

# The A-Team

asera<sup>care</sup> Hospice Volunteer Newsletter



## An Encouraging Word:

“Sometimes people get the mistaken notion that spirituality is a separate department of life, the penthouse of existence. But, rightly understood, it is a vital awareness that pervades all realms of our being.”  
 Brother David Steindl-Rast

## You Did It!

When it comes to dying, we're all amateurs. We haven't done it before - and when it comes our time we'll still be an amateur. At that time, I know that everything I have been in my life will come up before me. I will need comfort and reassurance, and certain things I know will help me to die.

Thank you for being that person, that presence, and that support for our patients on each of your visits.



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## Timely Tips and Reminders



**Reminder:** You may all get started on your next Aseracare University Patient's Rights: The Right Thing to Do; this is due no later than **April 30<sup>th</sup>**.

Follow these simple instructions:

- go to website HYPERLINK "<https://aseracarevolunteers.care2learn.com/>" <https://aseracarevolunteers.care2learn.com/>
- click the icon box that says "Volunteers! Click Here."
- login by entering your username and password

**Reminder:** When submitting your 'Volunteer Note V2', use the patient's full *legal name*. Some of you are just typing in a first name, nicknames, or even the wrong name.

**Tip:** Do you ever want to reference or reread an old volunteer newsletter? All of our newsletters are posted on the HVA. To access them go to the HVA Main Menu: NHD Repository> Doc Index then click on the link: Aseracare- Bloomington, MN under Hospice Newsletter Archives.

**Tip:** Vigil volunteers, if you are visiting with a family, remember to keep the conversation sacred as this is a sacred time. Redirect yourself and families to keep conversation about the patient life review (versus the weather or the economy).

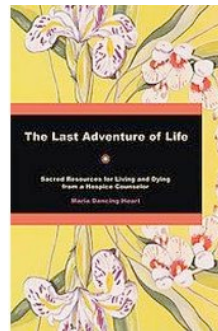
## Quaint Quips & Funnies ....to bring a smile

The older you get, the better you get---  
unless you're a banana!

## The Book Nook

### Recommended Books, CDs, and Media

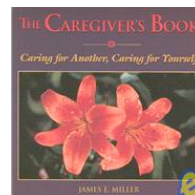
Here are two suggestions for books that that incorporate spirituality for the hospice setting for patients and caregivers alike.



***The Last Adventure: Sacred Resources for Living and Dying from a Hospice Counselor*** by Maria Dancing Heart as recommended on the HVA website. 2008.

288 pages. The author is a Yale graduate and an ordained minister who ministers in the area of

hospice and believes hospice in grounded in spirituality. Her book offers prayers, poetry, scripture, and meditations from many spiritual traditions. This is a good book for caregivers themselves and one that provides readings to share with patients.



***The Caregiver's Book*** by James Miller as recommended by Willowgreen. 2008. 80 pages. The author is a grief counselor and spiritual director. The small book offers both practical suggestions and

inspiration for the caregivers.

## Helpful Hospice Hints

### ☘ **Spiritual Distress: What is Spiritual Distress?**

Spiritual distress is a disruption in one's beliefs or value system. It affects a person's entire being. It shakes the basic beliefs of one's life.





**What are the Signs and Symptoms of Spiritual Distress?**

- Questions the meaning of life
- Afraid to fall asleep at night or other fears
- Anger at God/higher power
- Questions own belief system
- Feels a sense of emptiness; loss of direction
- Talks about feelings of being left by God/higher power
- Seeking spiritual help
- Questions the meaning of suffering
- Pain and other physical symptoms can be expressions of spiritual distress as well

**What can be done for Spiritual Distress?**

*Spiritual distress is common with terminal illnesses.*

Not everyone has it the same way or to the same degree.

Volunteers and Patients:

- Remember, not everyone has spiritual distress
- They may not feel up to talking with many people  
However, it is very important to have at least one person who they trust to talk to about their fears and concerns
- Do not be hard on them for not feeling very “spiritual”
- Allow them to be angry. Try to talk about that anger
- Try listening to devotional tapes
- Try listening to music without words
- Write poetry or work on an art project
- Forgive yourself

Volunteers

- Do not feel that you are bothering the team by asking questions
- Asking questions means that you care enough to ask the question
- Look for ways to keep and honor desired rituals and ways of life

- Provide calm, relaxing setting
- Be willing to be present without having to “do” something
- Treat the patient with dignity and respect
- As much as you can, enjoy this time together and look for ways to make memories
- Do not say “I know how you feel” because you do not. Instead, offer empathy for the continual loss of familiar meaning and identity associated with the illness
- Try not to “help,” rather provide support
- Support any desire to maintain links with friends and family
- Be willing to listen and reminisce
- Be open to giving spiritual support if asked or contact the team’s Spiritual Care Coordinators

You can find other HPNA Patient Teaching Sheets on end-of-life care at [HYPERLINK "http://www.hpna.org/PatientEducation.asp"](http://www.hpna.org/PatientEducation.asp) <http://www.hpna.org/PatientEducation.asp>.

*Approved by the HPNA Board of Directors October 2005*

**Interview Insights**

**Interview with Hospice Spiritual Counselor, Steve Robertson – December 4, 2009**

**Question** – In hospice care, you work with dying patients of all ages – for seniors (say 70+) are there fears expressed that you don’t hear from younger patients?

**Answer** – The fears expressed by seniors are different, often because they don’t comprehend the reality of the situation. They may know that something’s wrong, but they have a hard time verbalizing it. ‘I feel funny’ is a common expression; they don’t know how to express what they are feeling, and would never say, ‘I think that I might be dying.’ Fear is not an absence of knowledge, it stems from the inability to comprehend



what lies ahead. So if a patient says to me, ‘I feel funny’ I would say, ‘You know, it’s OK that you feel funny.’ I’m working now with a patient, Lucy who is a 98 year old woman, she has some dementia, but it is not debilitating. When she told me recently ‘I feel funny’ I told her ‘That’s OK, it’s normal.’ I said ‘Lucy, you have had a very long life, and now your body is starting to wear out. Sometimes you might feel differently than you ever have before, and it’s probably because your body is getting ready to die, do you understand what I mean?’ Lucy told me yes, that it must be just that. I asked her if she has any feelings about dying. She told me that she’s OK with it, that sometimes she feels sad about dying, but she doesn’t want to live forever, and it’s good to know why she sometimes doesn’t feel ‘right’. She told me she’s not in pain, but it’s just a different feeling. Again I told her, ‘That’s OK – that’s normal. That’s why you’re living here now, [in a nursing home] so that we can do more to help you, and always be there for you when you need help.’ Lucy said, ‘Yes, that’s right now I remember.’

I believe that telling the patients the truth is important, but you meet them where they are. Why would you go to a place that they can’t comprehend; how does that help them understand the dying process; how would that alleviate any fears they may have?

**Question** – Can you tell me more about meeting the patient “where they are”?

**Answer** – For example, when Lucy told me she was feeling ‘funny’. I would never say, ‘Well you are dying, remember?’ That would close down the conversation, and would show a lack of compassion. In my response to her, I told her that that is a normal feeling to have, I reminded her of her age, and that her body is probably starting to wear out, and then reminded her that she is probably getting closer to death.

It’s similar to how you respond to a 4 year old, when they ask you where babies come from – you don’t give them the whole biological story – when they’re 4 years old all you might say is that babies

grow in mommies’ tummies, and that might be all the information desired. As the child ages, and his/her curiosity and intelligence develop, you add more information. But you always tell the truth.

**Question** – In a recent review of the literature, I looked at how a patient’s spirituality and/or religiousness may affect his/her fears about dying. Literature, while somewhat mixed indicates that those with high intrinsic religiousness display less fear; those with low spirituality/religiousness have less fear; and, those with moderate religiousness display higher fears with regards to death. Can you share some of your observations, and knowledge from your work with patients, with regards to spirituality and religiousness?

**Answer** – Let me give you a couple of examples of patients, showing how I met them where they are, and also give a couple points of interest that I have told patients, that I think have been helpful to them.

Last year at Christmas time, I had a patient, Ben, who was agnostic. At first Ben had no desire to see me, a Spiritual Counselor, as he said he had no faith. As the reality of his eminent death approached, Ben reported feeling confusion and some fear with regard to dying; his nurse and social worker asked him again he if might like a visit with me, and he agreed. With regards to our differing individual beliefs, walking into his room, this is where I saw each of us.

During my visits, Ben eventually told me that he had no traditional religious beliefs, however, as we became closer, it was evident to me that Ben was clearly a spiritual person. It was the spirituality of each other that we discussed. We both learned that even in our differences, there were areas where we connected, and as we explored those connections over many visits, Ben reported to me he had less fear. The night before Ben died, he told me, “Steve if you are right about what happens to us after the death of our bodies, then I know that there is great happiness for me after this life. But if I am right, and there is nothing for us after this life, then it doesn’t matter. Neither one of us will know until we die. Either way,





we have nothing to fear. I am so thankful for your visits with me, and I want you to know that I am truly at peace now.”

It was through our conversations we both recognized where, even though our religious differences are great, our spiritual connection was strong.

I have another patient I am working with right now, who is a fundamentalist. He has great fear in large part because of his religious beliefs of heaven and hell; there is no room for shades of gray. When it comes to his death, as well as his spirituality, he is experiencing anxiety. Working with him to find our spiritual connection has been much more difficult.

This man has a tremendous fear of hell. I personally, do not believe in hell. I believe that if ‘God’ is all present, all knowing, and all loving, that there cannot be a place that is without ‘God’ – even hell. Hell is one thing that this man and I are currently talking about. It has been much more difficult to help this man find peace with his death, but it is an on-going process, and he has told me even these conversations are helpful. Finding a spiritual connection with others (through our conversations) is something that I know he has appreciated.

There are a couple of things I shared with him, that he has told me have also brought him comfort, and have helped reduce some of his fear. The first is that in the bible there is only one variation of a theme in every book. It is not that God is love, which most people guess. It is a variation of ‘fear not’; whether it is ‘fear not’, ‘be not afraid’, ‘have no fear’, or ‘there is nothing to fear’ – you will find a variation of this in every book. Humans fear what they cannot know, or cannot understand. This is why I believe that it is SO important to give patients as much information as we can about their condition – but meeting them ‘where they are’ as we do so. Always be honest with them.

The other thing that I told this man about is Cheyne-Stokes breathing. This occurs at the end of life ... it’s a breath in (Steve makes the sound) that sounds like a gasp, and it’s a guttural sound.

Whenever someone dies, they make this sound. Also, whenever a baby is born, its first breath of air sounds like this. So we make the same “sound” as our first breath, and our last breath. The Hebrew word for ‘God’ is also this very same sound (it cannot be pronounced, it’s a sound). So, our first ‘word’ when we are born is ‘God’, and our last word when we die is ‘God’.

## Monday Night Monthly Meetings



April 5, 2010  
7:00 p.m. – 8:00 p.m.



**Location:** Bloomington office  
**Topic:** Pet Therapy Extravaganza!  
**Class Objectives:** Learn a new trick.

- Dog Handlers will learn a new trick to enrich the lives of their patients through pet therapy
- Meeting and greeting Joan. She is our scheduler from Home for Life and would love to meet the volunteers in our program.
- Special mystery guest
- Get the insiders’ insight straight from the horse’s mouth in how to role model compassion and love for your patient



**All volunteers are encouraged to come regardless if you have been specifically trained in pet therapy.**

