counties in the Birmingham area. The app is available to download through Apple or Google Play. Dr. Bakitas, from the UAB School of Nursing and School of Medicine discussed the Heart Care CHF App and how it can be linked to palliative care through customization. Mr. Cooper, broadcasting from UAB, assisted

Dr. Bakitas by demonstrating how the Heart Care CHF App is utilized. Ms. Walker and Dr. Bakitas discussed linking Dr. Bakitas's resources to the ADPH website and Dr. Tucker agreed. Dr. Tucker recommended approval of the link to be added to the ADPH website; the motion was carried unanimously.

BOOK DISCUSSION (EXHIBIT "E" – Book was distributed to the Council members):

Dr. Tucker introduced Hattie Bryant to discuss her book *I'll Have It My Way: Taking Control of End of Life Decisions: a Book about Freedom & Peace*. Ms. Bryant discussed ways the Council could customize and utilize her book as a teaching resource. Dr. Geary added that different groups could co-sponsor the book.

NURSING HOME: PALLIATIVE CARE EFFORTS:

Ms. Kristi Acker stated that health care providers are confused about what palliative care really is. She explained that many providers have requested training on palliative care. Dr. Tucker and the Council discussed many ideas of what to produce as their first training resource video. Dr. Geary suggested someone from the Council speak at the State Survey Agency Directors' Meeting on January 31, 2017 – February 1, 2017, on palliative care. Kristi Acker and Richard Brockman expressed their interest in speaking at the meeting.

ADDITIONAL MEMBER DISCUSSION (EXHIBIT "F"):

The Council discussed the new DNAR form. The Council recommended approval of the form's card stock to be changed to light pink and for it to be two pages; the motion carried unanimously. Dr. Geary informed the Council that the form will be easily accessible by going to the ADPH website, Laws/Regulations, Advance Directives/Portable Physician Do Not Attempt Resuscitation Orders.

NEXT MEETING DATE:

The Council was informed that the date of the next meeting is Friday, February 10, 2017. Dr. Tucker informed the Council that topics for the next meeting should be sent to either him or Dr. Geary.

SUBSEQUENT MEETINGS:

The upcoming meetings for 2017 will be as follows: Friday, May 12, 2017; Friday, August 11, 2017; and Friday, November 17, 2017.

Rodney O. Tucker, MD, Chair
State Advisory Council on Palliative Care and Quality of Life

Walter T. Geary, Jr., MD
Assistant State Health Officer for Regulatory Affairs
Medical Consultant
Health Provider Standards
Alabama Department of Public Health

EXHIBIT "A"

STATE ADVISORY COUNCIL ON PALLIATIVE CARE AND QUALITY OF LIFE

QUARTERLY MEETING

**AUGUST 12, 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 Caine - 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
Peter Czapl – Alabama Durable Medical Equipment Association

Bureau of Health Provider Standards Staff:

Walter T. Geary, Jr., M.D., Bureau Director/Medical Director
Diane Mann, HR Director/Project Liaison
LaKesha E. Hopkins, M.S.H.R.M., Assistant to HR Director

Dr. Tucker called the meeting to order. He thanked everyone for coming and asked if anyone had any comments on the minutes from the last meeting. There were none. He then asked for a motion to have them approved. The minutes were approved and there were no corrections or additions necessary.

The first item on the agenda was the linkage to additional national websites in regards to palliative care. Dr. Tucker referenced to the voting on the website linkage that was discussed during the last meeting. The Council voted that there will be links to all of the websites that were suggested during the May 13, 2016 meeting. In addition to those links, Dr. Tucker would also like for the Council members to view HPNA.org and vote during the next meeting on whether or not that link will also be placed on the website.

Dr. Tucker asked if there were any pharmacies or nursing homes that have a link of anything pertaining to palliative care on their website. Mr. Brockman stated he knows they have a link and that he would check on the nursing home side. Dr. Tucker recommended that if anyone had any links from the Hospitals or Nursing Home Association regarding palliative care that would be considered good resources, please share them with the Council. Dr. Tucker added any

information on medication related topics in regards to palliative care or FAQs (frequently asked questions) can also be considered for linkage.

The next topic was the discussion of the Council's Mission Statement. Dr. Geary accepted the task of writing the new Mission Statement and Dr. Tucker asked him to discuss it with the Council. Dr. Geary distributed a handout with the Mission Statement that he created and the one that was taken directly from the Act. He explained that he wanted to make the statement more personable and wanted suggestions and comments from the Council. Once the statements were reviewed, Peter Czaplak stated that he thought Dr. Geary had done a very good job with the one he created. Dr. Tucker agreed and stated that the next problem would be what to do about the education program. He commented that we are establishing the website, bringing in consumer information in a standardized way, and accessing ADPH. The next step is to educate through the department about palliative care. This will probably be our mission for 2017. Ms. Marlowe interjected, "After reading the statement, we should have established an information piece." She went on to say "We're going to provide education and perhaps the Council is the way to create a network." Dr. Geary commented that one problem with the department being responsible to educate people is that none of us hold ourselves as experts. Therefore, it will be difficult to be able to present that from a variety of different perspectives as experts. There was discussion about the language in the Act and Dr. Geary felt that the legislature wants physicians and nurses to be more in tune with what palliative care is. Dr. Tucker commented that he was fine with the Mission Statement the way it is. Dr. Tucker stated that maybe the Council should target professional organizations as part of their educational program. Dr. Geary pointed out that we might be able to use the Department's Video Communication team to make short videos in order to educate the public and reach a younger audience as well. Dr. Tucker asked if it would be possible for them to come to the next Council meeting and show examples of their work. Dr. Geary said that he was sure they would. Dr. Tucker suggested that maybe the ADPH Video Communication Department would like to look at some of the videos that Palliative Care has made to get an idea of what is being discussed.

Dr. Tucker inquired if there were any other comments about the Mission Statement.

Mr. Brockman suggested that the Mission Statement should be changed to the following:

The mission of this Council is to promote Palliative Care in Alabama and by improving consumer awareness of the positive effect of compassionate palliative care on the quality of life and care for individuals and families living with life-limiting illness.

This will be accomplished through establishment of a consumer and professional information and educational program within the Department of Public Health; and by facilitating collaboration among palliative care providers, organizations, institutions and individuals.

The entire committee reviewed the changes and agreed that the statement was clear, concise, and the goal of the Council. The changes were voted on, a motion was made, it was seconded and the new Mission Statement was approved.

Kristi Acker covered the next topic of discussion, nursing homes and palliative care. She stated that she has called facilities in the nursing home community and has found that they just opened

the door for palliative care. However, it is mostly geared towards the end of life, not so much palliative care. Dr. Tucker stated that he was interested in knowing what happens to a patient in the nursing home as they deteriorate; terminal. Mr. Brockman discussed the requirements of a nursing home regarding advanced directives and short-term stay. There are really two phases for patients coming into a nursing home; episodic care and transformation. Mr. Brockman discussed how during the care plans phase palliative care, quality of life and end of life can be discussed with patients and their families. Dr. Tucker asked Ms. Acker what she meant by nursing homes are being open to palliative care. Ms. Acker commented that they were open to the in-services and training staff. She went on to say that she would like to make two points. First, the nursing homes do an excellent job in communication and pulling together resources. Secondly, the rehabilitation phase is where palliative care should be introduced. There is not really anything outside of the hospice model and the top concern is developing a network. Ms. Acker added that the top concern that she sees is helping communities develop a network of interdisciplinary team members.

Mr. Brockman stated that one thing to have is an integrated care network. This is a team that follows a patient all the way through, in every setting, regardless if they go home or stay in a facility. Dr. Tucker interjected that this was getting into our additional member discussion which is good because it helps us all be informed. Dr. Tucker stated that what they see on the hospital side is the transitioning into the two groups. They look at their visit as a benchmark and possibly something else happens to the patient enough times that they have to go into skilled nursing. Even if patients go into rehab and have a DNR while there in the hospital, there are a lot of problems as to whether that DNR is honored in a nursing home even though they have it in the hospital. Even when they're told they're better and can go home, there are still issues about staff discussing the DNR. However, when a patient goes into long-term care, different conversations take place, because the needs of the patient become different. The part of palliative care that can make a difference in the nursing home are communication and goals of care.

Dr. Geary asked if there was a national link to palliative care regarding nursing homes and if so what should we look for. Dr. Tucker stated there has been a lot of research done on that subject. Mr. Brockman commented that there is a probably information that we can look at. There was much discussion surrounding DNRs and how they are highly misunderstood. Dr. Tucker concluded that through this discussion the Council was able to see all the different complexities from our vantage point and he considers palliative care the glue that holds everything all together.

Mr. Czapla continued the discussion about how patients are placed in a nursing home because they need "a place to go," and how a lot of them are taken to rehab for 21 days for that same reason. Ms. Marlowe stated because families don't have "a place for them to go" until the family can get some other benefit justified. Ms. Dismuke stated she has two concerns. First, when individuals visit the website, what is available to them in Alabama? She believes there should be a list for each entity on what they offer regarding palliative care. Dr. Tucker commented that Dr. Bakitas explained the "Heart" app could be converted and used as a resource for Alabama. The app has been previously converted and has three applications. Ms. Dismuke's second concern is educating staff on getting medications to hospice patients. Ms. Marlowe agreed that facilities are interested in educating on medications and assessments. She went on to

state that facilities are aware they need the education, but what can be done about it.

Mr. Brockman referenced a convention that will be held in September and asked Ms. Marlowe to make a presentation on the early state of palliative care in nursing homes. Dr. Tucker stated that the Council will revisit the subject of palliative care in nursing homes at a later date.

Dr. Tucker also made reference to Hattie Bryant, the author of *I'll Have It My Way: Taking Control of End of Life Decisions: a Book about Freedom & Peace*, and reminded the Council that she is an advocate for patients. He would like to invite her to the next meeting to make a presentation. Also, Dr. Tucker would like to further discuss the "Heart" app and perhaps have the UAB School of Nursing on the phone and the ADPH IT Department present to discuss using the short videos to promote palliative care.

Dr. Geary began a discussion on the form for DNRs. He stated that once the DNR form is in the chart, it serves as the documentation across all entities. This will solve a lot of problems with patients that are terminal and being transferred. Mr. Brockman said a subset of this is that it brings respect to this form and you have to use it and not do anything else. Dr. Geary interjected that now only one physician has to sign the form. He went on to say that people do not understand that by not making a decision, they are really making a decision. Dr. Tucker asked Dr. Geary if the form has been approved. Dr. Geary commented that the form goes before the State Committee on October 3, 2016 and if approved, will become a rule unless there is some type of challenge. Dr. Miller would like for Dr. Geary to make a presentation to the Hospital Association regarding the DNR form. Dr. Tucker thinks the DNR form is a big improvement. Mr. Brockman agreed, it's a huge load off everyone's mind. Dr. Geary commented that the department will not be surveying this form. The burden is on the rules. Ms. Marlowe stated that we are heading in the right direction. Communicating with the family is the best thing to do and families are finally being heard.

The discussion continued in regards to DNRs until Dr. Tucker adjourned the meeting. The next meeting will be on December 2, 2016, at 10 a.m., at the RSA Tower, in Board Room 1586 located at 201 Monroe St., Montgomery, AL 36104.

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Palliative Care and Quality of Life

Palliative care is an approach that improves the quality of life for patients (and their caregivers) facing life-threatening illness. The approach involves prevention and relief of suffering by means of early identification, assessment and treatment of pain and related physical, psychosocial and spiritual problems. Visit the [World Health Organization](#) for more information on the palliative care approach to improving quality of life.

Mission Statement

The mission of this Council is to promote Palliative Care in Alabama by improving consumer awareness of the positive effect of compassionate palliative care on the quality of life and care for individuals and families living with life-limiting illness.

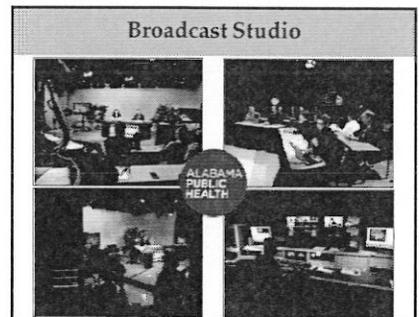
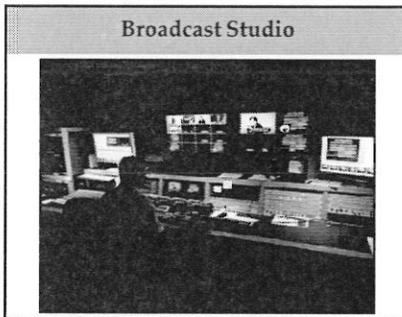
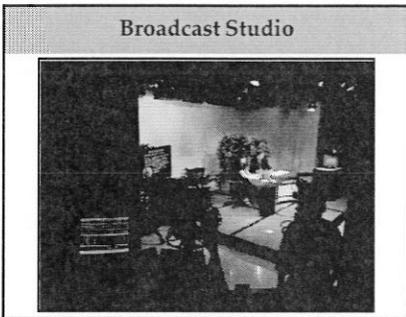
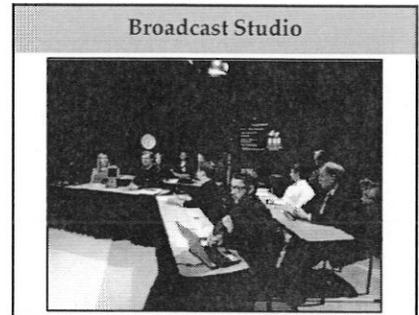
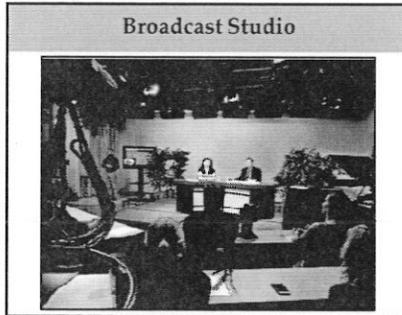
This will be accomplished through establishment of a consumer and professional information and educational program within the Department of Public Health; and by facilitating collaboration among palliative care providers, organizations, institutions and individuals.

EXHIBIT "C"

Alabama Department of Public Health
Distance Learning & Telehealth Division



State Advisory Council on
Palliative Care and Quality of Life
December 2, 2016



Program Marketing

• Example of main page that provides access to program and supporting materials through registration link



• Registration details for program access are customizable



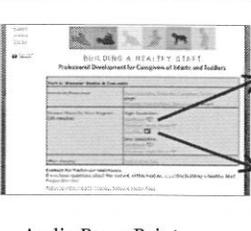
Building a Healthy Start Module Three Part One Pre-Test

1. Infants and toddlers are less vulnerable to disaster because of their small body size and physical dependence on caregivers.
 - True False
2. Child care programs do not need a NOAA weather radio if there is a community warning siren.
 - True False
3. During a disaster one you should count heads or names when gathering children, when exiting the room, when traveling, and when arriving at the meeting place.
 - True False
4. Identification tags or wristbands should include the child's name.
 - True False
5. When evacuating from a building, there should be "two ways out" from every classroom or nursery.
 - True False

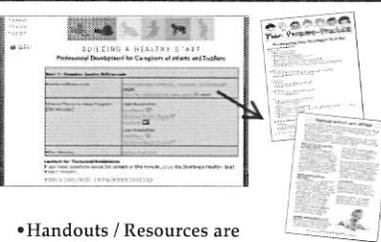
Optional pre-test available to quiz participants knowledge before program




Example of main program page

Audio PowerPoint or video faculty presentation

Handouts / Resources are posted for easy access during or after program



Building a Healthy Start Module Three Part One Post-Test and Evaluation

1. Infants and toddlers are less vulnerable to disaster because of their small body size and physical dependence on caregivers.
 - True False
2. Child care programs do not need a NOAA weather radio if there is a community warning siren.
 - True False
3. During a disaster one you should count heads or names of children when gathering children, when exiting the room, when traveling, and when arriving at the meeting place.
 - True False
4. Identification tags or wristbands should include the child's name.
 - True False
5. When evacuating from a building, there should be "two ways out" from every classroom or nursery.
 - True False

Optional post-test and evaluation available following program



Option to produce DVD/CD disk sets with video and reference materials





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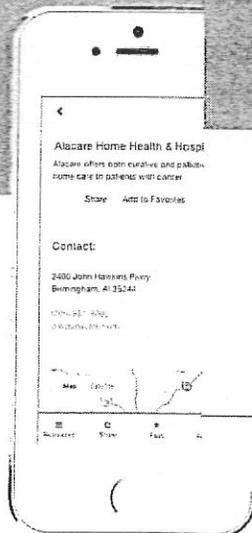
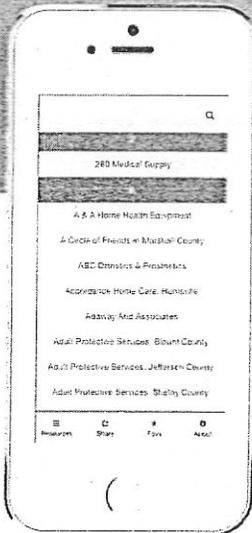
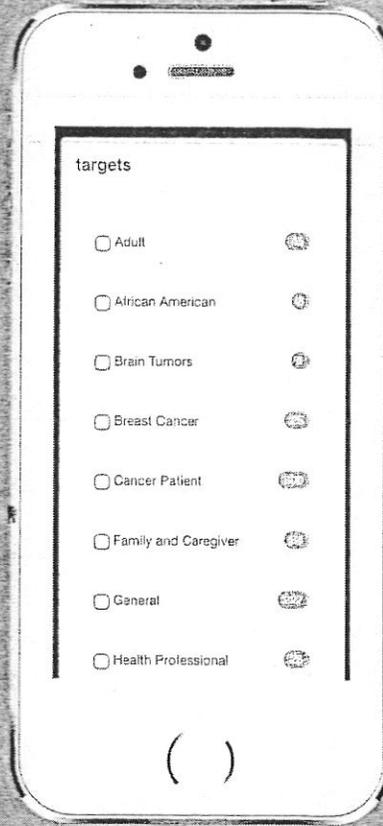
Alabama Department of Public Health



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 (334) 206-3878
 www.adph.org/alphn



EXHIBIT "D"



Download the free
Cancer Resources app today
cancerresources-al.org



Offers a variety of local and national resources for cancer patients and caregivers.

Provides a summary of resources with contact information and maps.

Provides an option to email selected resources to yourself or others.



Support for the Cancer Resources app comes from the Women's Breast Health Fund of the Community Foundation of Greater Birmingham as part of an effort to improve the quality of life for women who are breast cancer survivors as well as for their loved ones.

Developed in collaboration with the Software Engineering and Prototyping Lab at UAB | seap.cis.uab.edu

For more information or to add a resource, please contact:
Deborah Walker at dkwalker@uab.edu

I'll
HAVE
it my
WAY

Taking Control of End of Life Decisions

A BOOK ABOUT FREEDOM & PEACE

EXHIBIT "F"

Alabama Portable Physician Do Not Attempt Resuscitation Order
No CPR/ Allow Natural Death

Patient/Resident Full Name (PRINT) and Date of Birth:

Instructions. This order is valid only if Section I, II, III, OR IV is completed AND a physician has completed Section V.

Section I. Patient/Resident Consent.

I, the undersigned patient/resident, direct that resuscitative measures be withheld from me in the event of cardiopulmonary cessation. I have discussed this decision with my physician, and I understand the consequences of this decision.

Signature of Patient/Resident

Date

Section II. Incompetent Patient/Resident with DNAR instructions in Advance Directive.

The patient/resident is not competent or is no longer able to understand, appreciate, and direct his/her medical treatment and has no hope of regaining that ability. A duly executed Advance Directive for Health Care with instructions that no life sustaining treatment be provided was previously authorized by the patient/resident and is part of his/her medical record.

Signature of provider or facility representative

Print Name

Date

Section III. Health Care Proxy or Attorney-in-Fact Consent.

I, the undersigned, am the health care proxy or attorney-in-fact designated by the patient/resident to make decisions regarding the providing, withholding, or withdrawal of life-sustaining treatment for the patient/resident. I hereby direct that resuscitative measures be withheld from the patient/resident in the event of cardiopulmonary cessation. A copy of the proxy or attorney-in-fact designation (e.g., living will, power of attorney, etc.) has been made part of the patient/resident's medical record.

Signature of Proxy or Attorney-in-Fact

Print Name

Date

Section IV. Surrogate Consent.

I, the undersigned, am the surrogate certified to make decisions, in consultation with the attending physician, regarding the providing, withholding, or withdrawal of life-sustaining treatment for the patient/resident. After consultation with the attending physician, I hereby direct that resuscitative measures be withheld from the patient/resident in the event of cardiopulmonary cessation. I believe that this decision conforms as closely as possible to what the patient/resident would have wanted. I make this decision in good faith and without consideration of the financial benefit or burden which may accrue to me or to the health care provider as a result of this decision. A copy of the Certification of Health Care Decision Surrogate has been made part of the patient/resident's medical record.

Signature of Surrogate

Print Name

Date

Section V. Physician Authorization.

Based on the information above, I hereby direct any and all medical personnel, emergency responders, and paramedical personnel to withhold resuscitative measures, i.e., cardiopulmonary resuscitation, chest compression, endotracheal intubation and other advanced airway management, artificial ventilation, cardiac resuscitative medications, and cardiac defibrillation, in the event of cardiopulmonary cessation in the patient/resident.

I further direct the implementation of all reasonable comfort care such as oxygen, suction, control of bleeding, administration of pain medication by personnel so authorized, and other therapies to provide comfort and alleviate suffering by the patient/resident; and to provide support to the patient, family members, friends, and others present.

Signature of Physician

Print Name

Date