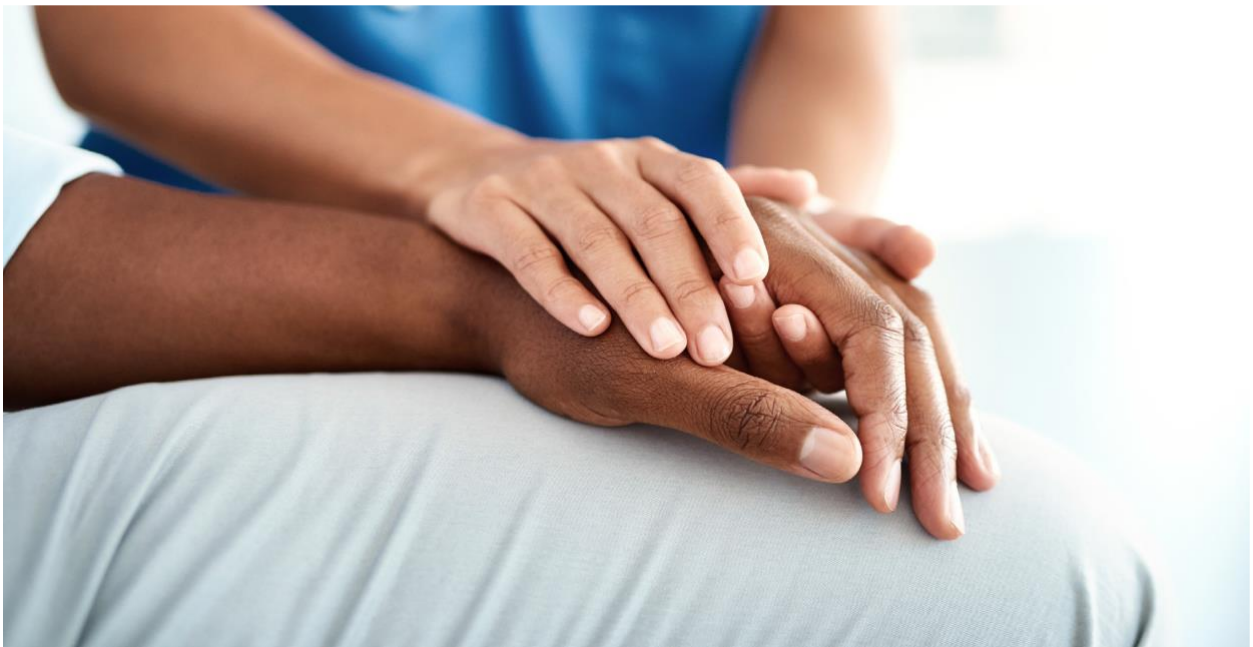


# “No One Dies Alone”



Orientation/Training Manual

Johns Hopkins Bayview Medical Center

**“No One Dies Alone”  
Orientation Program  
Stellia Karais and Paula Teague  
April 6, 2019**

- |       |   |
|-------|---|
| 11:00 | Introductions and experience with death and dying<br>Why did you become a NODA volunteer? |
| 12:00 | Lunch   |
| 12:30 | Orientation Manual  |
| 1:00  | Understanding the Medical Intensive Care Unit (MICU)                                      |
| 1:15  | Role Plays  |
| 2:00  | NODA Process of Notification  |
| 2:30  | Unit Tour<br>Anita Hetrick (Call 0-0494 before heading over)                              |



## Prayer of the Caregivers

Give us the grace this day  
to tend those in our care  
with full attention  
& true tenderness.

Remind us anew to use our hearts  
as well as our minds & hands  
in our practice.

Create in us a generosity of spirit that we may clearly see  
the unique spark  
in each person we serve,

that no one in our care today  
might feel themselves a burden,  
another chore on a long list.

Wake us to recognize  
the unspoken need,  
a cool cloth on a hot brow,  
soft hand upon a shoulder.

Let us remember we are One.  
Let us honor our call to  
the service of healing,

the small part we play in  
the repairing of the light,  
the consolation of the world.

*~Deborah D. Cooper*  
National Association of Catholic Chaplains

## No One Dies Alone Background

Ask someone, anyone, what he or she most fears about dying. The universal response is dying in pain and dying alone. We all wish for a painless death in the presence of someone who cares. Johns Hopkins Medicine has endorsed a program that is focused on the needs of someone who is nearing the end of life. Special attention is given to dignity, respect and comfort. Thus, families can be at the bedside of their loved ones and not watch them suffer. More important, patients no longer have to needlessly suffer.

But what happens to the person who has outlived his/her family and friends or the person who has no one. What if the patient has lived life away from family and mainstream society? Why should these people die without human companionship?

Mother Teresa said, "No one should die alone...Each human should die with the sight of a loving face." We can make this a reality. We can provide companionship to patients in the dying process who are truly alone, and in so doing, provide a gift of respect and dignity to another human being at the end of life.

For thousands of generations the family has given comfort to those leaving this life. The modern medical community is beginning to recognize the need to give attention to end-of-life issues and to provide this kind of care as well.

The plan is simple. Any employee or community hospital volunteer may be an end-of-life compassionate presence. The companion may choose the time, date, and the number of hours he/she will be available. A staff nurse refers a patient to the No One Dies Alone (NODA) program through a CORUS page. This notifies the volunteers that a patient who has no family or friends is in the dying process. The volunteers will schedule themselves to sit present to the patient dying alone. The companion comes in to sit with the dying person, thus, providing the support that all people deserve as they near the end of this life.

The expectation is simple: quiet presence, perhaps holding a hand. Being there is the most important thing. The goal is death with dignity.

*No One Dies Alone (NODA) is a program that offers companionship and support to patients who are nearing the end of life. No One Dies Alone provides a dignified death to individuals who have no family or close friends to sit with them at the end of life. At Johns Hopkins, hundreds of unaccompanied deaths occur each year within the hospital. Through this program, we can provide a compassionate presence for patients.*

### **Goals of the NODA Program**

- Provide a compassionate and caring presence for patients who are dying alone
- Support those who are dying alone so their death can be as dignified as possible
- Relieve the staff who are concerned about a patient who is dying alone

## Communication Skills

- Learning to communicate well is really about learning to be present to another
- In being present, we “communicate” to another that we are fully there in mind, body and spirit
- In being present, we “communicate” that we will not abandon the person
- In being present, we set aside our personal agenda and assumptions. We come with an open heart.

We are present through:

- Eye Contact:
- Touch
- Tone of Voice
- Affect and Attending Posture

We communicate with words only 7% of the time; we communicate with our body 55% of the time and our tone 38% of the time.

- Being empathetic:
  - Seeing how the patient sees
  - Affirming what the patient believes
  - Removing personal agenda
  - Viewing the experience of illness/dying/hospitalization from the patient’s perspective
- Emulating tenderness, gentleness, kindness and friendliness
- Focus on the patient and the patient’s needs
- Do what you say you will do, but be careful what you promise

**Dying is a sacred time of life  
...a stage filled with meaning and important life tasks.**

What You See	What Is Happening
<b>Early Stage:</b>	
<p>A decrease in both eating and drinking which may last from days to weeks.</p> <ul style="list-style-type: none"> <li>◆ Less interest in food; eating may become more of a burden than pleasure.</li> <li>◆ Occasional choking on fluids.</li> <li>◆ Feeling “full” quickly.</li> </ul>	<p>The body naturally begins to conserve energy and requires less nourishment.</p> <p>There is no “hunger” and no “suffering” with this process.</p> <p>IV fluids and artificial feeding will NOT promote comfort or prevent death.</p>
<p>Changes in physical appearance may last a few hours or days.</p> <p>Often the patient’s hands and feet may feel cool and may darken in color.</p>	<p>The circulation is slowing down and the blood is being reserved for the major internal organs.</p>
<b>Mid Stage:</b>	
<p>Patient will respond less and less to you and his/her surroundings.</p> <p>Eventually the patient is completely unable to speak or move.</p> <p>This usually happens during the last few days of life.</p>	<p>Patient is preparing for release and detaching from surroundings and relationships.</p> <p>This is a physical and spiritual response to the dying process.</p>

**Dying is a sacred time of life  
...a stage filled with meaning and important life tasks.**

What You See	What Is Happening
<p>Intermittent disorientation and restlessness may occur in most patients.</p> <p>This may increase in the last days.</p>	<p>This is due partly to the changes occurring in the patient’s metabolism.</p>
<p>You will notice a gradual decrease in the patient’s urine output. If the patient has a Foley catheter, the urine may appear very dark. The bowel movements may stop altogether or the patient may become incontinent during the last few days.</p>	<p>As the circulation decreases, kidneys and bowel function may be reduced.</p> <p>Muscles may relax causing incontinence for the patient.</p>
<b>Last Stage:</b>	
<p>Breathing becomes more irregular.</p> <p>Breathing may be shallow and have long pauses, which become more frequent and longer in duration as death approaches, especially during the last few days.</p> <p>Increasing sounds of congestion in the chest and a rattle in the throat may be heard during the last hours.</p>	<p>Circulation of internal organs will decrease, especially the heart and lungs.</p> <p>Throat muscles will begin to relax and the lungs will lose their ability to clear fluids.</p>





## **Physical Aspects of Dying**

Because we want the patient to die in peace and comfort, please let the nurse know if you notice any of the following signs that may indicate discomfort:

- Patient winces when moved
- Moans
- Holds body tense and stiff
- Breathing appears excessively labored
- Restlessness or agitation

You will know that the patient has died when:

- The patient has no pulse or heartbeat.
- The patient does not breathe
- The patient will not respond to your voice.
- The eyelids may be slightly open and the eyes fixed.
- The jaw will be relaxed.

### **Definition of Dying – Opt in Criteria for Referral**

#### Rule in Criteria:

- Medical provider has deemed patient dying within 24-48 hours
- Glasco Coma Scale of  $\leq 3$
- Family need respite
- Documentation that there is no family at onset of hospitalization – social work
- Family coming however there is a significant time gap before they can arrive

## What to Expect as a NODA Volunteer

### Step One: Notification

You will be notified by a text on your cell phone. This message will indicate that there is a NODA referral.

### Step Two: Signing Up for the Vigil

- You must self-schedule
- Schedule yourself for a time. No less than two hours and no more than four hours.

### Step Three: Preparation for the Vigil

- Call the unit where the patient is located and make sure you are still needed. Unit phone numbers are available.
- Bring materials such as music, reading with you to the hospital.
- Ask for nurse taking care of the patient if you have specific questions; e.g. faith tradition, what the patient might like. Remember that the nurse's time is valuable and you want to have the questions focused and not take up too much time.

### Step Four: When You Arrive for the Vigil

- Locate the patient's room.
- Introduce yourself to the nurse taking care of the patient and make sure they understand your role as a NODA volunteer
- Use hand hygiene precautions and "gel in and gel out"
- Check for any inflectional control procedures you should follow; e.g. wearing a mask, gown or gloves
- Pull up a chair near the patient. Try for a side of the bed where there is less equipment.
- Sit down and introduce yourself. Explain to the patient why you are there. For example, "I am... and I am a volunteer. I am honored to be able to spend some time with you at this special transition. I will...(tell them what you will do – sing, sit quietly, read, etc.) I will stay for a while and I will tell you when I need to leave."
- Remember to talk in a tone that can be heard by the patient but is not too loud or disruptive to others
- Engage in whatever practices you feel might be meaningful.

### Step Five: The Vigil

- Center yourself for the vigil – quiet your spirit.
- There are monitors in the room giving patient information that the nurse will attend to.
- Engage the patient's nurse if or when they step into the room.
- Take breaks as need. Remember to gel-out and gel-in in each time.
- Practice whatever is meaningful to you. You might:
  - Touch the patient's hand or arm if that seems comfortable
  - Sing
  - Provide instrumental music
  - Play a song
  - Pray aloud in a way that is inclusive of the person's faith
  - Pray silently
  - Breath ministry – matching your breath to the patient's
  - Meditate on the life and gifts of the person
  - Quietly imagine the patient surrounded with light and love
  - Read poetry or sacred writing (be inclusive)
  - Use a hand labyrinth and gently circle the labyrinth holding thoughts of the patient, their life and good death
  - Think about the person
  - Tell a story that has meaning

It is important to remember that the patient may be very sensitive to sounds so quiet or soft noise is important. Less is more!

If the patient is actively dying you might see fall in blood pressure, slower heart rate, slower and infrequent breathing, deep breaths with long pauses between. If the patient is struggling or seems to be suffering please let the nurse know.

### Step Six: Ending your Vigil

- If the patient is actively dying you may want to extend your stay until they have passed if you can. A nurse can help you determine the timing.
- When you need to leave talk to the patient and say that you have been honored to be with them and say that you are leaving.
- Contact the patient's nurse and let them know you are leaving.

### Step Seven: After the Vigil

- Document your vigil on the website for our record keeping
- Contact spiritual care if you would like to talk or debrief your experience. These conversations can take place in person or by phone.
- Provide information about the vigil on the website. We appreciate your feedback and suggestions to improve the volunteers' experience

## Resources

When we honestly ask ourselves which persons in our lives mean the most to us, we often find that it is those who, instead of giving much advice, solutions, or cures, have chosen rather to share our pain and touch our wounds with a gentle and tender hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing, not curing, not healing, and face with us the reality of our powerlessness, that is the friend who cares.

*-Henri Nouwen*

When you sit with a crying woman, just sit with her. Do it with all your mind, heart, and soul. Be fully present to her without this other agenda going on at the sidelines. In other words, do it without passing judgment on her, wanting to convert her to your point of view, desiring her appreciation, wondering what others might think, worrying about the weather, or generally getting caught up in one's own feelings, desires, opinions of the moment. Sit with an undivided heart. Such deep availability requires a hospitality that receives people as they are, without necessarily seeking to cure, fix, or repair their problems. When you are fully present, you are simply there with the heart flung open.

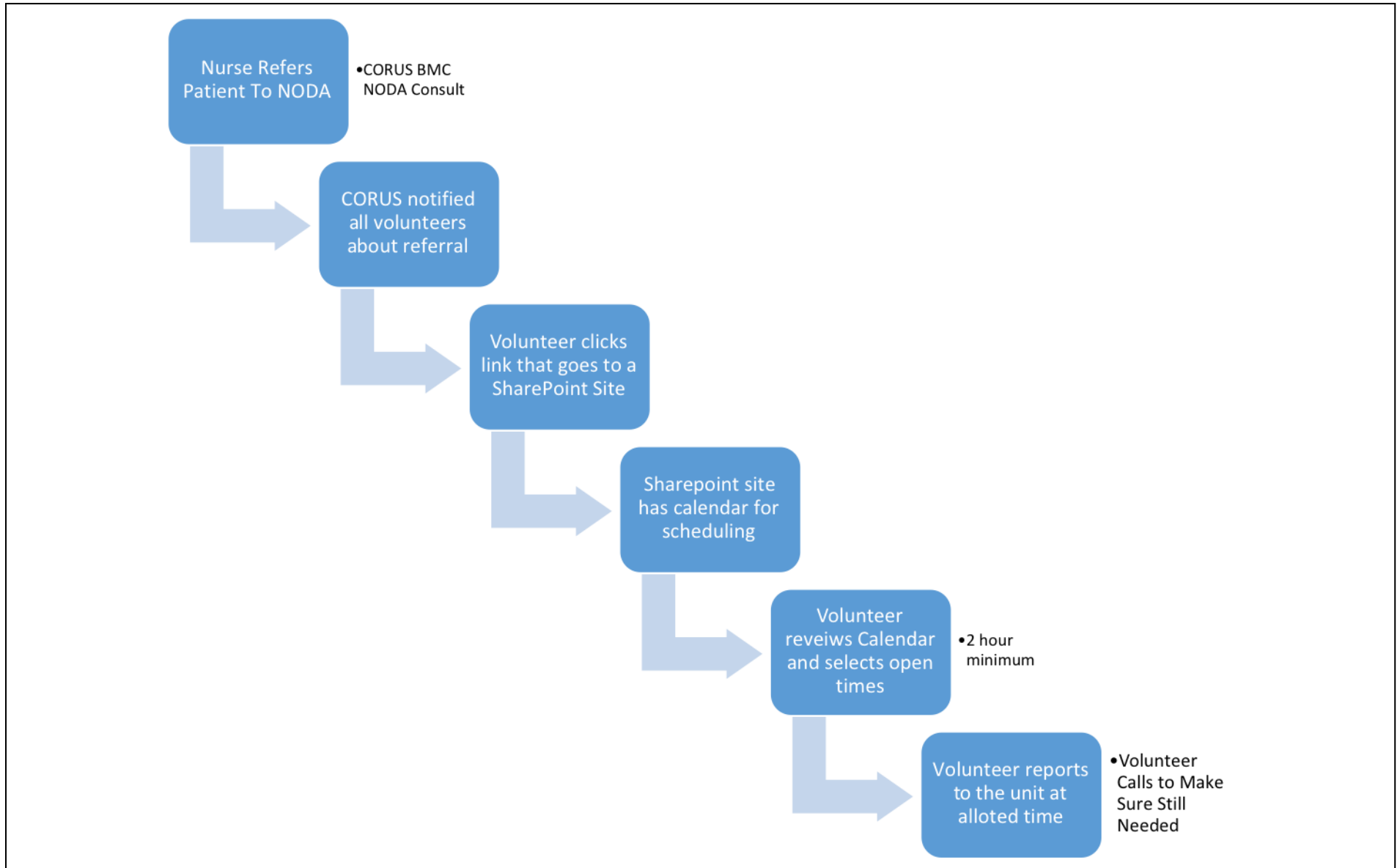
**From Weavings, Sue Monk Kidd**

Some Scriptures that can be helpful:

Psalm 23, 46, 62,63,139, 121, 145.

John 11:25, John 14:1-6, 2 Corinthians 1:3,4, 1 Thessalonians 4:13-18.

If Christian, the Lord's Prayer is usually comforting and something everyone knows.



**NODA REFERRAL PROCESS**

## Procedure

- Before volunteer reports for shift, call the unit where the patient is located. Ask for the charge nurse on the floor where pt is located.
- Ask the charge nurse if the patient is still in need of a NODA volunteer.
- If still needed, volunteer puts badge on and reports for assigned shift by checking in with the charge nurse.
- Volunteer speaks to patient's nurse. Become aware of patient's condition and any special needs.
- Volunteer should bring only items that can be kept in pockets. There is not storage for purses, bags etc.
- Tell patient's nurse/charge nurse that you are leaving.
- Volunteer removes badge.
- At end of shift, fill out evaluation sheet which is located on the SharePoint site.



**Important phone numbers**

Hospital Operator	410-550-0100
Spiritual Care	410-550-7569 (office) 410-283-4345 (pager)
Bayview On-call Chaplain (CORUS)	
Bayview Volunteer Office	410-550-0627
Medical Intensive Care Unit (MICU)	410-550-0494
Burn Intensive Care Unit (BICU)	410-550-0890
Surgical Intensive Care Unit (SICU)	410-550-0565
Cardiac Intensive Care Unit (CICU)	410-550-0875
Neuro Critical Care Unit (NCCU)	410-550-7871
Medical Unit A	410-550-0596
Medical Unit B	410-550-0480
Progressive Care Unit	410-550-0882
Wenz Orthopedic Unit	410-550-4086
Carol Ball Medical Unit	410-550-1500

### **NODA Volunteer Evaluation**

*Turn in completed form to Paula Teague – pteague1@jhmi.edu.*

**Unit:**\_\_\_\_\_ **Date:**\_\_\_\_\_ **Time:**\_\_\_\_\_

1. Was the notification process satisfactory? If not, comment below.

\_\_\_\_\_

2. Did the staff make you feel welcome? \_\_\_\_\_

3. When you arrived did the patient appear comfortable? \_\_\_\_\_

4. If you had any questions and/or concerns regarding the patient, did the staff address them satisfactorily? \_\_\_\_\_

5. Did you feel you were prepared for your role as a NODA volunteer once you arrived at the bedside? \_\_\_\_\_

6. What could be done to improve the role of the NODA volunteer?

7. Was this a valuable experience? \_\_\_\_\_

8. Anything you would like to share about your experience?

\_\_\_\_\_

9. Did you reach a chaplain to debrief? \_\_\_\_\_

Comments/Suggestions:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Some of the items you might bring with you:**

- Soothing music and music of patients' choice
- Bible, devotionals, and booklets for comfort, peace, information and support
- Blankets/Prayer Shawls: These will be sent with the personal artifacts at time of death.
- Cross to hold in the hand: Only place in the hand if you know the patient is Christian

## **Notes/Questions/Concerns**

# Volunteer Program at Suburban Hospital Ensures No One Dies Alone

Volunteers give comfort, bear witness.



By **Karen Nitkin** on 03/30/2015  
Sophie Casson

Published in [April 2015](#)

Tamiko Scian's fears evaporated the moment she entered the evening-dimmed hospital room and saw the elderly man lying still on the bed, breathing quietly. "He looked at ease," recalls Scian. "I walked in and whispered in his ear. I identified myself and told him I would be with him for a few hours."

Scian, a human resources specialist at Suburban Hospital, had been nervous about signing up for the hospital's No One Dies Alone program because she lacked clinical experience. But she volunteered anyway, moved to action by the holiday spirit of giving and because she missed her own recently departed grandparents. As the man edged toward death, Scian held his hand, read Bible passages, played classical music on an iPod and sang "This Little Light of Mine."

Though the man did not speak, Scian felt a deep connection with him, and she says she was honored to witness and ease his final moments. "I could feel his spirit in the room," she says.

Scian is one of 29 Suburban employees volunteering with No One Dies Alone since it began in February 2013. Of the current volunteers, 19 work in food services, information technology and other nonclinical jobs, says Pamela Fogan, director of volunteer services. Fogan is still seeking more volunteers.

The program is as simple and meaningful as it sounds, providing quiet support to patients who would otherwise die without a companion or witness.

About one patient per month meets the criteria of being close to death, without support of family or friends, and receiving only comfort care. When an eligible patient is expected to die in 24 to 72 hours, a group email goes out, inviting volunteers to sign up for two-hour or four-hour shifts.

“You don’t come into this world by yourself,” says volunteer Patricia Gabriel, a nurse educator. “And you shouldn’t leave by yourself.”

## **Remorse and Inspiration**

The seeds for No One Dies Alone were planted on the other side of the nation, where a dying patient asked Sandra Clarke, a nurse at Sacred Heart Medical Center in Eugene, Oregon, to sit with him. She tended to her other patients first, and the man passed away before she returned to his side. Her remorse inspired her to create the program in 2001. The concept has since been embraced by hospitals nationwide.

Customization is encouraged to fit the needs of each hospital. Suburban’s team rewrote Clarke’s orientation materials and created supply bags for volunteers to use, containing battery-operated candles, an iPod loaded with classical and gospel music, a printed labyrinth that volunteers can trace with their fingers for prayers, books about death and different religions, and a journal for jotting down thoughts as they sit with a dying patient.

Suburban is the only hospital within the Johns Hopkins Health System with the program so far, says Rev. Barbara McKenzie, a chaplain at Suburban, though all the hospitals have pastoral care departments that provide spiritual support to people coping with illness, trauma or grief.

During a recent 90-minute orientation, six potential volunteers—four women and two men—learned that a person’s final hours may be characterized by sporadic breathing, agitation and bursts of lucidity.

The volunteers are taught to read the body language of a person who can no longer speak: a deep, contented breath when a loving hand is placed on a shoulder, a brow that unfurrows at the sound of a soothing voice. “Always assume they can hear,” social worker Marie Tax tells the group.

Most program recipients are elderly people without loved ones nearby. Once, volunteers tended to a dying man while his wife, who was in her 90s, navigated two hours of Montgomery County public transportation to be by his side when he passed. In another case, a son flew to Maryland from Manhattan to say goodbye to his father but could not stay until the man died.

For Gabriel, used to the problem-solving adrenaline of the emergency room, the program offers an opportunity to “just be in the moment,” honoring the life that is departing. “There is a sense of honor and respect that you’re able to be there,” she says.

**Carol McLeod, Suburban Hospital Volunteer for the No One Dies Alone Program and the Patient and Family Advisory Committee**

March 23rd, 2017|[Everyday Hopkins](#)|By [Everyday Hopkins](#)



"Sometimes they hear me, and sometimes they don't, but I know deep down that they feel my presence."

I have spent the last 30 years of my life with people in the very last moments of life. I know this would be uncomfortable for some people, but I believe it is my calling.

I spent my early adult years supporting my husband in graduate school, raising three wonderful children and singing in local musical ensembles. When my children graduated from college, I went back to school — first exploring music therapy, and then nursing. I graduated as a registered nurse at age 50 and went on to be what I was meant to be — a hospice nurse.

Back in those days, in the early years of the AIDS epidemic, we were unsure of what we were dealing with, but there were so many patients who needed our care, and we did our best to keep them pain-free and comfortable.

An inpatient hospice facility isn't a frightening place. It's actually quiet and loving, and the family members of the patients tend to bond together to form a village of sorts. They share their pain and grief in ways that many people never understand.

But family can't be there day and night, and sometimes patients pass away when their loved ones are at home getting much-needed rest or dealing with the reality of their lives. Without fail, these family

members always wanted to know who was with their loved one at the end. It was important to them that nurses and other hospice staff members were there to gently guide their family member to the other side.

Now I'm 82, and I've been volunteering at Suburban Hospital for almost 10 years. My "day job" is in the Emergency Department, where I'm a greeter, gopher and helper. I also serve on the Patient and Family Advisory Council.

I am also proud to serve on the No One Dies Alone Committee. NODA is a special program that provides dying patients with a companion if they don't have friends or family nearby. No medical care is involved, so NODA volunteers come from many different departments here at Suburban.

What a privilege it is to sit with people who are in the last hours of their lives and help them find peace. I hold their hands and hum my favorite songs to them. Sometimes they hear me, and sometimes they don't, but I know deep down that they feel my presence.

I truly believe there's nothing more fulfilling and meaningful than helping a person die peacefully and quietly. It is a true gift.