March 24, 2015

Dear Friends, Colleagues, and Students:

We would like to invite you to read and enjoy the information contained in our Biannual Newsletter. In this issue you will find valuable information in the article “Advance Health Care Directive—Why it is important and how to have the conversation with a loved one.” Perhaps you are a caregiver or know of one, many tips are given in the article “A Look at Caregiving.” We wanted to bring back our newsletter in order to keep everyone updated on our work and educational offerings we are involved in; while also being a resource to those who are not always able to attend our educational sessions in person. We hope it is a resource to you. Happy spring!

MARK YOUR CALENDAR FOR UPCOMING EVENTS:

**Every First Tuesday of the month**

**Brown Bag Ethics Journal Club**
12:00 - 1:00 pm, located at our office, 917 Vassar NE (parking available in the back)
Group discussion on contemporary ethics issues, facilitated by Dr. David Bennahum.
Participation via phone and video conferencing available.

**Social Determinants of Healthy Aging Series**
4:30 - 6:30 pm, in Domenici Center West, Room 2112
April 7 - “A Buddhist Perspective on Healthy Living”
May 5 - “A Jewish Perspective on Healthy Aging”
June 2 - “A Mormon Perspective on Healthy Aging”
CME’s available for above offerings. NASW-NM available for Social Determinants.

Social Determinants is available in live-stream video and archived videos on our website.
Advance Health Care Directive- Why it is important and how to have the conversation with a loved one

April 16th is National Healthcare Decisions Day. Part of our work at the Institute is explaining what advance directives are and helping individuals think about and discuss this topic with their family. We would like to encourage you to put an advance directive in place for yourself, a parent, or a loved one. Here we explain why it is important, provide tips on starting the conversation with a loved one, and explain some resources that will help guide the conversation.

First off, what is an advance directive? For those of you who are not very familiar with the term, an advance health care directive or advance directive is the generic term for any document that gives instructions about your medical care and/or appoints someone to make medical treatment decisions for you if you are unable to speak for yourself. A living will and a durable power of attorney for health care are both types of advance health care directives.

It is advisable that an individual, who is 18 years or older have an advance directive, regardless of one’s health status. So whether a person is young, old, in good health or not, we encourage all adults to think about and have one in place. Life is unexpected; one does not know when a life-threatening accident, deterioration of health, or the need for critical care will occur, and this can happen at any point in one’s life. In addition, one’s family does not always know what one’s wishes are, especially if one has never had this type of conversation with them. Oftentimes, families want to do the right thing and they want to make decisions based on what the loved one would want; but they are unclear as to what that is. There can be disagreement between various family members as to what the family member’s wishes truly are. This places the family in conflict during a very trying time. By having the conversation with loved ones and writing your wishes in an advanced directive; it provides the clarity and peace of mind to you and your family.

Starting the conversation, how do I go about it?

There are several things one can consider. The first is that this doesn’t have to be seen as a difficult topic to discuss. One way to approach it is to let the other person know that you care about them and their standard of health care treatment. You would like to talk to them about how they feel on these topics, so that you can honor their wishes and do what is best for them.

The important thing is to simply start the conversation, which then gets the person thinking and explaining to you their preferences. You will want to set aside time when you can genuinely engage in a full conversation with the person. This is not something you mention as you are running out the door or when you do not have time to talk. A conversation can be had over dinner or coffee. It also may take several conversations. Perhaps the first conversation is a general one and the next one leads to more specifics, including writing down the person’s preferences and filling out an advance directive.
When a person does not have an advance directive and is unable to speak for themselves, the health care team will need to determine a decision maker. They will turn to the following...

According to the New Mexico Uniform Health Care Decisions Act, the following people, in the following order would make your health care decisions:

1) Spouse  
2) Significant other  
3) Adult child  
4) Parent  
5) Adult brother or sister  
6) Grandparent/Grandchild  
7) Close friend/or person who knows you well

Resources to help guide the conversation:

- Watching a video is a great way to introduce the topic. There are many educational videos on YouTube which provide helpful tips on how to talk about advance directives with a loved one. Simply go to: www.YouTube.com and search the terms: “advance health care directives” or “discussing advance directives”. It contains a wealth of information.

- Having the documents you need to walk you through the conversation is also important. One such document is the Values History Form—this is a supplemental form, which helps with understanding and talking about one’s beliefs and values for end-of-life care. Go to our website: http://hscethics.unm.edu, from there you will click on the tab “Advance Directives” and then “Values History.”

- Go to our website for the NM Advance Directives form and other forms that are all downloadable for free. Go to: http://hscethics.unm.edu, then click on the tab: “Advanced Directives.” The downloadable forms are at the bottom right of the page. If you would prefer to have these mailed to you, simply call or email us. We are able to mail the forms to you for $5.00 - $10.00, depending on what is requested.

- Another great tool is the Five Wishes, it is known as a “living will with a heart.” It is laid out in a workbook format and can be found at: www.fivewishes.org. This format makes it very easy to fill out. It is also available at our office for $5.00 and we can mail it to you for an additional fee.

- Ask a third party to lead the group discussion, perhaps a family doctor or health care professional you feel comfortable talking with.

- There are several apps one can download to one’s phone, computer or electronic device.
  * Both are found on the Google Play Store online:

  - **My Health Care Wishes Pro** - Created by the ABA, the information is both convenient and confidential—personal information is stored on your phone and not on an outside server or cloud service. Your agent/s will also have the information on their phone. ($3.99 to download)

  - **Advance Directives Incendant** - Allows you to fill out information on the application and then have a paper copy emailed to you. ($.99 to download)
**The Advance Health Care Directive contains 3 parts:**

**Part 1: Is a power of attorney for health care.**
Here you name someone who will make decisions on your behalf, should you not be able to speak for yourself. The person who you name is called your agent, proxy, or representative. There is also a space to name an alternate, should your first choice be unavailable. It is a good idea to list these alternates, if you have them. In this section you are able to specify if you want to withhold certain information or decisions from your agent. You can be as detailed as you want. Unless related to you, your agent cannot be the owner, operator, or employee of a health-care institution where you are receiving care.

**Part 2: Here you give specific instructions about any aspect of your health care.** This includes your wishes regarding life-sustaining treatment, use of artificial nutrition and hydration, and the provision of pain relief. Here you can list if you would like to make an organ or tissue donation. Space is provided for additional wishes.

**Part 3: Here you designate a physician to have primary responsibility for your health care and space for designating an alternate physician.**

This form is “optional” - meaning you do not have to use it, you can modify it or fill it out partially. You can also create your own document which explains your wishes, which can simply be written on a piece of paper. You also have the right to revoke or replace the form at any time.

**Communicating with your agent:**
A large part of the advance directive is deciding on who will act as an agent on the person’s behalf. This is the person that is assigned the role of health care decision maker for the individual if he or she can not speak for themselves. If you are assisting a family member in filling this out, you will want to make sure the agent feels comfortable acting in this role, before you assign it to them. They should be made fully aware of the individual’s wishes and are willing and able to take on the responsibility. The same holds true for the alternate. Once the paperwork is filled out, you will want to make copies of it and distribute it to your primary care physician, your agent and alternate as well as any family or friends that you want to make aware. Keep your copy in a handy place; it should not be kept locked up. If you decide to update the paperwork (which you can do at any time), you will want to destroy the old copies and give the appropriate individuals the updated copy.

Again, we want to encourage you to start thinking about having an advance directive for yourself or assisting a family member with creating one. Starting the conversation early on is recommended as it is much easier to do when a person is healthy than when the person is sick, hospitalized, or involved in a traumatic situation. In so doing, it provides peace of mind and clarity for everyone involved, thus diminishing potential misunderstanding and conflict in the future. **If you have any questions about the forms, please call or email our office. We would be happy to answer any questions you may have.**
A Look at Caregiving

Last semester, our Social Determinants of Healthy Aging Series focused on long-term care issues. This past November we held the session: “Caregiving: Who are they? What are the related stressors What are some related supports,” presented by our director, Anne Simpson, MD, CMD, and Susan Stuart, BUS, CMC, NMG, Owner of Decisions in Care and Geriatric Care Manager. Here is a brief overview of what was discussed.

Caregiving is important as it affects many individuals. Every year over 50 million people take care of someone, with an estimated value of $400 billion in unpaid services provided each year. This number is likely to increase as baby boomers age and as technological advances allow individuals to live longer. Caregivers can be family members, spouses, or friends, and can range in age. They can care for children, developmentally disabled individuals, seniors, military veterans, or anyone who needs help accomplishing daily tasks. Caregiver duties can include: assisting with personal hygiene, dressing, preparation and feeding of meals, transportation, financial management, house management (inside and out), medication, and overall health care management.

It is important to understand that when we talk about caregivers, we are not just talking about adults. Caregivers can be children, from at least 5 to 18 years old, who care for an adult. It is a hidden crisis and often called a “hidden population,” as many are unaware of the situation outside of the family unit. A lack of awareness also stems from few studies conducted on this segment of the population and a lack of acknowledgement from assistance sources, including local and federal government entities. The American Association of Caregiving Youth (AACY) is the only national organization dedicated to understanding this issue and providing resources. According to the AACY, “Over 1.4 million children provide care for a family member unable to manage life independently.” This number is likely to increase with the rise in life-expectancy rates.

A child can become a caregiver for any number of reasons and can often be the primary caregiver living alone with the person cared for. These children are dealing with very serious illnesses and medical conditions that require very sophisticated medical care including such things as: preparation of multiple medications, assistance with catheters and injections, which can be extremely dangerous and overwhelming for both the young person and the cared-for individual. There are many adverse physical and psychological affects, which can include any of the following: anxiety, isolation, depression, a loss of being a child and engaging in child’s activities (playing, extracurricular, etc.), a loss of friends, and an academic decline. One of the worst outcomes is that individuals will drop out of school. According to a 2006 study conducted by the Gates Foundation, “22% of high school dropouts in the United States leave school to care for a family member.”

It is important that schools, the community, and family members are aware of the issue and make every effort to have an adult caretaker or facility take on the adult caregiving duties. Organizations that provide caregiving support need to include children. Government entities need to recognize the need for assistance for individuals who are depending on children to care for them. School districts would do well with establishing a “caregiver-friendly” school system where students and staff are trained to support their students and understand that this may be the reason for a decline in school participation, sleeping during class, or a student’s drop in grades. If you suspect abuse, neglect, or exploitation of a child or an adult, you have an obligation to call the Children, Youth and Families Department at: 1-855-333-SAFE (7233) or #SAFE from your cell phone or Adult Protective Services at: 1-866-654-3219 or 505-476-4912.

Susan Stuart in her presentation discussed how caregiving can affect an adult’s life. The life changes, challenges and negative outcomes can be applied to a child, even more so, due to a child’s age and psychological development.
A Look at Caregiving (continued):

She explained that caregiving will often be an abrupt change to one’s daily lifestyle and habits. It can come on unexpectedly with an accident or with a change in an individual’s diagnosis. The caregiver will often need to balance work, school, or both, caregiving, and one’s own personal and family life. This can lead to stress, also known as caregiver stress syndrome. Symptoms of this include: depression, anxiety, nervousness, and fatigue. It is crucial to recognize the high stress placed on one’s system when taking care of someone. This can be alleviated by having respite care in place and setting aside time off from one’s caregiving duties. Oftentimes, individuals will feel reluctant to take time off, due to feelings of guilt for leaving a loved one or friend. One shouldn’t feel this way, as taking personal time off benefits both the health of the caregiver and the individual they are caring for and is a necessary part of balancing life and long term caregiving.

Valuable resources for caregivers and individuals needing long term care:

- The National Association of Professional Geriatric Care Managers: [www.caremanager.org](http://www.caremanager.org) Provides more information on certified care managers in your area.

- New Mexico Aging and Long Term Care: [www.nmaging.state.nm.us](http://www.nmaging.state.nm.us) provides information and resources available to seniors and can help guide you through the services an individual may need.

- Alzheimer’s Association: [www.alz.org](http://www.alz.org) offers respite care for qualified individuals; call your NM chapter: 505-266-4473, or call the 24/7 helpline at: 1-800-272-3900.

- American Association of Caregiving Youth: [www.aacy.org](http://www.aacy.org) provides resources and support to youth.

Tools for the Caregiver:

⇒ One of the ways to alleviate stress is by being part of a caregivers support group. By talking with others who are facing the same types of issues, problem solving occurs and stress goes down. Being part of a group can be done in person, over the phone, or through email.

⇒ If you are a child or teen caregiver - let others know about the situation you are in, especially teachers. Stay involved with school and outside activities. Talk with someone you trust about the issues you are facing on a regular basis.

⇒ Identify your circle of support; this can include family, friends, or your church group that you can rely on.

⇒ Make a wish list of tasks you would like help with, like running errands, baking cookies, or mowing the lawn. When someone offers their help, you have this list handy and can ask for something specific.

⇒ Call on or hire a care manager who can assist the family to navigate resources and identify needs an individual may have. Care managers can reduce stress, provide concrete solutions, explain programs the individual will be eligible for, help plan for the future, and assist in crisis situations, among other things.

We encourage you to view the presentation in its entirety online.

From our home page: [http://hscethics.unm.edu/](http://hscethics.unm.edu/) you will find “Social Determinants of Healthy Aging,” click on the link: “View presentations online.” Click on: November 2014 for this presentation.
Social Determinants – Spring Session

Our Social Determinants of Healthy Aging Series continues this spring with a focus on how faith communities address healthy aging as a life continuum.

We have held two seminars under this focus. February 3rd was the first, titled: “A Christian Science Perspective on Healthy Aging,” presented by Shannon Horst, a former media and legislative liaison, Christian Science, NM and a reintroduction of the program given by our director, Anne Simpson, MD, CMD. We had a great group and it became particularly interesting during the Q & A portion. On March 3rd, we held: “Promoting Healthy Aging in a Christian Community” presented by Helen Hamilton, RN, MSN, Director of Health Ministry, UNM HSC Black Health Resource Center and Charles Becknell, Jr., Associate Minister, Emmanuel Missionary Baptist Church, and Associate Director/Lecturer, Africana Studies, UNM. A great deal of valuable information was presented. We have a diverse group of faiths scheduled to participate. Please see page 1 for the listing of upcoming seminars.

We encourage you to come and listen to the presentations. These are free and open to the public and 2 credits of CME and 2 NASW-CE are offered.

All of our presentations are in video format and available to view online. You can view these by going to our homepage: http://hscethics.unm.edu/ then click on: “View the Presentations Online” found on the right side under: “Social Determinants of Healthy Aging.”

Advance Life Planning Presentations

Are you a member of a local club or group?
Is your group interested in learning about advance life planning?

The Education Subcommittee of the HSC Biomedical Ethics Committee is actively looking for opportunities to speak to local groups or organizations. The presentation helps individuals think about and understand such issues as: what an advance health care directive is, why it is important to have one, what palliative and hospice care are, and what a DNR (do not resuscitate) form is. The presentation is followed by a Q & A session for the audience. Presentations are given by committee members in the health care, legal, and related professional fields, who are well-informed on these topics. Through education, it is our hope individuals will gain the needed tools and understanding for making medical treatment decisions for themselves and family members. If you are interested in a presentation for your group, or know of an organization who would benefit from a presentation, please contact: Cathy Combs or Sarah Treviso at 505-272-4566. The presentations are free and open to the public.
We would like to offer greater educational programming for the community as well as provide a fellowship scholarship within the Institute. In order to do this we are seeking committed donors who are interested in supporting our efforts.

If you are interested in supporting the Institute: Go to our homepage: http://hscethics.unm.edu/ Click on the button: “Support the Institute” on the bottom left corner. Or you can fill out the information below and mail it to us. Or call our office to make a donation over the phone.

Yes, I would like to support the Institute for Ethics with my gift of:

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