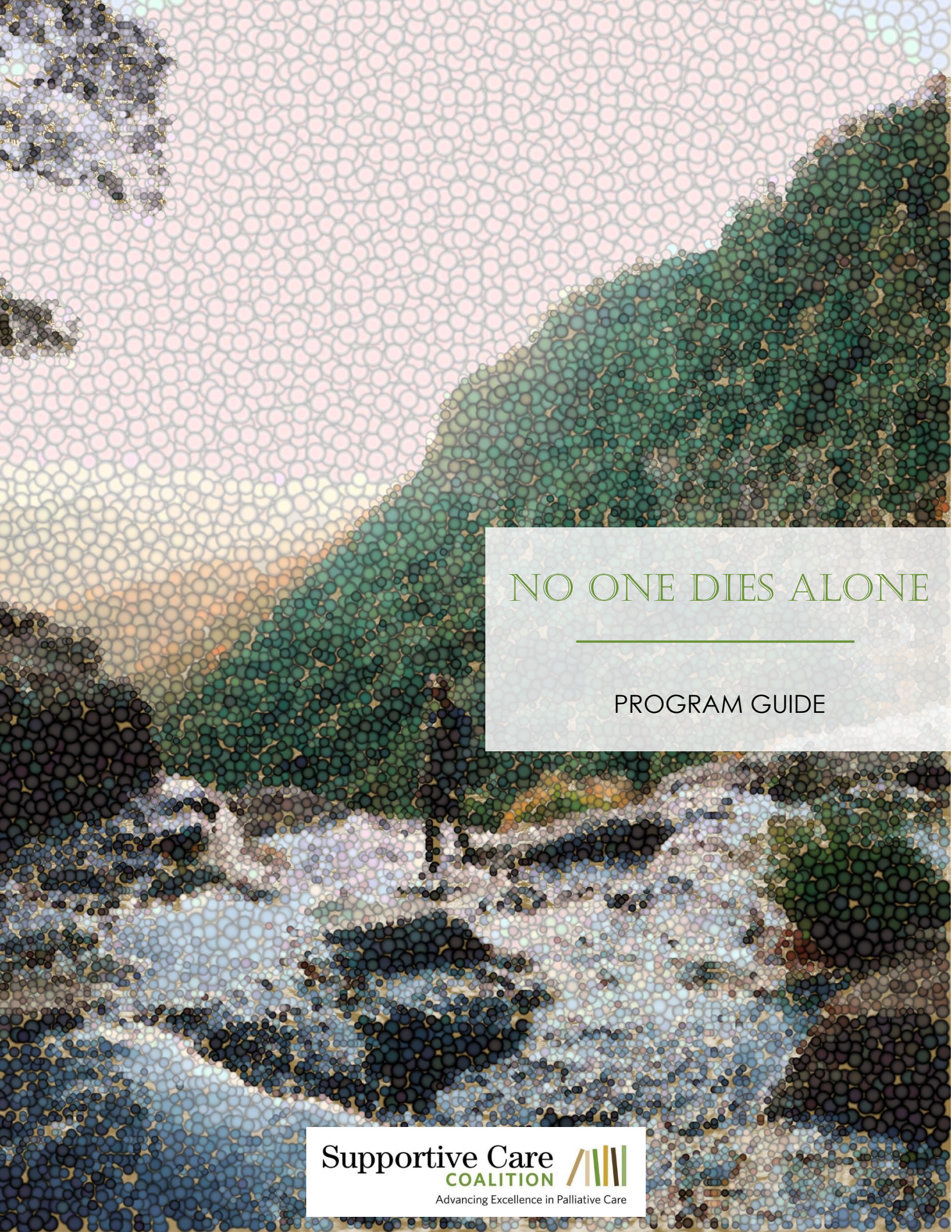


NO ONE DIES ALONE

PROGRAM GUIDE

Supportive Care COALITION

Advancing Excellence in Palliative Care

INTRODUCTION

This manual is intended to assist hospital-based palliative care teams with implementing a No One Dies Alone (NODA) program within the inpatient hospital setting. It is based on the program launched in November 2001 at Sacred Heart Medical Center in Eugene, Oregon by Sandra Clarke.

Questions about this manual or about this No One Dies Alone program can be directed to Denise Hess at denise.hess@providence.org.

CONTENTS

SECTION 1 | BUILDING YOUR PROGRAM

This section of the manual is designed to help you establish your NODA program through the following steps:

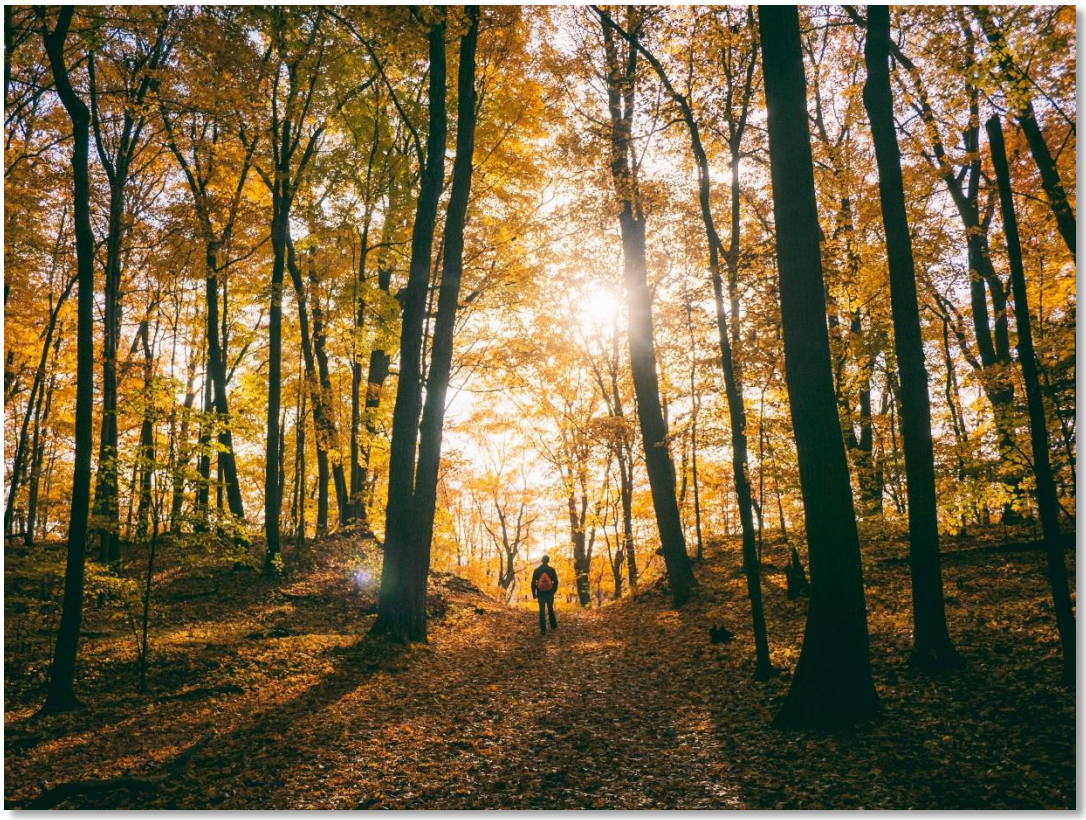
Gather the key stakeholders who will form your NODA committee

Design your activation protocol

Author your policy and procedures

Begin assembling your NODA leadership team

Launch your first volunteer recruitment campaign



STEP ONE | GATHER KEY STAKEHOLDERS

> *We have wanted a NODA program in our hospital for years – it fits with our mission and it aligns with the vision of the Sisters who started our hospital system.*
>
> *- NODA Committee Member*

A successful No One Dies Alone (NODA) program is the result of the commitment of key stakeholders who have come together because of a shared vision for companioning people who would otherwise die alone within their health care setting. The first step in creating a NODA program is identifying these stakeholders.

KEY QUESTION | WHO?

Based on your particular setting, you may need to include individuals from some or all of the following departments:

Palliative Care

Spiritual Care

Mission

Volunteer Services

Nursing Education

Nursing/Administration

Other: Community (General, Faith-Based)

Questions to explore

1. How does NODA connect with the mission of our ministry/facility?
2. What departments need to be involved in designing our NODA program?
3. Which key people need to be involved in designing our NODA program?
4. What additional staff are needed for support?
5. Who will be on the NODA committee?
6. Do we need a logo? If so, who will design it?
7. Do we need a brochure? If so, who will design it?
8. What services area(s) will we cover (inpatient, outpatient, skilled nursing, hospice, other)?
9. Who will be the lead coordinator? What will their responsibilities be for
    a) Communication with volunteers, staff, patient, family
    b) Scheduling volunteers
    c) Recruiting volunteers
    d) Training volunteers
10. Will our volunteers be assigned a weekly/monthly shift or operate on call/as needed?
11. Do we need funding to start? If so, where will we get it?

STEP TWO | DESIGN ACTIVATION PROTOCOL

> *Initially, we limited our NODA patients to only the imminently dying that were completely alone. After about one year we realized that these criteria were too narrow. We then expanded our "activation criteria" to include nearing death, family/friends who rarely come, and family respite. This has increased the number of patients we companion and simultaneously increased our NODA volunteers' engagement and staff visibility. With the expanded criteria our program is beginning to create culture change in our hospital.*
>
> *- NODA lead coordinator*

The scope of services of your NODA program is one of the most important discussions for the NODA committee to have. The main way of defining your scope is by outlining your "criteria for admission" to your NODA program. Depending on your particular setting, you may choose to have fairly narrow criteria for NODA patients due to high patient volumes or a small volunteer group. Conversely, you may choose to broaden your NODA criteria to keep your volunteers engaged and foster hospital-wide culture change. A discussion of your NODA program's scope of services begins with the following questions.

KEY QUESTION | WHAT?

What will be our scope of services? What types of patients qualify for NODA companionship?

1. Alone
2. Alone with some family/friends
3. Respite for family/friends
4. Actively dying
5. Nearing death
6. Terminal diagnosis/hospice eligible
7. Seriously ill, but not terminal
8. Other

After determining what types of patients will qualify for NODA companionship, it is important to outline the steps of your activation protocol from the patient in their hospital bed to the volunteer at the bedside.

1. Who activates NODA?
2. How do they activate NODA?
3. Who receives the notification?
4. What hours/days is NODA activation available?
5. How are patients screened?
6. How is patient/family permission for NODA obtained?
7. How are NODA volunteers contacted?
8. How are NODA volunteers scheduled?
9. How are the bedside staff kept informed about NODA volunteers?
10. Who notifies NODA volunteers when the patient dies?

SAMPLE CRITERIA FOR ACTIVATION OF NO ONE DIES ALONE VOLUNTEERS

Patient is at least ONE of the following

- Expected to die
- On comfort measures
- About to be compassionately extubated
- Has end-stage terminal disease

AND patient has at least ONE of the following

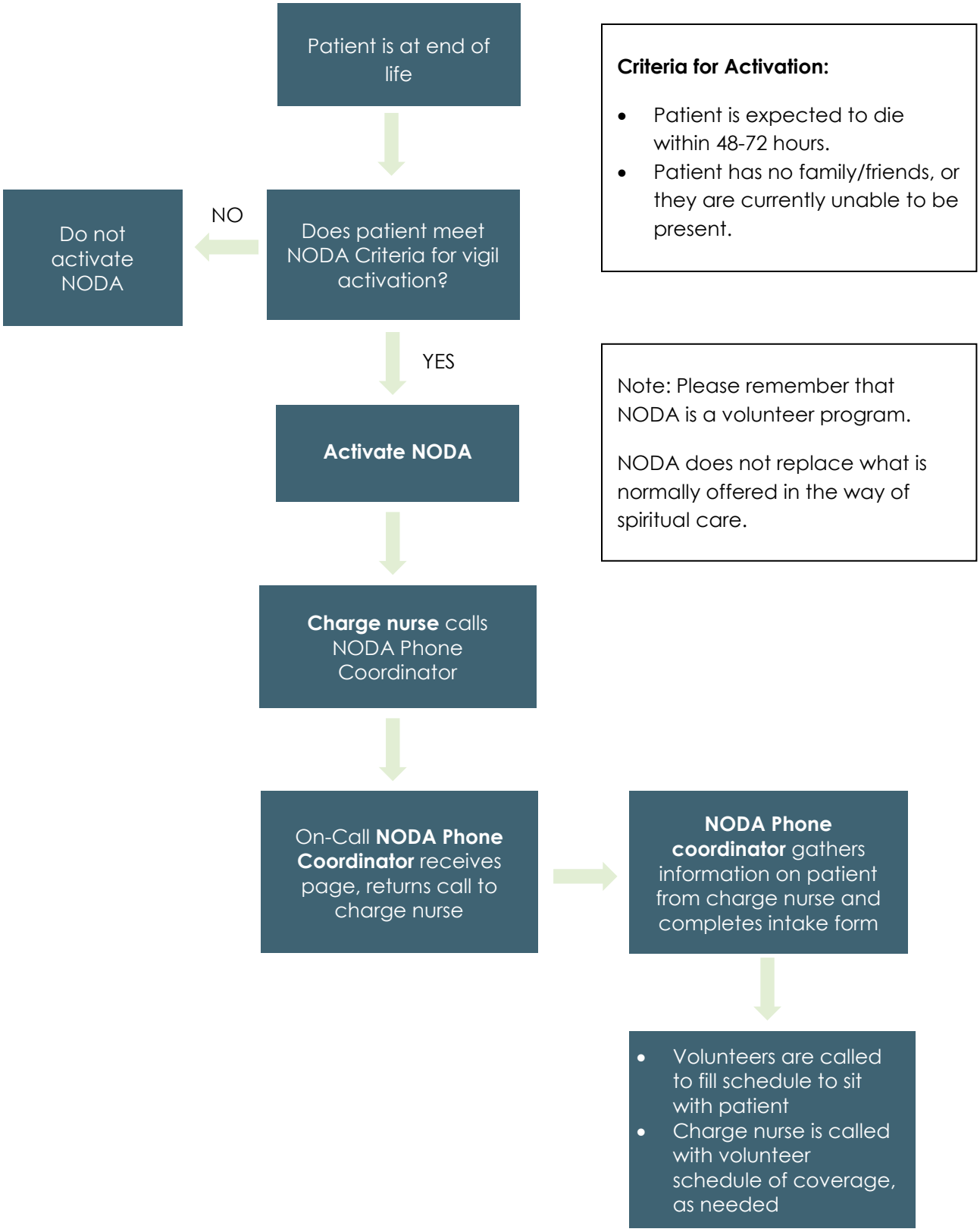
- No family/friends currently involved in patient's life
- Has family/friends who are currently unable to be present with patient
- Has family/friends who would benefit from NODA for respite or companionship

If patient meets the criteria for activation

- Contact charge nurse to contact NODA phone coordinator [Phone #]
- Phone coordinator gathers patient information from charge nurse
- Volunteers are scheduled to sit with patient
- Charge nurse is called with volunteer schedule of coverage, as needed
- Charge nurse or patient RN calls NODA phone when patient dies

(Interested in becoming a volunteer? Contact the NODA phone coordinator)

No One Dies Alone (NODA) Activation Protocol



Criteria for Activation:

- Patient is expected to die within 48-72 hours.
- Patient has no family/friends, or they are currently unable to be present.

Note: Please remember that NODA is a volunteer program.

NODA does not replace what is normally offered in the way of spiritual care.

STEP THREE | DRAFT POLICY AND PROCEDURES

> *Our policy was our guiding light when we were pulled toward "mission drift." Our policy always brought us back to our foundational vision and commitment to patients.*
>
> *-NODA committee member*

KEY QUESTION | WHERE?

Most hospital settings will require your NODA program to develop and get approval for your program by developing policies and procedures. These will vary widely from setting to setting, but in general it is first essential to determine where you will be providing NODA companionship. Most likely, separate policies and procedures will need to be developed for each setting. Since NODA is a volunteer program, it is recommended that you work closely with your organization's existing volunteer department for guidance on the development of your policy and procedures.

1. Where will we provide NODA companionship? Hospital only? Off-site skilled nursing facility? Off-site hospice unit?
2. Who are our volunteers? Existing staff? Existing volunteers? Community members? Others?
3. Who will draft the NODA policy/procedures?
4. Who or which department will own the policy/procedures?
5. How often will they be updated?
6. Do we need input from Human Resources?
7. What do state labor laws say about staff who volunteer at their place of work?

Sample Policy and Procedure

Purpose

NODA volunteers will extend caring concern to the patients and community of [Hospital] by providing a reassuring presence at the bedside of a dying patient who would otherwise be alone.

Policy Statement

Through the efforts of volunteers, No One Dies Alone provides a reassuring presence to dying patients who would otherwise be alone. With the support of the nursing staff, NODA volunteers offer patients the most valuable of human gifts: a dignified death.

Primary Responsibilities

Under the supervision of the nursing staff, volunteers will act as "Compassionate Companions" by sitting with the patient, perhaps holding their hand, reading to them and assisting in comfort measures as directed by the nurse.

Qualifications

- Active employee or active hospital volunteer with Volunteer Services Department
- Sensitivity to, concern for and empathy with spiritual needs of patients
- Ability to sit for long periods of time (preferably two to three hours minimum)
- Ability to attend NODA Orientation

Hours

Volunteers are on call on an "as needed" basis. When the volunteers are called to actually vigil with a patient, preferably they offer two to three hours of their time.

Volunteer Orientation

- Orientation will be offered as needed for new volunteers.
- Topics covered in orientation will include
    1. NODA history and orientation
    2. Patient activation protocol
    3. Palliative Care and Comfort Care
    4. Volunteer role and appropriate activities
    5. Patient's rights and ethics
    6. Compassionate communication
    7. Employee volunteer policy
    8. Spiritual Care at the end of life

Volunteer Registration for Employee Volunteers

- Volunteers sign up to be a NODA volunteer by contacting the Director of Volunteer

Services.

- Once volunteers are accepted into the program and complete NODA orientation, their addresses, home, and work phone numbers and their availability are added to the NODA database.
- Volunteer Phone Coordinator will assist in scheduling NODA volunteers to sit at the bedside.

Referral Criteria

- No One Dies Alone is for [Hospital] patients who are expected to die, on comfort measures, about to be compassionately extubated or have end-stage terminal disease and meet at least one of the following criteria: have no family/friends currently involved, or have family/friends who are only able to be present on a limited basis, or have family/friends who would benefit from NODA for respite or companionship.
- A copy of NODA protocol is provided to each nursing unit.
- NODA volunteers do not act as or replace protective care staff ("sitters").
- Once the patient's nurse or physician has determined the patient meets the NODA referral criteria, a NODA vigil is activated by contacting the charge nurse. The charge nurse will then contact the NODA Volunteer Coordinator who will then contact NODA volunteers to create a schedule for the vigil.

Activation Process

- NODA Volunteer Phone Coordinator reviews referral with charge nurse who initiated vigil
- Permission for NODA companionship obtained from patient or patient surrogate
- All active NODA volunteers emailed or called as needed
- NODA Volunteer Coordinator creates schedule of coverage for patient
- NODA volunteers cover as many hours as possible with patient

NODA Volunteer Position Scope and Procedures

- Call patient's floor/unit before arriving to confirm patient is still there
- Retrieve NODA Comfort Care Cart from the volunteer workroom and sign in on the computer
- Go directly to the nursing unit you have been assigned to and introduce yourself to the staff
- Proceed to patient's room
- Follow guidelines and procedures as outlined in the NODA Orientation Handbook, located in the Comfort Care Cart.
- Do not perform or assist in any usual and customary patient care done by medical personnel

- Observe patient for signs of discomfort and report this or any change in condition to the staff
- Follow Universal Precautions when having contact with the patient. You must wear gloves if there is a risk of blood or bodily-fluid exposure
- Adhere to [Hospital] Privacy/Confidentiality Guidelines
- Wear your volunteer identification badge at all times
- Ask the nurse if you have any questions about the patient. Have the staff call pastoral care if you or the patient has any spiritual needs
- Be yourself during vigil
- Answer the phone, phone coordinator may have questions or answers for you
- Offer to stay or exit based on the family's comfort level and preference when they arrive. You might introduce yourself saying, "I was keeping (patient's name) company until you arrived. I am happy to stay and sit with you or leave if you'd rather be alone." In some situations, the family member may request that you stay. Feel free to do so, if you feel comfortable. If not, feel free to excuse yourself.
- Feel free to write about your time with the patient in the NODA journal before leaving the nursing unit
- Call the phone coordinator if the patient dies while you are present
- Return Comfort Care Cart to volunteer workroom if you are not expecting another volunteer to follow you
- Email or phone the NODA Volunteer Coordinator to share the highlights of your NODA visit

NODA volunteers may help in any way the staff requests as long as the task is something the volunteer is comfortable with and has been trained to do and it does not endanger his or her physical or emotional well-being.

This policy was developed in collaboration with the following involved departments:

Palliative Care, Spiritual Care, Volunteer Services

RESPONSIBILITY FOR REVIEW AND MAINTENANCE OF THIS POLICY IS ASSIGNED TO: [Hospital leadership]

Reviewed and Approved:

SECTION TWO | IMPLEMENTING YOUR PROGRAM

> *From the minute I heard about NODA, I knew it was the place for me. I have had personal experience with family and friends who have died alone and want to do my small part to help others who would otherwise be alone.*
>
> *- NODA volunteer*

STEP ONE | VOLUNTEER RECRUITMENT

KEY QUESTION | HOW TO BUILD YOUR VOLUNTEER POOL?

The foundation of a successful NODA program is directly connected to the commitment and competency of the volunteers. Therefore, designing an effective volunteer recruitment plan will help build a strong, sustainable, and safe program while also ensuring compassionate, respectful care for NODA patients. Some programs only accept volunteers who are current hospital employees or volunteers. The benefit of this approach is that your volunteers will come with prior experience in the health care setting. If you choose to recruit volunteers from existing staff, check with your human resources department since some employee contracts prohibit employees from volunteering within the organization where they work. Some programs also accept volunteers from the community. The benefit of this approach is access to a group who may not be working and will have more availability to companion. Community volunteers also help spread the word about the NODA program within their community networks providing a steady influx of new volunteers. If you choose to recruit community volunteers, work closely with your organization's volunteer department since the community-based volunteers will need to complete all of the paperwork, testing, and background checks that all other hospital volunteers must complete. A best practice is to personally interview all potential volunteers, especially those from the community.

1. Who will you recruit (existing employees, existing volunteers, community, other)?
2. How will you recruit them?
3. NODA training length and location?
4. Teaching style (didactic, experiential, interactive, PowerPoint?)
5. What components will you include? (Circle all that apply)
    a. Dying process
    b. Spiritual care of the dying
    c. Communication basics
    d. Ethics/mission
    e. Comfort Care Cart
    f. Simulation/experiential/standardized patients
    g. Volunteer information: scheduling, communication, paperwork
    h. Other
6. Who will provide the training?
7. Do you need a manual? Do you need to provide written educational materials/handouts? (See Appendix A for a sample training manual)

RESOURCE ONE | VOLUNTEER RECRUITMENT LETTER – CURRENT HOSPITAL VOLUNTEERS

SAMPLE EXISTING VOLUNTEER RECRUITMENT LETTER

Dear [Hospital] Volunteers,

For almost two years, [Hospital] has provided a unique, volunteer-based ministry to patients who are at the end of life called "No One Dies Alone" (NODA). Founded in 2001 by a critical care nurse from Sacred Heart Medical Center in Eugene, Oregon, the vision of the NODA program is to provide compassionate companions for individuals who would otherwise die alone. In our facility, patients in need are identified by their health care team and our NODA volunteers are called upon to provide a reassuring presence at the bedside of the dying patient during their last days and hours.

Since the introduction of this program in our facility, our team of over 50 volunteers has provided countless hours at the bedside of patients in our hospital or hospice suites who have limited or no friends or family to be present with them in their last days and hours of life. Our volunteers seek to provide one of the most valuable human gifts—a dignified death. You may even know one of our volunteers since they are a part of our bedside, administrative and volunteer staff.

All NODA volunteers are graduates of our NODA training program. This program involves training in compassionate communication, comfort care, health care ethics, and spiritual care. The training also includes an opportunity to practice being a compassionate companion through a live simulation with one of our "Smarties" in the Institute of Nursing classroom. After completing the training, NODA volunteers are then placed on the volunteer list and called when needed. There is no minimum time commitment per month, only a willingness to participate as you are able.

If you are interested in becoming a part of this unique ministry, our next volunteer training will be held on [date] from 12:30 p.m. to 5:00 p.m. Space is limited. Please contact [coordinator] to reserve your spot. If you are interested in becoming a NODA volunteer but can't attend this training, contact [coordinator] to be added to a waitlist for a future session.

SAMPLE STAFF RECRUITMENT LETTER

Colleagues in ministry,

For almost two years, [Hospital] has provided a unique, volunteer-based ministry to patients who are at the end of life called "No One Dies Alone" (NODA). Founded in 2001 by a critical care nurse from Sacred Heart Medical Center in Eugene, Oregon, the vision of the NODA program is to provide compassionate companions for individuals who would otherwise die alone. In our facility, patients in need are identified by their health care team and our NODA volunteers are called upon to provide a reassuring presence at the bedside of the dying patient for as long as is needed.

Since the introduction of this program in our facility, our team of over 50 volunteers have provided countless hours at the bedside of patients in our hospital or hospice suites who have limited or no friends or family to be present with them in their last days and hours of life. Our volunteers seek to provide one of the most valuable human gifts—a dignified death. You may even know one of our volunteers since they are a part of our bedside, administrative and volunteer staff.

All NODA volunteers are graduates of our NODA training program. This program involves training in compassionate communication, comfort care, health care ethics and spiritual care. The training also includes an opportunity to practice being a compassionate companion through a live simulation with one of our "Smarties" in the Institute of Nursing classroom. After completing the training, NODA volunteers are then placed on the volunteer list and called when needed. There is no minimum time commitment per month, only a willingness to participate as you are able.

If you are interested in becoming a part of this unique ministry, our next volunteer training will be held on [date], from 8:00 a.m. to 12:30 p.m. Please reply to this email or contact [coordinator] to sign up for this or future training sessions.

SAMPLE EMAIL RE: INTEREST IN NODA – Community Member

Hi Joy.

Thanks for calling back with your email address.

Here's some general information about NODA. Let me know what you think.

In order to determine if our program is the best fit for you, I wanted to share a few more details about how we work. First of all, we are an "on-call" volunteer-based service. That means our team of 50+ volunteers are on-call at all times. However, I would also add that we are an "at-will" group meaning that when we have a new patient, I send out an email to all of our volunteers and they sign up for one to four hours of time as their schedules allow. For some of our volunteers, this means that they visit our patients during the day time, some come after work, some prefer to visit late at night.

While there is not a minimum required number of hours for each volunteer, the general expectation is that each volunteer will give their time as they are able. In general, our volunteers live no more than 20 to 30 minutes from the hospital. Over the course of a given year, we average about 1.5 patients a month—although, just like with other things—our NODA patients seem to come in threes.

The process of becoming a volunteer is as follows (1) Interested people schedule an interview with me to confirm that NODA is a good match for both of us; (2) Potential volunteers attend the half-day NODA volunteer training; (3) Potential volunteers complete the hospital's general orientation process (including TB screening and a background check); and (4) Volunteers are eligible to companion patients. This process takes a few months. Our next volunteer training is scheduled for June 26 from 12:30 p.m. to 5:00 p.m. We have a maximum of 16 spots available in each training session.

In addition to the one-time training, we have team gatherings several times a year. Email access is essential since it is our primary form of communication. A cell phone is helpful, but not essential.

My hope is that you would be able to join our NODA team! If you are still interested, please reply to this email including your availability for an interview Mondays from 9:00 a.m. to noon.

Best regards,

[Coordinator]

VOLUNTEER INTERVIEW

Name:

Address:

Phone (day) (night)

Email:

Volunteer experience:

Why do you want to be trained as a NODA volunteer:

How many hours would you be available per month to volunteer?

Are there hours/days of the week you are not available to volunteer?

What qualities do you bring to NODA?

Do not write below this line _

Reference ___

STEP TWO | CURRICULUM AND FACULTY

> *From the beginning, we knew we would utilize our simulation lab to train the NODA volunteers since this would allow us to create a safe, experiential learning environment best suited for adult learners.*
>
> *- Nurse Simulation Lab Educator*

KEY QUESTION | CURRICULUM & FACULTY?

Once you have formalized a plan for volunteer recruitment, the next step is to begin designing a training program with the volunteers in mind. Since you will be designing a learning experience for adults with varying levels of experience in health care and end-of-life settings, we highly recommend using a simulation lab and/or role-play-based curriculum.

The following questions will guide you in creating a customized learning experience for your particular volunteer pool.

1. Length of NODA training?
2. Location?
3. Style? (didactic, experiential, interactive, PowerPoint, other)
4. What topics will you include? (Circle all that apply)
    a. Dying process
    b. Spiritual care of the dying
    c. Communication basics
    d. Ethics/mission
    e. Comfort Care Cart
    f. Simulation/experiential/standardized patients
    g. Volunteer information: scheduling, communication, paperwork
    h. Other
5. Who will provide the training? (Circle all that apply)
    a. Palliative care physician
    b. Palliative care nurse
    c. Palliative care social worker
    d. Palliative care chaplain
    e. Mission Leader
    f. Volunteer Coordinator
    g. Ethics Committee chair/member
    h. Religious representative (priest, sister, spiritual care department lead)
    i. Other
6. Do you need a training manual? Do you need to provide written educational materials/handouts? (See Appendix A for a sample training manual)

RESOURCE FIVE | OUTLINE OF NODA TRAINING

Topic	Learning Outcomes	Faculty Member
Dying process		
Spiritual Care		
Communication		
Ethics/Mission		
Comfort Care Cart Items		
Simulation		
Logistics		
Other		

KEY QUESTION | FUNDING?

A NODA program can be sustained with very little resource outlay if led and implemented by existing staff. If you have opted for a half-day training, expenses can be minimized by starting after breakfast or after lunch and just providing light refreshments. Remaining printing costs can usually be absorbed by an existing department.

However, there are many foundations who are interested in securing grant funding for NODA program growth. When this happens, there is an opportunity to utilize funds:

- To update or expand Comfort Care Cart items to include electronics such as iPads to provide music and media to patients
- To provide volunteers with additional training opportunities such as Healing Touch, end-of-life doula training, or other similar opportunities
- To host a more elaborate volunteer appreciation gathering
- To hire a NODA coordinator
- To offer other opportunities as appropriate

STEP THREE | CONDUCT TRAINING

> *The NODA volunteer training program prepared me for what I actually experienced when companioning my first patient. During the training, I had role-played the silent patient and my first patient was completely quiet during my entire visit! I am so glad I knew what to expect.*
>
> *- NODA volunteer*

As mentioned above, the ideal volunteer training program uses a simulation lab or participant role-play. Done in a safe, non-judgmental learning environment, volunteers have the opportunity to try out their own skills while also watching their co-learners try out theirs.

Successful simulation includes

- Working closely with the simulation lab nurse educators. They are the experts in creating safety for the learners and running the lab.
- Co-creating a variety of end-of-life simulated situations to prepare volunteers for what they are likely to experience as they companion NODA patients
- Limiting the size of the class so that each participant has an opportunity to take a turn as the NODA volunteer for the "Smartie" (patient simulator) while other participants observe
- Pre-briefing to cover ground rules (especially confidentiality) and set the stage for psychological safety
- Post-briefing to highlight key learnings
- Role playing with patient actors when simulation lab is not available (patient actors are not well-suited to play the patient who dies during the NODA volunteer's visit)
- Having a facilitator present with each volunteer training group participating in the simulation
- Giving permission to the volunteer to stop the simulation if they are not comfortable or are triggered in any way
- Having the support of chaplaincy or social work if a volunteer needs extra time and space to debrief about their simulation experience

SAMPLE SCHEDULE FOR VOLUNTEER TRAINING

No One Dies Alone Orientation

12:30-12:45: LUNCH AND INTRODUCTION- Coordinator

12:45-1:00: WELCOME AND INTRODUCTION TO MISSION AND NODA HISTORY- Mission Leader

1:00-2:00: DIDACTIC SESSIONS

- PRINCIPLES OF PALLIATIVE AND COMFORT CARE- Nurse & Coordinator
- SPIRITUAL CARE & THE POWER OF PRESENCE- Manager, Spiritual Care
- ETHICS: PATIENT RIGHTS, HIPPA, CONFIDENTIALITY- Mission Leader & Ethics
- OVERVIEW OF NODA: IMPLEMENTATION, LOGISTICS- Director, Volunteer Services

2:00-2:45: SESSION 1- Simulation with "Smarties"

2:45-3:00: BREAK

3:00-3:45: SESSION 2- Simulation with "Smarties"

3:45-4:45: DEBRIEFING- Nurse and Coordinator

4:45-5:00: COMMISSIONING- Mission Leader

NODA VOLUNTEER TRAINING – FOUR SIMULATION SCENARIOS

If you are able to use standardized patients/patient actors or a nursing simulation, you can use the following scripts to train your volunteers to practice interacting in four situations they are likely to encounter when companioning patients. Volunteers in training are put into small groups of four. Each member of each small group practices companioning the "Smartie" or patient actor while their small group members watch. The simulation begins with the small group facilitators reading aloud the following background information.

Scenario 1: (non-verbal patient, comfortable, dies during visit) Thanks so much for signing up to companion our NODA patient! Her name is Lucie Darden and you will find her in room 450 in the main hospital. She is not on any kind of contact isolation. She is on comfort measures and she is NPO meaning she cannot take anything by mouth, but moistened swabs and lip balm are okay. She is 89 years old and dying of end-stage dementia. Prior to coming to our hospital, she has been a long-term resident of Driftwood Skilled Nursing Facility. According to her cousin, who lives in Columbus, Ohio, Ms. Darden has been widowed for about ten years. She and her husband never had any children and she was her parents' only child. She and her husband moved to California from Ohio for her husband's work many years ago, loved the weather, and decided to stay. Her cousin and a few other distant relatives in Ohio are all she has left of family. She is a Christian and would enjoy having the Bible read to her and being prayed for. She also loves cats and had a pet cat until she had to move into the nursing home. As her dementia progressed, she became non-verbal. During her time in the hospital with us, she has been quiet and comfortable. Her cousin says that she would absolutely love to have someone hold her hand and talk to her. After your visit, send me an email or give me a call to let me know how things go! Thanks, [Coordinator]

Scenario 2: (non-verbal patient showing non-verbal signs of discomfort) Thanks so much for signing up to companion our NODA patient! His name is Tom Barnes and he is in room 106 in the main hospital. He is not on any kind of contact isolation. He is on comfort measures and he is NPO, meaning he cannot take anything by mouth, but moistened swabs and lip balm are okay. He is 67 years old and dying of esophageal cancer. He has had a long, hard road of treatment with a lot of pain. He is divorced and estranged from his ex-wife and children. He has been living alone in an apartment until this hospitalization. A few days ago, he was able to tell us that he would like a volunteer companion to visit him. Lately, he has not been able to say much at all. He is not religious, but his landlord says that he loves the outdoors, especially the beach. Other volunteers have reported that he has been running a bit of a low-grade fever and has really enjoyed a cool washcloth on his forehead. Also, he likes country music and having his feet rubbed. After your visit, send me an email or give me a call to let me know how things go! Thanks, [Coordinator]

Scenario 3: (minimally verbal patient, in pain, unable to be soothed, repeatedly says, "I need to get home") Thanks so much for signing up to companion our NODA patient! His name is Sam Reese and he is in room 460 in the main hospital. He is not on any kind of contact isolation. He is on comfort measures and he is NPO, meaning he cannot take anything by mouth, but

moistened swabs and lip balm are okay. He is 69 years old and dying of a brain tumor. Until he got sick, he had been the long-term caregiver for his adult son who has cerebral palsy. His son lives in a group home and will not be able to visit. Earlier in Mr. Reese's hospitalization, he let us know that he was very worried about his son's well-being after his death. He has been wishing that there was a way to see his son. He is Jewish but not connected with a faith community. Lately, he has been more and more confused and somewhat anxious at times. Other volunteers have found that calm, gentle responses have helped him with this. After your visit, send me an email or give me a call to let me know how things go! Thanks, [Coordinator]

Scenario 4: (slightly disoriented and talkative patient whose daughter arrives during visit, patient dies after daughter arrives) Thanks so much for signing up to companion our NODA patient! Her name is Betty Jones and she is in room 212 in the main hospital. She is not on any kind of contact isolation. She is on comfort measures and she is NPO meaning she cannot take anything by mouth, but moistened swabs and lip balm are okay. She is 91 years old and dying of end-stage heart failure. She has been talking in her lovely Southern drawl with the other volunteers that have visited. She is Southern Baptist and likes being read to from the psalms. Her daughter Cecy has been visiting intermittently—she lives quite a distance from the hospital and works full-time. If she arrives, you can offer to stay with her and her mom or leave to give them privacy—whatever they prefer. After your visit, send me an email or give me a call to let me know how things go! Thanks, [Coordinator]

NODA Scenario 4 with Unexpected Family Member Arrival

Family: Good morning. I'm Cecy, Betty's daughter. Nice to meet you. Thanks for visiting with Mom.
(If volunteer offers to leave, ask him/her to stay "I can't stay long. I'm on my lunch break. I'd really appreciate it if you stay.)
Family: Hi, Mom. How are you?
Patient: I'm fine, dear. I am so glad you are here.
Family: Is there anything you need?
Patient: Can you hold my hand?
Family: Of course, Mom. Jenny and the kids will be coming this evening to see you. They miss you.
Patient: I'm so tired. I'm just so tired.
Family: Rest mom.
Patient: I think I'll just close my eyes for a minute.
Family: Of course. Go ahead. (patient sleeps and family member begins to share with volunteer)
Family to volunteer: I wish you could have met Mom before she got sick. She was quite a lady. I don't know what I am going to do without her. We've been best friends all of my life. I don't think you ever really outgrow the need for your mom. (silent tears)
After patient dies: (Silence/tears, holds mom's hand) I love you, Mom.

STEP FOUR | CREATE COMFORT CART

While at the bedside, a NODA volunteer may be quietly reading a book, knitting, or holding the patient's hand. When possible, NODA volunteers are encouraged to avoid turning on the television, music, or adding additional noise to the already noisy hospital environment, unless of course, the patient requests any of the above. Since volunteers may be companioning a patient for anywhere from one to four hours, it can also be helpful to provide additional resources in a "Comfort Care Cart" for use by the volunteers.

One of the most important items in the Comfort Care Cart is the NODA volunteer journal. If a journal is used, it is very important that HIPPA guidelines are followed while journaling. No patient or family names should be used, nor any specific identifying information. The purpose of the journal is for the volunteer to reflect on their experience while companioning and to pass on any relevant information to the next volunteers who will companion the patient. The journal cannot be left in the patient's room but must be in a secure location in between volunteer visits.

The Comfort Care Cart should include texts from religious traditions as possible. However, NODA volunteers should only read aloud religious texts to patients who have confirmed they are of that religious tradition. Likewise, with prayer. NODA volunteers should only offer spoken prayer to patients who have confirmed that they would like to receive prayer. NODA volunteers who have their own faith tradition are encouraged to read their own sacred texts and pray according to their tradition silently while in the presence of the NODA patient, unless specifically instructed otherwise.

The Comfort Care Cart should include readings, prayers, poems, and blessings that would be acceptable to people of all faiths or no faith at all. These texts can always be read aloud to NODA patients, if the patient agrees.

COMFORT CART ITEMS

iPads - These can be checked out from the volunteer office Monday through Friday from 9:00 a.m. to 5:00 p.m.
Journal - Please use this to express any thoughts you may have and to pass on information for the next volunteer. Make sure and use abbreviations (for example Mr. D) when referring to patients.
Holy Bible
New Testament Psalms
The Muslim Prayer Book
Mourning & Mitzvah by Anne Brener (A Guided Journal for Walking the Mourner's Path Through Grief to Healing with over 60 guided exercises)
365 Tao by Deng Ming-Dao (A contemporary book of meditations on what it means to be wholly a part of the Taoist way, thus, to be completely in harmony with oneself and the surrounding world)
Prayers for Healing by Maggie Oman (365 blessings, poems and mediations from around the world)
Praying Our Goodbyes by Joyce Rupp (A spiritual companion through life's losses and sorrows)
Prayers from the Heart by Richard J. Foster (Collection of prayers according to three aspects of the human journey—looking inward, upward, and outward)
Prayers for a Thousand Years by E. Roberts & E Amidon (Inspirations from leaders and visionaries around the world)
Parting by J.S. Holder & J. Aldredge-Clanton (For end-of-life companions, offering collective wisdom for helping terminally ill folks toward a peaceful transition)
Life Meditations by Edward Lavin, S.J. (Thoughts and Quotations for All of Life's Moments)
Gratitude by Dan Zadra
Beauty by John O'Donohue (Rediscovering the true sources of compassion, serenity and hope)
From Beginning to End by Robert Fulghum
After death, Life! by Ruqaiyyah W. Maqsood (Thoughts to alleviate the grief of all Muslims facing death and bereavement)
Death & Dying by Carol Peacock (A guidebook for grieving)
To Begin Again by Naomi Levy (The journey toward comfort, strength and faith in difficult times)
Have a Little Faith by Mitch Albom (A story about faith, hope and serving others)
Tuesdays with Morrie by Mitch Albom (An old man, a young man and life's greatest lessons)

EXCERPTS FROM NODA JOURNAL

Today I am here to visit Mr. H. When I arrived, I introduced myself just after the nurse had given him medication. Mr. H asked for his applesauce. I asked the nurse to bring me some applesauce and Mr. H asked the nurse to bring me some applesauce also because he thought I should have some too because I eat a lot. I laughed and asked him, "how did he know." After helping him eat some applesauce I talked with Mr. H a bit and then he went to sleep.

I came to visit Mr. H again this afternoon. He was eating applesauce and was momentarily oriented. I re-introduced myself and reminded him that we had listened to the radio last night. He smiled when I reminded him of "The Who" and "The Rolling Stones"—he gave me a big grin and said, "We had a good time last night." I've found Mr. H to be a very friendly man. He has a good heart. He is kind to everyone who enters his room and always says "thank you." God bless and protect you Mr. H—you are a kind man and it's been wonderful sharing time with you.

Mr. H had an accident. I called the nurse to change him and he said, "thank you." He then said, "I'm sorry. I don't mean to be trouble." I responded by telling him that he definitely is no trouble, that he is here for everyone to care for and love him just as he deserves. Then he said, "Thank you." Later, I asked if he wanted a massage on his feet. He said, "yes, thank you." I left around 2p and said goodbye. I told him I would probably be back later tonight to see him again.

STEP FIVE | IMPLEMENT VOLUNTEER SCHEDULING SYSTEM

When the NODA coordinator is notified of a potential NODA patient, has confirmed the appropriateness of the referral, and secured permission from the patient and/or patient surrogate, a timely call for companions is crucial. Thankfully, there are excellent, no-cost, online scheduling tools that can simplify the volunteer scheduling process and assist with data collection.

SignUp Genius is one such online platform with a "Basic" plan that is sufficient for the needs of most NODA programs. The NODA coordinator is usually the SignUp Genius administrator and after creating a calendar for the NODA patient (without using any patient identifiers), a link to this calendar can be emailed to the entire NODA volunteer team and volunteers can add themselves to the NODA patient's schedule.

Instructions for creating your first sign up can be found here

The initial

RESOURCE TEN | INITIAL EMAIL ALERT TO VOLUNTEERS

Dear NODA Volunteer Team:

I have just learned that we have a new NODA patient in the hospital. He is a older man dying from end-stage cancer. His physicians expect him to die in the next two-three days. He has outlived his wife, his sister, and the rest of his family lives on the East Coast and will not be able to come to the hospital. He is not on any type of contact or airborne isolation. You can schedule your visit with Mr. M on the SignUp Genius calendar here [add link]. Once you sign up on the schedule, I will send you his confidential information in a secure email. Thank you in advance for providing your compassionate presence to Mr. M. As always, send me an email update after your visit so we can all follow along with Mr. M's journey.

STEP SIX | COMMUNICATION WITH VOLUNTEERS

All of the following email communications must happen within a HIPAA-compliant environment. For most hospitals, this will mean sending the following information in an encrypted form. If the NODA volunteers choose to print out the patient information, they must be instructed on proper destruction of the patient information, again in compliance with HIPAA and patient confidentiality guidelines.

RESOURCE ELEVEN | COMMUNICATION: INITIAL EMAIL TO VOLUNTEERS

SAMPLE INITIAL EMAIL TO SCHEDULED VOLUNTEER

Hi —Thanks so much for your willingness to sit with Mr. Beckworth.

Here is his info:

His name is George Beckworth. He is 82 years old, Baptist, legally blind from childhood, loves bowling, and has many very frail friends and a caregiver who may visit occasionally. He is on contact isolation for MRSA of the nares. (This means that an open wound on your body would have to touch the inside of his nose for the bugs to contact you.) He suffered a major heart attack where his brain did not receive enough oxygen and so he is now only very minimally responsive. Staff caring for him reported that he is responding to touch and sometimes opens his eyes to the sound of voices. His friends might come and visit if they are able. Most of them know about NODA volunteers. As usual, you can introduce yourself and offer to leave or stay—whatever you feel is best.

According to his caregiver, he is and always has been a very social person and LOVES company.

He is in the hospice suites in room 20. Please put on the yellow gown and gloves before entering his room and please remove them before exiting his room. The NODA Comfort Care Cart and journal are in the volunteer office unless your shift happens to be immediately after another volunteer. The phone number at the unit is [#]. It is always a good idea to call before your shift just in case Mr. Beckworth has died. I will do my best to call you before your shift if Mr. Beckworth is no longer with us.

As always, send me an email after your time with Mr. Beckworth (just refer to him as Mr. B) letting me know how things went so I can pass on the information to the other volunteers.

Call me if you have any questions, schedule changes, concerns or feedback. I am here for you.

Thanks in advance for your commitment to NODA,

[Coordinator]

SAMPLE EMAIL UPDATES: ONGOING AND POST-DEATH

Subject: Update on dear Mrs. B

Hi Team—

Mrs. B was companioned by Beth, Lynn, and Jeni today. Beth and Lynn both reported that she slept during their visits—comfortably and peacefully. Later in the day during Jeni's visit, her breathing began to be labored. She seems to be making her way home. At the moment, it looks like Mrs. B's Saturday schedule is completely open, Karen plans to visit on Sunday, Mark on Monday. She might pass away tonight or tomorrow. If you are on the schedule you can always call the unit (#) to find out if she is still with us before coming to the hospital for your shift.

Compared with our last gentleman who kept you all very busy, Mrs. B is mostly quiet, peaceful, and non-interactive. I have heard from NODA volunteers over the years that when sitting with someone who does not seem aware of our presence, we can feel not all that useful. However, with patients like Mrs. B, "just being there" is more than enough.

I have been re-reading The American Book of Dying by Richard Groves and he shares, "The first and most important rule is to just show up….When you do show up, take several moments to ground yourself before spending time with your friend—that is, become present by letting go of your own past and present concerns. Your friend will immediately sense whether you are emotionally available to them."

And some words that I think apply well to our time with non-responsive patients: "It is normal to feel inadequate at times like this. Try to be natural—just be yourself. Be aware of any tendency to pretend you are comfortable—it probably means you are not. Simple gestures and casual conversation cannot go wrong. The greatest gift you have to offer now is yourself. A simple rule of thumb is when in doubt, trust your instincts. Generally, it will be a relief to your companion that you are not assuming an artificial role."

Never forget, your presence is the greatest gift you have to offer.

Thank you for offering yourself, over and over again for our patients. I will keep you posted on Mrs. B's condition.

Blessings,

[Coordinator]

SAMPLE EMAIL UPDATES: ONGOING AND POST-DEATH

Subject: Our dear NODA lady has passed

Good morning, team—

I have just learned that at around 6:00 am this morning our dear lady peacefully passed from this life to the next. Thank you Maheen, Becky, and Barbara M. who completed NODA training Tuesday and bravely volunteered to companion our patient in her last days and hours. Thank you to Peter and Meera who were among those who companioned her yesterday. And thank you to all of you who were waiting in the wings to spend time with her: Barbara F., Marianne, Tertia, Lynn, and Alyssa. And, thank you to those of you who were following along holding her and us in prayer—too many of you to name!

Every NODA patient we companion is unique. Some ask for bananas, some tell stories of their life at sea, and some say thank you over and over again for the company and tenderness you all provide. Some are in the ICU while the hospital ethics committee meets to discuss the best way to care for this most vulnerable patient. Some are in and out of being here with us and venturing off into another place, one volunteer will have a conversation with the patient; the next volunteer will sit in quiet with the patient.

Many of you who companioned our dear lady noticed that her breathing sounded like loud snoring, that she began to take longer and longer pauses between breaths, and that her eyes were open and fixed on a point in the corner of the ceiling. These are all signs that death is near. She was also not able to talk with us or squeeze a hand to let us know she knew we were there, although one of you found that she did flutter her eyes just barely when you spoke to her or placed a comforting hand in her hand or on her shoulder.

With this dear lady, we were sitting vigil.

Sitting vigil is a practice that has roots extending back into ancient history. Some believe that this practice was born out of the ancient Greek belief that the god Charon, the wounded healer, would assist and companion the dying person across the river Styx which separated the land of the living from the land of the dead. Other have compared sitting vigil to the role of a midwife or doula at the time of birth. In fact, our counterparts in the hospice movement are called "doulas." However we look at sitting vigil, at its heart, it is accompanying, walking alongside, and bearing witness as a one-of-a-kind human being transitions from this life to death and beyond. Just as we recognize the birth of a child to be a vulnerable and sacred moment, so too we recognize the death of our patients as a sacred, even holy, transition.

So, thank you all once again for sitting vigil—whether physically or spiritually through prayer—with our patient. I am convinced that her dying was eased and dignified by your tender loving care.

Take care of yourselves and be well, [Coordinator]

SECTION 3 | MAINTAINING YOUR PROGRAM

> *Being a NODA volunteer can be deep and solo work. Starting from our training experience together, it has been helpful for me to stay in touch with other NODA volunteers, either during the ongoing educational events, or during our celebrations. I have found a community of like-minded friends.*
>
> *NODA Volunteer*

STEP ONE | CARE FOR THE VOLUNTEER

Over time, providing companionship for the dying can be emotionally and psychologically depleting if volunteers are not provided opportunities to process their experiences with others in the NODA program. Also, many NODA volunteers, once they begin companioning, are interested in continuing their education. The following resources provide frameworks for regular volunteer debriefing and training events. While not outlined, an annual NODA volunteer appreciation gathering is a wonderful addition to the program. Also, do not underestimate the power of ongoing email communications to help the volunteers feel connected to the current patients and to one another.

RESOURCE ONE | VOLUNTEER DEBRIEF

SAMPLE NODA DEBRIEF GATHERING

Light breakfast, check contact information

Welcome & reflection: coordinator (introduce guests)

Appreciation of volunteers: mission leaders

Changes in NODA:

1. On-call scheduling update
2. Expanding criteria (handout)

Debrief with journal excerpts: coordinator and nurse

Announcements: coordinator

1. New volunteer training
2. Hand washing/isolation protocol

SAMPLE NODA EDUCATIONAL GATHERING: ADVANCED COMMUNICATION

Communication basics

1. Providing information/knowing your scope
2. Summarizing/mirroring
   Pairs:
   1. "I get encouraged when _____"
   2. "What I hear you saying is _____"
3. Validating/follow the feeling
   Pairs:
   1. "A few days ago a situation came up and I was feeling _____, but now I feel _____"
   2. "I get the impression that you felt _____ and now you feel _____"

Advanced communication skills

1. Listening and response styles
2. Practicing dialogues in pairs

Announcements

Webinars and resources on death and dying

Communication Practice- Version A

Sit face-to-face with your partner. You have version A; check that your partner has version B. Read exercise 1 to yourself and follow the instructions. It's not necessary to use the exact wording, but something close to it.

1. You speak first by completing this thought:

"What drew me to NODA was _____"

2. You listen. At some point, show you were listening by summarizing, or putting into your own words what your partner just said, without changing the meaning or adding anything. You can start by saying something like:

"What I hear you saying is _____ Is this right?"

3. You speak first by completing this thought:

"My biggest hopes and/or concerns about becoming a NODA volunteer are _____"

4. You listen. Observe not only what your partner is saying, but also the attitudes and feelings that go with the words. Try to identify the emotion your partner is having. At some point say something like:

"It sounds like you are feeling _____ Am I right?"

Communication Practice- Version B

Sit face-to-face with your partner. You have version B; check that your partner has version A. Read exercise 1 to yourself and follow the instructions. It's not necessary to use the exact wording, but something close to it.

1. You listen first. At some point, show you were listening by summarizing, or putting into your own words what your partner just said, without changing the meaning or adding anything. You can start by saying something like:

"It sounds like you were drawn to NODA by _____ Is this right?"

2. You speak first by completing this thought:

"What drew me to NODA was _____"

3. You listen. Observe not only what your partner is saying, but also the attitudes and feelings that go with the words. Try to identify the emotion your partner is having. At some point say something like:

"I get the impression that you feel _____ Am I right?"

4. You speak first by completing this thought:

"My biggest hopes and/or concerns about becoming a NODA volunteer are _____"

Listening and Response Styles

In the following scenarios, each statement is an expression of an aspect of the situation. Little or no information is given to you about the nature of the person speaking. Following each statement is a series of five possible responses.

> **First select the response that represents UNDERSTANDING, next select the other responses and put the letter representing each one on the line provided.**

In exploring the intentions underlying the responses, we will refer to the person with the problem as the **sender** and the person giving the responses as the **receiver**. There are five possible underlying intentions. Select the one you believe applies in the dialogues presented and place the appropriate letter (A-E) on the line provided.

A. EVALUATIVE: A response that indicates the receiver has made a judgment of relative goodness, appropriateness, effectiveness, or rightness of the sender's problem. The receiver has in some way implied what the sender might or ought to do.

B. INTERPRETIVE: A response that indicates the receiver's intent is to teach, to tell the sender what his problem means, or how the sender really feels about the situation. The receiver has either obviously or subtly implied what the person with the problem might or ought to think.

C. SUPPORTIVE: A response that indicates the receiver's intent is to reassure, to pacify, to reduce the sender's intensity of feeling. The receiver has in some way implied that the sender need not feel as he does.

D. PROBING: A response that indicates the receiver's intent is to seek further information, provoke further discussion along a certain line, or question the sender. The receiver has in some way implied that the sender ought or might profitably develop or discuss a point further.

E. UNDERSTANDING: A response that indicates the receiver's intent is to check out with the sender whether the receiver correctly understands what the sender is saying, how the sender feels about the problem, and how the sender sees the problem.

Dialogues

1. "I tell you I hate my father. I hate him! I hate him! And there's no reason for it. He is a minister—a good and righteous man. He has never laid a hand on me, but I have this awful feeling against him, and it makes me feel so terrible because there's no reason for it. It is a sin to hate your father—especially if you don't have any real reason for it. I...it worries me."

1. _____I don't blame you for feeling guilty about hating him, especially since you can't figure out what he has done to make you hate him. And then, too, even though you see only your hatred of him, I bet that underneath it you have some love for him, and this plays a part in your feelings of guilt.
2. _____A while ago I felt the same way, but I hated my mother. I guess lots of kids do. I just avoided her for a while until things settled down, and things are fine now.
3. _____That's really strange that you feel that way. You should get things straightened out. A good relationship with your father is a great thing.
4. _____You're worried that you hate your father without reason and yet feel sinful for hating him.
5. _____What's your father like? You say he's never hit you, but maybe he has not allowed you to do some of the things you wanted to do. What do you think?

2. "I have the strangest feeling. Whenever anything good happens to me, I just can't believe it. I act as though it never happened, and it worries me. I wanted a date with Mary and stood around for weeks before I got up the courage to ask her out. She said "yes", and I couldn't believe it. I couldn't believe it so much that I didn't keep the date."

1. _____You've got to get with it and get a more realistic idea about women. They're human too, you know, and want to go out just as much as you do.
2. _____It just doesn't seem real when something good happens to you?
3. _____You have probably denied yourself so strongly that anything good could happen to you that when it does it seems unreal.
4. _____Maybe these feelings of unreality are connected with a particular time of your life. What do you mean when you say, "Whenever anything good happens to me?"
5. _____It's not a big thing. Lots of people get the same kinds of feelings. You'll snap out of it.

3. "I've lived in the same town, in the same house my whole life, but I don't really know people. At school, I just can't seem to make friends. I try to be nice, but I feel uncomfortable inside. Then I tell myself I don't care. You can't really trust people, everyone seems to be out for himself, and I don't want any friends. And sometimes I think I really mean it."

1. _____Here's what we can do. You can join this club I belong to. Our group is small, and we want more members. We go horseback riding and things like that, so even if you are afraid to make friends at first, at least you can have fun.

2. _____When you first meet someone, how do you act? What do you say to them?

3. _____It's gone on so long it almost has you convinced. Is that right?

4. _____Maybe you're not wanting friends is just to cover up for something else.

5. _____It's pretty hard to be without friends. I would really work on that. There are lots of things that you could do to learn how to make friends, and the sooner you start, the better.

4. "I'm afraid to be alone. I really am. I'm afraid I'll kill myself, and I don't want to, but I get so depressed. I get caught in a terrific clutch of fear—it's unreal, but it's there. And I get so anxious I could scream. I want to get outside and I'm afraid to go to the doctor for an examination. I'm afraid he'll tell me I have cancer. My mother had it as well as my grandmother and my aunt. I've lived with it all my life, and it's hell. And when this first came up—see, I break out in a sweat just talking about it. I just can't talk to my father. God, is there any help?"

1. _____Aside from your fear, have you had any symptoms of cancer?

2. _____This terrific fear just never lets you alone.

3. _____If you have any reason at all to think that you might have cancer, you really should try to control your fear enough to have a medical examination. It's stupid to worry if there's no reason, and you shouldn't waste time if you do actually have cancer.

4. _____Whenever you get that scared, why don't you call me? I'm not saying that I'll be of any help, but maybe you'll feel better if you talk to someone.

5. _____You feel that you might have cancer because so many people in your family had it, and you're letting that fear creep into every aspect of your life.

5. "I'm in a tough spot. I'm in love with a really great girl, and she loves me. I'm sure of that. But I'm not good enough for her. I can't ask her to marry me. I've got a criminal record. She doesn't know about it, but I know it'll come out some day. No. I couldn't marry and have children. I've got a record and that proves to the world that I'm not worthy."

1. _____Well, it would be unfair to her to marry and discover about your past later. You have to tell her about it now.

2. _____You feel afraid to face her with your record because she might break up with you, and you just couldn't stand that.

3. _____Why are you so sure that she wouldn't be able to accept you if she knew about your past?

4. _____Possibly you could have her talk to a friend, maybe they could lead her to understand that your past does not necessarily mean that you couldn't have a happy future together.

5. _____You see yourself as not good enough for her.

6. "Because of my handicap, I can't do any of the things my sister does. I can't dance, go riding, date boys. I wish I were Charlene. You can't know the feeling I get deep inside me. I want to be able to have pretty clothes like hers and have fun. It makes me sick inside. She can't help it; she was born that way, and I can't help it because I was born this way—and I get this feeling. I love my sister, really I do. But I just sit and cry until I am sick. I know it's a sin to feel as I do, but she has everything and I have nothing."

1. _____Since you realize that you aren't going to be able to do many of the things your sister does, aren't there some other things you'd like to do?

2. _____I can see why you'd envy her, but since you can't compete with her it's not much use in using up your energy with envy. You've got to settle down and build your own life.

3. _____In other words, you are jealous of your sister because you can't compete with her, and you feel guilty about your envy because you love your sister, too.

4. _____How do you react to her directly, and how does she react to you in some of these situations?

5. _____You say in one breath that you envy your sister. You say next that you love her. Your feelings of guilt could be due to these contradictory feelings.

7. "I graduated from my community college last month, and I thought, now what? I looked for a job, and right there I had a problem. I couldn't make up my mind what to do. I thought I ought to transfer to a university, or maybe I'd be happier if I joined the Navy. Nothing stood out as a clear choice. Everything looked bad, and I felt—well, what's the use? Am I going crazy? Am I always going to be so stuck that I won't be able to move in any direction?"

1. _____You're wondering what it's all about.

2. _____Why don't you want them and why do you want them? Maybe there's a clue that will help you out.

3. _____This is one thing many of us have faced. It will disappear in time. Why not just take anything until you get things clear in your mind?

4. _____You don't need to remain messed up, or you may not be messed up now. You're confused, yes, but if you set your mind to it, I bet you'll overcome your confusion and move ahead all right.

5. _____You're confused and upset about it. This can happen, I guess, when we suddenly find ourselves having to make decisions after a long time in high school where even minor decisions were made for us.

8. "I'm dating this guy. He is very hot looking, and he has a good job, but he is so controlling that it makes me nervous. Last week he told me he didn't want me to see my friends anymore because it takes so much time away from the two of us. It feels good that he wants to spend so much time with me, but I'm kind of isolated from my friends and family, and he is always telling me what to do."

1. _____He sounds scary. You should get rid of him. What are you doing with a guy like that?
2. _____You seem to be really worried about staying in this relationship.
3. _____He is fun to be with, but the controlling part makes you wonder if this is what you want. So, you are not really comfortable with him.
4. _____Could you see yourself married to him?
5. _____I once dated a guy like that, and he wasn't so bad. It will all work out. Why don't we all go out together one night?

9. "My parents are driving me crazy. I'm not a little kid anymore, but they want to treat me like one. I like to go out with my friends, and they say I can't go out on school nights because my grades are most important. I'm 19 years old, and I think I know when I should and should not go out. My mother was married when she was my age, but she has forgotten. Now we are fighting constantly, and I hate to go home. It is a mess. I used to get along so well with my parents."

1. _____What do you say to them? Do you explain that you know what you are doing?

2. _____When you live with your parents you really have to live by their rules. They're paying the bills.

3. _____ You will work it out with them, and everything will be okay between you again. I once had a bunch of fights with my parents, but now we are good.

4. _____ It really makes you mad when they tell you what to do, because inside you know you know what you are doing.

5. _____ You love your parents and hate the friction between you.

SAMPLE EMAIL ENCOURAGEMENT

HOPE

When strangers take your hand and ease your many pains…there is hope.

When compassion and understanding lift up frail and failing bodies…there is hope.

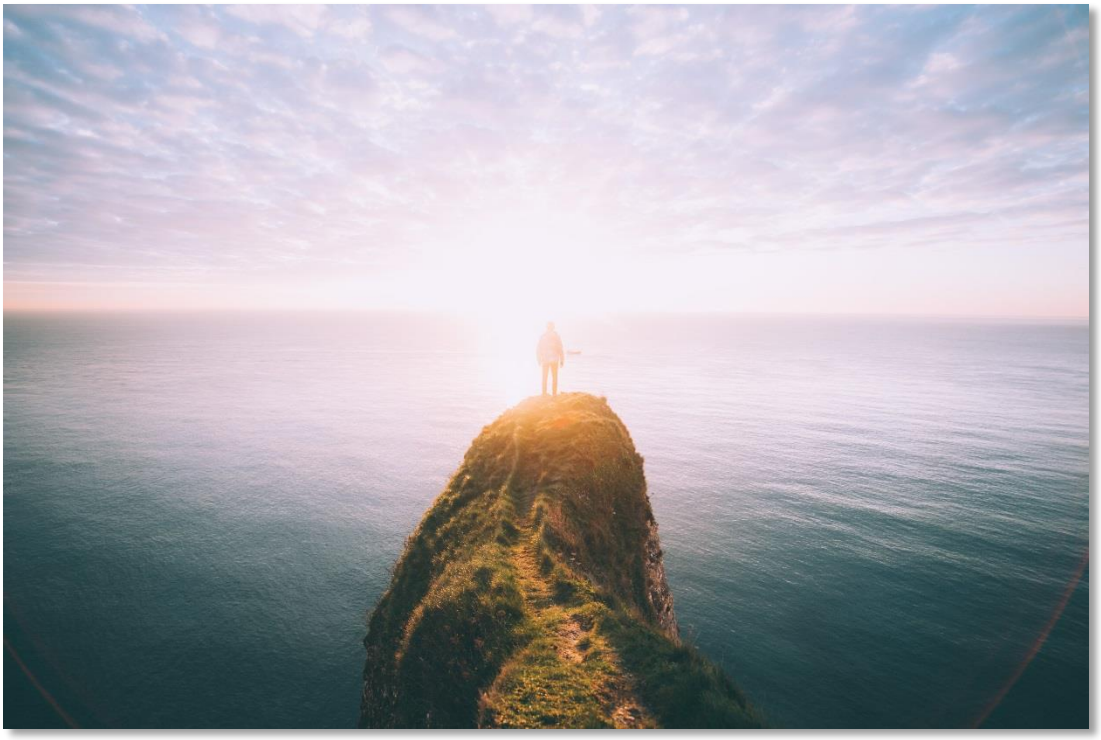
When shattered pieces of a broken spirit are gathered together and allowed to soar…there is hope.

When a lifetime of anger and turmoil can be replaced by waves of peace and serenity…there is hope.

When the darkness of despair is chased away by the radiant beams of a simple smile…there is hope.

When the sick and ailing are empowered to steer a dignified course to death…there is hope.
(Jason Spring, MD)

Sharing HOPE one person at a time



SAMPLE EMAIL ENCOURAGEMENT

11 Tenets of Companioning

Companioning is about honoring the spirit; it is not about focusing on intellect.

Companioning is about curiosity; it is not about expertise.

Companioning is about learning from others; it is not about teaching.

Companioning is about walking alongside; it is not about leading or being led.

Companioning is about being still; it is not about frantic movement forward.

Companioning is about discovering the gifts of sacred silence; it is not about filling every painful moment with talk.

Companioning is about listening with the heart; it is not about analyzing with the head.

Companioning is about bearing witness to the struggles of others; it is not about judging or directing those struggles.

Companioning is about being present to another person's pain; it is not about taking away or relieving the pain.

Companioning is about respecting disorder and confusion; it is not about imposing order and logic.

Companioning is about going to the wilderness of the soul with another human being; it is not about thinking you are responsible for finding the way out.

Dr. Alan D. Wolfelt, Director of the Center for Loss and Life Transition in Fort Collins, Colorado.

SAMPLE EMAIL ENCOURAGEMENT

LISTEN

When I ask you to listen to me and you start giving advice,

you have not done what I asked.

When I ask you to listen to me and you begin to tell me

why I shouldn't feel that way, you are trampling on my feelings.

When I ask you to listen to me and you feel you have to do something to

solve my problems, you have failed me, strange as it may seem.

Listen! All I ask, is that you listen.

Not talk or do--just hear me.

And I can do for myself; I am not helpless.

Maybe discouraged and faltering, but not helpless.

When you do something for me that I can and need to do for myself,

you contribute to my fear and weakness.

But, when you accept as a simple fact that I do and feel what I feel,

no matter how irrational,

then I can quit trying to convince you and I can get about the business of

understanding what's behind this irrational feeling.

And, when that's clear, the answers are obvious

and I don't need advice.

Irrational feelings make sense when we understand what's behind them.

So, please listen and just hear me. And, if you want to talk,

wait a minute for your turn,

and I'll listen to you.

- Anonymous -

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SAMPLE EMAIL ENCOURAGEMENT

St. Hugh of Lincoln (1140 –1200)

The story is told that Hugh, the Abbot of the Carthusian Monastery at Witham, and later Bishop of Lincoln, one day rode out on a mission for his monastery. His secretary, the young monk, Reginald, accompanied him. As they traveled, they passed a leper begging at the roadside. Hugh pulled up his horse and got down and embraced the leper. After greeting him, he mounted again and rode on his way. His secretary was silent for a while and then he spoke up.

"Abbot Hugh," he said, "When St. Martin of Tours embraced a leper, that leper was healed."

"Ah, yes!" the Abbot replied, "But when Hugh of Lincoln embraces the leper, Hugh of Lincoln is healed!"

Gracious and loving Spirit of Healing and Power, we place all the sick, and especially our NODA patient, under your care. We ask you to bless them and heal him. We ask your blessing on all who enter his room to bring him comfort and support, that each would know your guidance and love, and experience your compassion and healing in their hearts and lives. And, we ask your blessing also on all members of the staff that, as they serve, you might empower them and minister through them. Amen.

SAMPLE EMAIL ENCOURAGEMENT

Just Stay
A nurse took the tired, anxious serviceman to the bedside. "Your son is here," she said to the old man. She had to repeat the words several times before the patient's eyes opened.

Heavily sedated because of the pain of his heart attack, the old man dimly saw the young uniformed Marine standing outside the oxygen tent. He reached out his hand.

The Marine wrapped his toughened fingers around the old man's limp ones, squeezing a message of love and encouragement. The nurse brought a chair so that the Marine could sit beside the bed.

All through the night the young Marine sat there in the poorly lighted ward, holding the old man's hand and offering him words of love and strength. Occasionally, the nurse suggested that the Marine move away and rest awhile. He refused.

Whenever the nurse came into the ward, the Marine was oblivious of her and of the night noises of the hospital—the clanking of the oxygen tank, the laughter of the night staff members exchanging greetings, the cries and moans of the other patients. Now and then she heard him say a few gentle words.

The dying man said nothing, only held tightly to his son all through the night. Along towards dawn, the old man died. The Marine released the now-lifeless hand he had been holding and went to tell the nurse. While she did what she had to do, he waited. Finally, she returned. She started to offer words of sympathy, but the Marine interrupted her.

"Who was that man?" he asked.

The nurse was startled. "He was your father," she answered.

"No, he wasn't," the Marine replied. "I never saw him before in my life."

"Then why didn't you say something when I took you to him?"

"I knew right away there had been a mistake, but I also knew he needed his son, and his son just wasn't here. When I realized that he was too sick to tell whether or not I was his son, knowing how much he needed me, I stayed."

The next time someone needs you, just be there. Stay.

STEP TWO | DATA COLLECTION

Collecting NODA volunteer data is essential for measuring the impact of your program. The following is a sample of suggested measures.

Patient Name	NODA Start				NODA End	Disposition
Don Jones	2.13.19	Volunteer			2.20.19	Death
		Name	Date	Length of Visit		
		Sarah Smith	2.13.19	3 hours		
		Jackie Nelson	2.13.19	2 hours		
		John Frank	2.13.19	2 hours		
		Hillary Lewis	2.14.19	3 hours		
		Rachel Johnson	2.14.19	4 Hour		
		Lauren Jones	2.15.19	3 hours		
		John Frank	2.15.19	1 hour		
		Sarah Smith	2.15.19	2 hours		
		Sarah Smith	2.16.19	2 hours		
		Ben Davis	2.16.19	3 hours		
		Greg Miller	2.16.19	4 hours		
		Ben Davis	2.17.19	3 hours		
		Jackie Nelson	2.17.19	2 hours		
		Hillary Lewis	2.17.19	3 hours		
		Ben Davis	2.18.19	3 hours		
		Bob Wilson	2.18.19	4 hours		
		John Frank	2.19.19	4 hours		
		Rachel Johnson	2.19.19	2 hours		
		Jackie Nelson	2.19.19	1 hour		
Patient Name	NODA Start				NODA End	Disposition
Patty Allen	2.15.19	Volunteer			2.25.19	Transfer
		Name	Date	Length of Visit		
		Sarah Smith	2.15.19	3 hours		
		Jackie Nelson	2.15.19	2 hours		
		John Frank	2.16.19	2 hours		

STEP THREE | STAFF AWARENESS

Hospital or facility staff support are key to identifying NODA patients, helping NODA volunteers have positive experiences at the bedside, and most importantly to connect all care givers to the meaning and values of the sponsoring organization. Regular all-staff communications help raise staff awareness about your NODA program.

RESOURCE FOUR | MISSION LEADERSHIP

SAMPLE LETTER FROM MISSION LEADERSHIP FOR ALL STAFF

Our Vision Coming into Focus

No One Dies Alone Program Introduction – [Mission Leader]

I would like to provide an introduction to the "No One Dies Alone" program at [Hospital]. The program offers a unique, volunteer-based ministry to ease the way of patients who are at the end of life and who are otherwise alone or with very limited contact.

No one is born alone, and in the best of circumstances, no one dies alone. Yet sometimes, patients are alone when approaching death and have neither family nor close friends able to be continually present with them as they near the end of life. The program was created to provide these individuals with the most valuable of human gifts—a dignified death.

We believe that the No One Dies Alone program really touches the heart of our mission, our vision, and our values in the ministry. The Sisters of [Name] live a special charism in their service to the poor and vulnerable, the sick, and the dying. We know that it is in keeping with the legacy of the sisters and the ongoing vision of our ministry to provide for those who are most vulnerable at the end of their lives.

This is why we embrace those at the end of life with a compassionate presence, even when the natural tendency in our culture—and often within ourselves—is to separate and to step away at that particular moment on a person's journey. We journey with others through a loving, compassionate presence that often goes much beyond any words we might share or actions we might offer.

The original program model was founded in 2001 by Sandra Clark, a critical care nurse from Sacred Heart Medical Center in Eugene, Oregon. It was the lonely death of one elderly patient that led Sandra to conceive of a volunteer companion program for hospital patients who would otherwise die alone. We thank Sandra and Sacred Heart Medical Center for helping us create our own program for dying programs.

The No One Dies Alone program began in [year] in the [Hospital] and continues to serve the needs at this ministry. Since the introduction of this program in our facility, our team of over 50 volunteers have provided countless hours at the bedside of patients in our hospital or hospice suites who have limited or no friends or family to be present with them in their last days and hours of life.

The patients are identified by their health care team and the NODA volunteers are called upon to provide a reassuring presence at the bedside of the dying patient for as long as is needed. You may even know one of our volunteers since they are a part of our bedside, administrative, and volunteer staff.

All volunteers for the No One Dies Alone program are graduates of our training program. They receive training in compassionate communication, comfort care, health care ethics, mission, and spiritual care. The training also includes an opportunity to practice being a compassionate companion through a live simulation with one of our "Smarties" in the Institute of Nursing classroom. After completing the training, NODA volunteers are then placed on the volunteer list and called when needed. There is no minimum time commitment per month, only a willingness to participate as you are able.

The major components of the program include the volunteer selection process, training, patient referrals, spiritual care chaplain support, and program coordination. You may have seen the program highlighted in a recent article from the Los Angeles Times entitled, "No One Dies Alone Program offers comfort to the end" (July 5, 2012).

Those are the informational details, but I invite you to really experience the loving power of this program from the perspective of several individuals in the Los Angeles Times video. You will witness this through one of our patients, Mr. Taylor Hall, who was gracious enough to let us journey with him on his final days.

[Coordinator], our program coordinator will share her passionate, committed efforts with the important collaboration involved in implementing the program among the volunteers, palliative care team, mission, spiritual care, and education/development.

You will also hear from two of our employees who are also volunteers [Name] and [Name], as they share stories from the journal of our NODA volunteers. The journal provides a medium to capture the personal experiences of our volunteers while also providing information for other volunteers who may be assisting.

And you will hear from [Name], Director of Volunteer Services, who has a tremendous commitment to the sisters, to our Mission, and to all of our program volunteers.

After the video, we end with a panel discussion for questions and answers that will include [NODA Team: Coordinator, Lead Nurse, Director of Volunteer Services, and Director of Nursing Education] – all of whom have been invaluable members of the No One Dies Alone Program Team.

I leave you with the words of Mother Teresa who reminded us of the dignity of the human presence:

"No one should die alone...Each human should die with the sight of a loving face."

-Mother Teresa

APPENDIX A | NODA WORKSHEETS

WORKSHEET ONE

1. What departments need to be involved in designing your NODA program?

2. What key people need to be involved in designing your NODA program?

3. Who will be the lead coordinator?

4. Who will you ask to be on the NODA committee?

5. How does NODA connect with the mission of your ministry/facility?

6. What will be your scope of services? (circle all that apply)

    a. Alone
    b. Alone with some family/friends
    c. Respite for family/friends
    d. Actively dying
    e. Nearing death
    f. Terminal diagnosis/hospice eligible
    g. Seriously ill, but not terminal
    h. Othe

7. What will be the steps of your activation protocol from the patient in the bed to the volunteer at the bedside?
    a. Who activates NODA?

    b. How do they activate NODA?

    c. Who receives the notification?

    d. What hours/days is NODA activation available?

    e. How are patients screened?

    f. How is patient/family permission for NODA obtained?

    g. How are NODA volunteers contacted?

    h. How are NODA volunteers scheduled?

    i. How the bedside staff are kept informed about NODA volunteers?

    j. Who notifies NODA volunteers when the patient dies?

8. Who will draft the NODA policy?

9. Do you need input from Human Resources?

10. Do you need a logo? If so, who will design it?

11. Do you need a brochure? If so, who will design it?

12. What services area(s) will you cover (inpatient, outpatient, skilled nursing, hospice, other)?

13. Who will be the lead coordinator?

14. What will their responsibilities be for

    a. Communication with volunteers, staff, patient, family

    b. Scheduling volunteers

    c. Recruiting volunteers

    d. Training volunteers

15. Will your volunteers be assigned a weekly/monthly shift or operate on call/as needed?

16. Do you need funding to start? If so, where will you get it?

WORKSHEET TWO

1. Who will you recruit (existing employees, existing volunteers, community, other)?

2. How will you recruit them?

3. How long will NODA training be?

4. Where will you hold the NODA training?

5. What will your style of training be? (didactic, experiential, interactive, PowerPoint, other)

6. What components will you include? (circle all that apply)

    a. Dying process
    b. Spiritual care of the dying
    c. Communication basics
    d. Ethics/mission
    e. Comfort cart
    f. Simulation/experiential/standardized patients
    g. Volunteer information: scheduling, communication, paperwork
    h. Other

7. Who will provide the training?

8. Do you need a manual? Do you need to provide written educational materials/handouts?

NODA training schedule in outline:

Introduction:

I.

a.

b.

c.

II.

a.

b.

c.

III.

a.

b.

c.

IV.

a.

b.

c.

V.

a.

b.

c.

WORKSHEET THREE

1. Who is responsible for communication with volunteers?

2. Who will schedule volunteers?

3. How will volunteers know what is happening with a NODA patient?

4. How will volunteers know when a patient has died?

5. How will you care for and support the volunteers?

6. How will you continue to educate the volunteers?

7. How will you collect NODA statistics?

8. Who will keep this data current?

9. What is your plan to maintain bedside staff awareness of the NODA program?

10. How will you raise community awareness about NODA?

11. What is your vision for your NODA program five years from now?

    How many volunteers?

    Who is leading?

    Which settings of care?

    Which patient populations served?

12. Your NODA roll-out timeline:

In the next month:

In the next three months:

In the next six months:

In the next year:

In the next two years:

By five years from now:

APPENDIX B | NODA VOLUNTEER MANUAL

The following pages contain information, education, and operational resources that you can use to assemble a NODA volunteer training manual of your own. It can be helpful to have the volunteers read the manual before coming to the in-person training.

PRE-VOLUNTEER TRAINING PAPERWORK

April 22, 2013

Thank you for your willingness to become a No One Dies Alone volunteer. Enclosed are a few forms that we would like you to fill out and bring with you to your scheduled orientation on [DATE].

All volunteers must have a blood test to screen for TB and check immunities to various diseases and infections. This is at our cost and you will be given more details about this at the orientation. I am enclosing information on the vaccines you will be offered if your blood test shows that you are not immune. It will be up to you if you would like the vaccine.

We will also submit the background check after the orientation.

If you have any questions, please give me a call or email me and I will be glad to help you.

Sincerely,

[Name]

Director, Volunteer Services

[Phone number]

[Email]

NODA Volunteer: Step-by-Step Guide for Volunteers

1. Watch your email for notifications from the NODA Coordinator about new patients in need of NODA companionship.

2. When a companion is needed, you will receive a brief email indicating whether or not the patient is on contact isolation and a link to the SignUp Genius calendar for the patient.

3. After you add yourself to the patient's SignUp Genius calendar, you will be provided with the following information: patient name, room number and room phone number, nursing unit and unit phone number, current condition of the patient (including whether the patient is in isolation), and information about volunteers coming before or after you.

4. Please call the nursing unit before you come to the hospital, as the patient may have died.

5. If you need to pick up the Comfort Care Cart, it will be located in the volunteer service's office.

6. Please wear your NODA Volunteer ID badge at all times when companioning.

7. Upon your arrival, introduce yourself to the staff (mainly the charge nurse and the patient's primary nurse). They should be expecting you.

8. Once you are in the patient's room, you assume the role of compassionate companion. If you have any questions about the patient, ask the nurse. Ask the staff to contact the on-call chaplain if you or the patient should have any spiritual needs.

9. During the vigil, simply be yourself. Treat the patient as you would one of your own friends or family members, with respect for the patient's individuality. Whatever your own beliefs, allow the patient to initiate any religious behavior rather than initiating it yourself.

10. If the phone rings, please answer it. The phone coordinator may have questions or information for you.

11. If the family arrives, you should simply say, "I am a volunteer and I was keeping [patient's name] company until you could arrive." Offer to stay or depart depending on the family member's preference. Let the phone coordinator and nursing supervisor know of this development.

12. Call the phone coordinator if the patient dies while you are present.

No One Dies Alone at [Hospital]

NODA Program Vision

Dedicated to providing caring, bedside companionship for the dying who are alone at the end of life.

Our Mission

[Name] Health System continues the healing ministry of Jesus in the world of today, with special concern for those who are poor and vulnerable. Working with others in a spirit of loving service, we strive to meet the health needs of people as they journey through life.

A Little about NODA

NODA (No One Dies Alone) was founded in November 2001 by Sandra Clark, CCRN, at Sacred Heart Medical Center in Eugene, Oregon. The lonely death of one elderly patient led Sandra to conceive of a volunteer companion program for hospital patients who would otherwise die alone. The NODA program has won several awards and has inspired hospitals around the United States and beyond to create similar programs. We thank Sandra and Sacred Heart Medical Center for helping us create our program for dying patients within [Hospital].

NODA Serves

Individuals in need are identified by a patient's health care team. A NODA volunteer is then called upon to provide a reassuring presence at the bedside of the dying patient for as long as needed.

A Dignified Death

No one is born alone, and in the best of circumstances, no one dies alone. Yet sometimes, patients are alone when approaching death and have neither family nor close friends able to be continually present with them as they near the end of life. The NODA program was created to provide these individuals with the most valuable of human gifts—a dignified death.

Your Role as a Volunteer

There is no nursing experience or skills required. As a volunteer, you will assist in comfort-care measures as requested by the patient or directed by the nurse, such as

- Holding the patient's hand
- Reading to the patient
- Holding the vigil
- Attentive to patient's comfort

The Dying Person's Bill of Rights

- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness; however, its focus may change.
- I have the right to be cared for by those who can maintain a sense of hopefulness; however, its focus may change.
- I have the right to express my feelings and emotions about my approaching death in my own way.
- I have the right to participate in decisions concerning my care.
- I have the right to expect continuing medical and nursing attention even if "cure" goals must be changed to "comfort" goals.
- **I have the right not to die alone.**
- I have the right to be free from pain.
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to have help from and for my family in accepting my death.
- I have the right to die in peace and with dignity.
- I have the right to retain my individuality and not to be judged for my decisions, which may be contrary to the beliefs of others.
- I have the right to discuss and enlarge my religious spiritual experiences, regardless of what they may mean to others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have the right to be cared for by caring, sensitive, knowledgeable people who will try to understand my needs and will be able to gain some satisfaction in helping me face my death.

This Bill of Rights was created at a workshop on "The Terminally Ill Patient and the Helping Person" in Lansing, Michigan, sponsored by the Southwestern Michigan In-Service Educational Council and conducted by Amelia J. Barbus, associate professor of nursing, Wayne Street University, in 1975.

Comfort Measures for Your Companion

- For soothing music and images, turn on *The Care Channel* (Channel 3) on the television.

- Play recorded music using the CD player and CDs from the Comfort Care Cart You may also bring your own music selections with you to the vigil.

- Bring favorite poems, stories or select readings from the books included in the Comfort Care Cart.

- Do not be afraid to be yourself—cry, laugh, carry on conversations, read, eat a meal in the room.

- Remember hearing and touch are the two last senses that remain until death.

- Your companion will feel comforted by your presence.

- You may adjust pillows, moisten lips, add or subtract blankets, adjust room temperature as you think may be beneficial for your companion.

- Call the nursing staff, **using the call light at the bedside** if you feel your companion is experiencing pain, is uncomfortable or anxious.

What is Pain Control at the End of Life?

Morphine: Information for Patients and Families

Effective pain control at the end of life is possible when patients and families work cooperatively with the palliative care team and their attending physicians toward this goal. We would like to share with you the basic principles, which guide us as we work with you to maintain a pain control plan.

Addiction is not a problem when morphine is taken on a regular basis to control pain.

Addiction describes antisocial behavior, drug-seeking behavior, and continued use of the drug despite negative consequences.

- What can occur is tolerance, which refers to the need for an increased dose of morphine over time to obtain the same amount of pain relief
- Physical dependence can also occur so that if morphine is stopped abruptly, withdrawal symptoms can occur

Unwanted side effects of morphine can be managed and either eliminated or minimized.

- **Constipation** is anticipated, so a bowel regimen with stool softeners and laxatives is begun at the same time that morphine is prescribed.
- **Nausea and vomiting** occur in about 30 percent of people at the beginning of morphine therapy. Anti-vomiting medication can eliminate these symptoms which tend to subside after a week or two of taking morphine.
- **Drowsiness, unsteadiness, and confusion** tend to be more common with people over 70 years of age. Fortunately, these side effects often subside after a few days.
- **Dry mouth, sweating, and difficulty urinating** are less common side effects.
- **Jerking movements of arms and legs** can occasionally occur and can be minimized with medication.

What are Comfort Care Orders?

A Guide for Relatives and Friends of Dying Patients

The doctor is writing a special set of orders for your relative/companion to make his or her last hours or days as comfortable as possible. The orders are meant not to prolong life but to allow nature to take its course. Comfort care orders will ensure a pain-free, quiet passage from this life in as dignified a manner as possible.

- We will only take blood pressure, pulse, and temperature readings once a day, or not at all.

- We will not do lab tests, needle pokes, or medication unless needed for comfort.

- The hospital chaplain will call on you. If you wish, your own clergy person may be contacted to provide emotional and spiritual support.

- We will not awaken your relative at night for procedures like weighing or blood sugar readings.

- We will position your relative as you and the patient desire to make him or her as comfortable as possible. We will not change position if it is painful. (Signs of pain can be grimacing, tensing up, or moaning.)

- Your relative can eat or drink anything he or she can tolerate, including food and alcoholic drinks you may bring from home. It is OK if your relative does not want to eat or drink.

- If your relative cannot drink fluids, we will moisten his or her mouth with dabs of water and keep lips from drying out with ointment. You can do this as you wish. We may also use a suction tube to clear mucus from your relative's mouth for comfort and to prevent choking. Eyes can also get dry. We can provide special eye drops if this happens.

- Too much fluid in a dying person's body can cause more discomfort. Lungs can fill up, making breathing difficult and wet sounding. Uncomfortable swelling in the legs, arms, and torso can appear, and people may even vomit, making it necessary to pass a breathing tube into their stomach. Studies are showing that natural dehydration, which occurs during the dying process, may release natural painkillers, making the process less painful than we may imagine. This is something you may want to read about.

- We may make a referral to our social services department for help planning discharge, (such as help from hospice) if there is a possibility your relative will leave the hospital.

- We will give your relative pain medications and anti-nausea medications if needed, usually through the intravenous route but sometimes by mouth. Also, if breathing sounds moist and labored, we can give medication to dry up secretions so breathing is less difficult. (The morphine that is given for pain also allows people to breathe with less effort and struggle.)

- We can also give medications for anxiety, restlessness, and confusion. If your relative is "not all there" and is having disturbing delusions and hallucinations, these medications can be calming and allow a more peaceful rest. Depending on what is ordered by the doctor, we may insert a catheter into the patient's bladder, so he/she will not have the discomfort of using a bedpan or having to get up to a commode. This will avoid potential skin problems that can occur when people are incontinent.

- If you have questions or concerns about comfort care orders, please do not hesitate to ask the physician and nurses caring for the patient. We know this is a very difficult, stressful time for you and want to ease as much of the burden as we can.

Helping Another through the Process of Dying

Communication

Families and friends are often concerned about how to express their feelings: "I would like to talk about how I feel and what is happening, but I do not know what to say." "What if I cry? I do not want to make him/her feel bad." It is normal to feel sad and tearful when someone you care about is dying. These emotions can be difficult to express.

- It may be helpful to share your feelings with the facility chaplain or with your clergy. He or she can help you or your loved ones find ways to discuss these difficult topics.

Weakness

As a person's strength gradually decreases, he or she will spend more time resting. Sleep will become deeper and longer. With the loss of energy, a person will usually show less interest in activities, people, and surroundings.

- Be aware of the person's energy and consider limiting the number of visitors and the length of visits as appropriate.

Changes in Appetite

As the body's needs change, the appetite frequently changes. The person will gradually stop eating and eventually may even refuse liquids. Watching someone refuse to eat and drink can be difficult. Although you may be used to offering food as a way of showing love or concern, please understand that the person is more comfortable this way.

- Ask the nurse for suggestions about what foods and fluids the person may tolerate more easily during these changes.
- Respect the person's decision; do not force foods or fluids.
- Offer touch, conversation or supportive silence.

Decrease in Urine

When the person begins to drink less, he or she has less need to urinate. Urine color changes from yellow to tea color or dark brown. The odor may also become strong because the urine is more concentrated.

Loss of Bowel and Bladder Control

As weakness increases and the muscles relax, the person may experience the loss of bowel and bladder control. This change can be upsetting to both the patient and the family; however, it is a normal result of the changes in the body.

Restlessness

For a variety of reasons, the person may become restless or agitated. Some of the reasons include changes in the body, a decrease in the oxygen level, fears, and physical and emotional discomfort. The nurse may have helpful suggestions for easing restlessness. Here are some to try:

- Do not try to restrain the person's movements, this may actually increase the restlessness.
- Speak softly in a calm, natural way.
- Lightly massage the forehead, hands or feet as a way to soothe the person.

Confusion

Changes in the body can cause confusion. Sometimes medications also cause confusion. If you are concerned that medications are causing confusion, talk to the nurse.

- Always identify yourself when approaching someone who is confused.
- Use simple statements, tell the person what you plan to do, such as "I'm going to put this cool washcloth on your forehead."

Vision-like Experiences

As a person approaches death, he or she may begin talking to someone who is not physically present in the room. Often this someone is a family member or a friend who has died. Sometimes this person will also report seeing the place in which he or she will travel after death. These experiences are usually very comforting to the person. They are a normal and natural part of the dying process.

Encourage the person to talk about visions and experiences he or she is having. Try to be open to hearing what the person is sharing. Let the person know that these experiences are normal.

Decreased Responsiveness

As the dying process continues, the person may sleep more. It may become increasingly difficult to awaken him or her. The ability to hear continues long after the ability to respond is lost. Being spoken to and hearing familiar voices can be very comforting to the person.

- Speak naturally. Know that you will be heard.
- Do not try to awaken the person.
- Notice if gentle touch soothes the person.

Congestion

As the person becomes less responsive, congestion may occur in the chest and throat. Congestion causes a variety of gurgling and rattling sounds. Suctioning is not usually recommended because it can cause discomfort and increase congestion. Although the gurgle and rattling sounds cause little to no distress to the person, they can be disturbing to the family. The nurse can tell you if medications or treatment would minimize congestion.

- Raise the head of the bed or turn the person onto his or her side to ease congestion.

Breathing Changes

Breathing changes as death draws closer. The person may experience periods of faster, shallow breathing, followed by deeper, irregular breaths, including periods of up to a minute when no breaths are taken. Sometimes a moaning sound occurs when the person breathes out. This does not mean the person is in pain or suffering—it is simply air moving relaxed vocal chords.

- Raise the head of the bed slightly and share any concerns with the nurse.

Temperature

The person's skin, especially on the hands, legs, and feet, may become increasingly cool to touch and may appear darker or blotchy. The brain may send confusing messages to the body causing the person to experience periods of hot and cold.

- Put on or remove blankets according to what the person wants.

Saying Good-bye

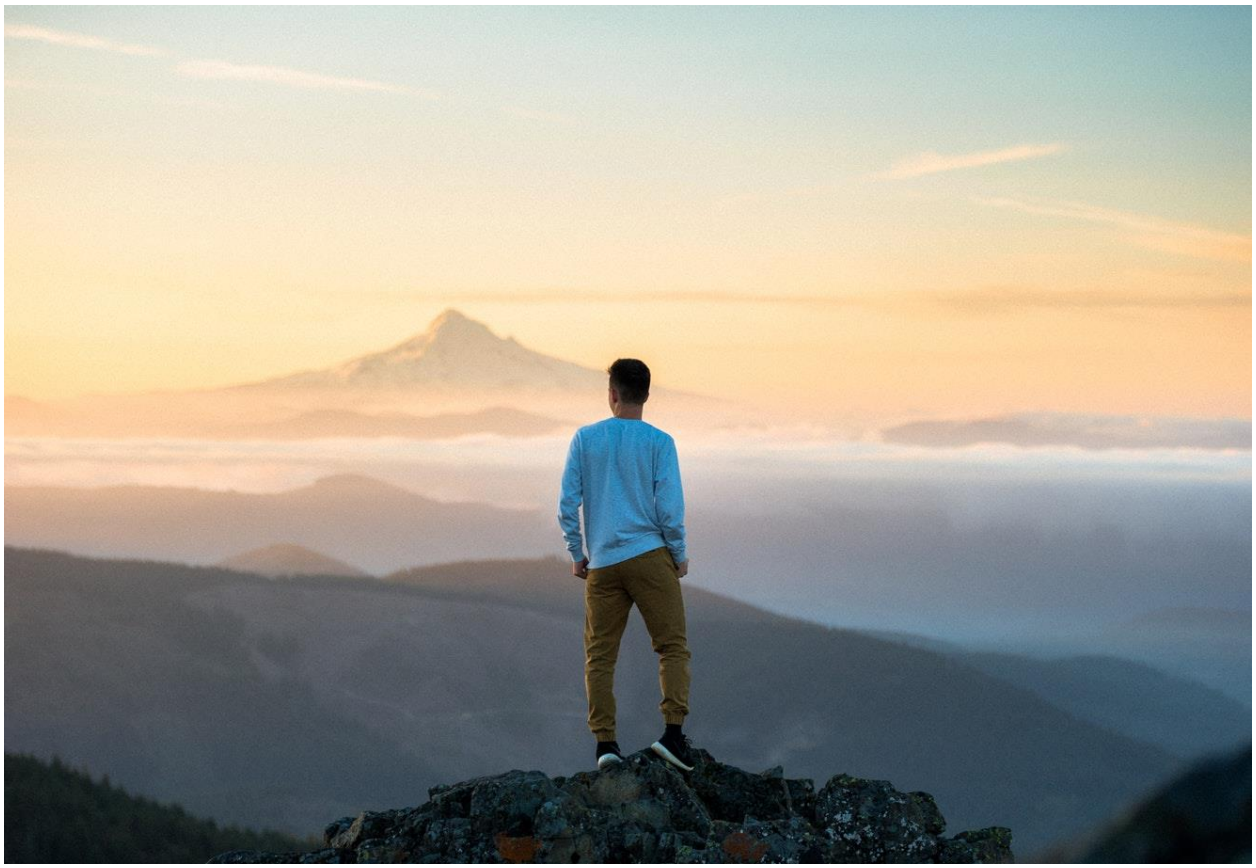
It is hard to let go of someone you love, but it is a great and necessary gift. A dying person sometimes lingers, even at risk of discomfort, if he or she feels that the family is not prepared to let go.

- Say good-bye in your own way. This may include offering words of love, forgiveness, or gratitude, quietly holding a hand and sending love, or talking about meaningful or funny times.
- Tears are a natural part of saying good-bye. You do not need to hide your tears or apologize for them. They are normal expressions of grief and love.

Dying the "Right Way"

Our ultimate gift is to allow someone to die in his or her own way. This is not the time to try and change someone; this is the time to offer acceptance, comfort, and support.

- It is natural to want to share your thoughts and feelings in an open and significant way. Discuss your desires with any member of the staff. We will support you in any way we can to make this time easier and more meaningful to you.



What You See	What is Happening	What You Can Do to Help
A decrease in both eating and drinking which may last from days to weeks. Less interest in food. Eating may become more of a burden than a pleasure. Occasional choking on fluids. Feeling "full" quickly.	The body naturally begins to conserve energy and requires less nourishment. There is no "hunger" and no "suffering" with this process. IV fluids and artificial feeding will NOT promote comfort or prevent death.	Moisten the patient's mouth with toothettes and swabs frequently. Offer sips of fluid or chips of ice. Offer bits of food if desired. Follow the patient's wishes about taking food and fluids.
Change in physical appearance may last a few hours or days. Often the patient's hands and feet may feel cool and may darken in color.	The circulation is slowing down, and the blood is being reserved for the major internal organs.	Offer blankets if the patient seems uncomfortable or expresses a desire for one - never use electric blankets or heating pads. Because of circulation changes, the patient will often throw off the covers with attempts to cool him/herself.
Patient will respond less and less to you and his/her surroundings. Eventually the patient is completely unable to speak or move. This usually happens during the last few days of life.	Patient is preparing for release and detaching from surroundings and relationships. This is a physical and spiritual response to the dying process.	Assume that the patient can hear everything. Say your name and speak softly. Touch gently and frequently. Do not ask questions which require answers. You may find prayers or meditation helpful at this time.
Intermittent disorientation and restlessness may occur in most patients. This may increase in the last days.	This is due partly to the changes occurring in the patient's metabolism.	Gently touch the patient. Talk reassuringly. Remain calm. The patient may need medication to help decrease the restlessness.

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.	As the circulation decreases, kidneys and bowel function may be reduced. Muscles may relax causing incontinence for the patient.	Remain calm. Patient may need underbody pads. Patient may need diapers. Foley urinary catheters, if needed, are usually not uncomfortable for the patient.
Breathing becomes more irregular. 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. Increasing sounds of congestion in the chest and a rattle in the throat may be heard during the last hours.	Circulation to internal organs will decrease, especially the heart and lungs. Throat muscles will begin to relax, and the lungs will lose their ability to clear fluids.	Elevate the head of the bed or use pillows to elevate the head. Turn the patient on his or her side to increase comfort. O2 does not help at this stage. Medications will be useful. The patient is not aware at this stage. Mouth care increases comfort. Suctioning does not help. Transdermal scopolamine patch may help to dry secretions.

Dying is a sacred time of life—a time filled with meaning and important tasks

How will you know your companion has died?

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

Please feel free to stay with your companion for a while. Inform the attending nurse of the patient's death.

When to Call a Chaplain

1. The patient requests a chaplain.
2. The patient asks for a prayer, sacraments, blessing, or other spiritual practices.
3. The patient expresses fear, sadness, anger, forgiveness issues, remorse, family issues, etc.
4. The patient feels there are major decisions that need to be made.
5. Religion or spirituality is obviously important to the patient. (Examples; They have a Bible out, rosary present, a religious statue or picture displayed, etc.)
6. Ethical questions arise.
7. You feel uncomfortable with your emotions, have questions, or the experience is bringing up issues for you that must be dealt with immediately.
8. Uninvited religious visitor appears. (You may also call security.)

The chaplain's role is to remain faithful to the [Name] Health System's commitment to the well-being of the whole person and to the core value of compassion. As spirituality is an integral dimension of human life, chaplains provide an environment for patients to connect with their own spiritual sources of meaning, comfort, and hope in the midst of their hospitalization. The role of professionally trained chaplains is to assist patients without inserting their own religion, beliefs, thoughts, or ideas.

You may call for a chaplain by phoning the Spiritual Care office at ext. #. If it is after hours you may call the House Supervisor at ext. # and discuss if it is appropriate to have the on-call chaplain paged.

The Centers for Disease Control and Prevention (CDC) Guidelines to Prevent Hospital Associated Infections

These are the safety tips used to keep the patients and health care workers in the health care setting protected from infectious diseases. Hand hygiene is one of the most important ways to prevent the spread of infections including the common cold, flu, and other hard-to-treat infections. Hand hygiene is most important in protecting you and our patients from acquiring hospital-associated infections. CDC recommendations for Hand Hygiene:

1. Why do we have to do hand hygiene?

   To prevent hospital infections
   - In the United States, hospital patients get nearly 2 million infections each year. That's about 1 infection per 20 patients!
   - Infections you get in the hospital can be life threatening and hard to treat.
   - All patients are at risk for hospital infections.

2. When do we need to wash our hands?
   - Before entering the patient room
   - Before exiting the patient room
   - After blowing your nose, coughing, or sneezing
   - After touching hospital surfaces such as bed rails, bedside tables, doorknobs
   - After using the restroom
   - Before putting on gloves. Wearing gloves alone is not enough to prevent the spread of infection.
   - After removing gloves

3. How do we wash our hands?
   With soap and water
   - Wet your hands with warm water. Use liquid soap if possible. Apply a nickel-or quarter-sized amount of soap to your hands.
   - Rub your hands together until soap forms a lather and then rub all over the top of your hands, in between your fingers, and the area around and under the fingernails.
   - Continue rubbing your hands for 15 seconds. Need a timer? Imagine singing the "Happy Birthday" song twice.
   - Rinse your hands well under running water.
   - Dry your hands using a paper towel if possible. Then use your paper towel to turn off the faucet and to open the door if needed.

   With an alcohol-based hand rub
   - Follow directions on the bottle for how much of the product to use.
   - Rub hands together and then rub in between your fingers and the area around and under the fingernails.
   - Continue rubbing until your hands are dry. If enough rub was used to kill germs, it should take at least 15 seconds of rubbing before your hands feel dry. You should not rinse your hands with water or dry them with a towel.

4. Which is better soap and water or alcohol hand sanitizer?
   Both are equally good.

Use soap and water:

- When your hands look dirty
- After you use the bathroom
- Before you eat or prepare food

Use an alcohol-based hand rub:

- When your hands do not look dirty
- If soap and water are not available

[Hospital] follows several types of precautions:

1. **Standard Precautions**

   Standard Precautions are infection prevention practices that apply to all patients. You do not see any sign outside the patient room. Before you enter any patient room you need to wash your hands. Depending on the anticipated exposure to blood, bodily fluids, secretions, and excretions (except sweat) you may need to include gloves, a gown, a mask, and eye protection.

   Do not touch a patient in areas where the skin is not intact (areas of the skin that appear chapped, broken, rashes or having lesions), or in areas that are bandaged.

2. **Contact Precautions- RED Color**

   When you visit your assigned patient room, observe for CONTACT sign outside the patient room. Contact Precautions are infection prevention practices that apply to the patient's condition which require extra care to prevent coming in contact with the patient's environment. Please ask the nursing staff if you have any questions and follow these guidelines when your patient is in CONTACT Precautions:

   Steps to take before you enter the patient room

   1. Locate Personal Protective Equipment or PPE (gown, gloves, and mask). You can find them in the isolation cart which is located outside the patient room. If you cannot find the isolation cart outside the patient room, please ask the nurse.
   2. Wash hands with soap and water or alcohol hand sanitizer.
   3. Put on the gown.
   4. Put on the gloves.
   5. Wear a mask/goggles if you suspect exposure to bodily fluids.

   Steps to take before you exit the patient room

   1. Remove your gloves
   2. Remove your gown
   3. Wash your hands with soap and water or alcohol hand sanitizer

Note: If the patient room has "CONTACT precaution" sign and YELLOW sign, please wash your hands with soap and water only.

3. **Droplet Precautions- Green Color**

   Droplet Precautions are infection prevention practices that apply to patients who have organisms transmitted through close respiratory or mucous membrane contact.

   Steps to take before you enter the patient room

   1. Wash hands with soap and water or alcohol hand sanitizer
   2. Wear a mask
   3. Wear the gown/ gloves if you suspect exposure to bodily fluids

   Steps to take before you exit the patient room

   1. Remove the mask
   2. Wash your hands with soap and water or alcohol hand sanitizer

4. **Airborne Precautions-Blue Color**

   DO NOT ENTER IF THE PATIENT'S ROOM HAS "AIRBORNE PRECAUTIONS" SIGN OUTSIDE THE ROOM

If you have any question before, during or after visiting your patient, please contact the patient's nurse, NODA coordinator or Infection Prevention department.

Communicating with Compassion

THE FOUR QUALITIES AND FOUR SKILLS OF A COMMUNICATOR

FIRST QUALITY: ATTENTION

Being aware of the signs, signals, and clues that indicate what is important to someone

Aspects of Attention

-Listening, seeing, feeling

-Asking permission (to enter, visit, help, support)

-Observing the subtleties in a person's body language, tone of voice, facial expressions

-Responding to the other's signals, following their lead

-Going with what the other wants to talk about or discuss

-Recognizing what is appreciated and what isn't

Obstacles to Paying Attention

Following your own agenda instead of the other's lead

-Not asking permission

-Not giving any choices, or a sense of control

-Intruding, interrupting, controlling

-Getting caught up in your own feelings, opinions, and needs

-Focusing only on what you are doing to, or doing for the other, and avoiding being with

Making Assumptions

-Assuming the worst, assuming the best

-Assuming the other person wants your help, or your company

-Never asking questions to check that you understood

-Ignoring the signals, being insensitive

FIRST SKILL: SUMMARIZING

Saying in your own words what was said to you, reflective listening

Aspects of Summarizing

-Putting the other person's statements into your own words and speaking it back briefly

-Reflecting back what you heard

-Clarifying that effective communication is occurring

Obstacles to Summarizing

-Merely parroting back the same words

-Elaborating, communicating assumptions

-Stating as fact instead of leaving opportunity for clarification and feedback

SECOND QUALITY: ACKNOWLEDGMENT

Letting others know that you recognize and appreciate them as unique individuals

Aspects of Acknowledgment

-Taking a genuine interest in the person

-Talking about what's special, important, or interesting to the other

-Commenting on how the other has made a difference

-Recognizing abilities, qualities, and strengths

Obstacles to Acknowledgment

Giving advice

-"What you really need to do is think positive."

-"Make sure you take your vitamins." "You ought to get more exercise."

-"I read this great book that says you should drink more water."

Invalidating/discounting/denying someone's feelings, perspective or experience

-Diminishing feelings: "Don't cry!" "Don't worry. It's not as bad as you think."

-Being patronizing: "There, there, it'll be all right."

-Using clichés: "It could have been worse." "Every cloud has a silver lining."

One-upmanship

-Telling comparative story: "You think your stitches are bad, you should see the scar from my gallbladder operation." "This is nothing, you should've seen Fred when it happened to him."

-Telling your tale of woe: "When I gave birth to you, I was in labor for 48 hours. You've never felt such a pain."

-Telling horror stories about surgical mistakes, incompetent doctors or malpractice lawsuits: "I heard one of your doctor's patients just died."

SECOND SKILL: VALIDATION

Identifying and communicating the feelings that go with the words

Aspects of Validation

-Displays a deeper acknowledgement, beneath the surface level to the feeling level

-Communicates acceptance for whatever feelings the other may be experiencing

-Recognizes the whole person, head and heart

-Conveys empathy

Obstacles to validation

-Can be misconstrued as just sympathy

- Can be stated as a fact rather than a question

-Can depend on our own comfort level with different emotions

-Can be missing the non-verbal communication

-Transference

THIRD QUALITY: ALLIANCE

Letting others know that you are there with them

Aspects of Alliance

-Finding common ground

-Presence

-Warmth, comfort, kindness

-Appropriate use of touch

-Appropriate use of humor

Obstacles to Alliance

Separating yourself:

-Showing no warmth, no feeling, no empathy

-Being distant and aloof

-Taking yourself too seriously

-Finding no common ground

-Staring, or its opposite, no eye contact

-Talking about the other as if they were not in the room

-Talking down to someone, being condescending

Feeling sorry:

-Commiserating: "Poor dear, I feel so sorry for you." "It must be awful."

THIRD SKILL: THE OPEN-ENDED QUESTION

Asking agenda-free questions

Aspects of an open-ended question

-Cannot be answered with a "yes" or "no"

-Structured to facilitate deeper conversation

-Often begin with "Who?" "How?" "When?" "What?" or sometimes "Why?"

-Can open with "Tell me more about…" or "Help me understand…"

Obstacles to open-ended questions

-Prying

-Pursuing one's own curiosity

-Ignoring signs that the person does not want to share

-Displaying insensitivity to boundaries

FOURTH QUALITY: ACCEPTANCE

Allowing things to be the way they are

Aspects of Acceptance

-Helping people feel safe and comfortable with you

-Being non-judgmental

-Showing no pretenses

-Having humility. Being willing to say, "I don't know"

-Letting go of wanting, it has to be a certain way

-Giving permission to speak freely

Obstacles to Acceptance

Avoiding and Pretending

-Pretending that the situation is different from the way it really is

-Pretending to know the answer when you don't

-Avoiding the difficult issues that people may want to talk about

-Avoiding the obvious or inevitable

Rescuing/Fixing it

-Trying to rescue people from their problems

-Trying to fix it, change it, or make it all better

Negativity

-Getting irritated, complaining, blaming, finding fault

-Being critical, judgmental, sarcastic, cynical, bitter

-Being indifferent, blasé… "Whatever"

-Getting defensive, taking it personally, being inflexible

-Communicating guilt or blame: "If only you hadn't smoked all these years, this never would have happened." "Think of all the worry you've caused Mom." "I read that you're responsible for your own illnesses."

FOURTH SKILL: UNCONDITIONAL POSITIVE REGARD

Acceptance and support of another regardless of what the person says, does, and feels

Aspects of Unconditional Positive Regard

-Being non-judgmental

-Freeing the other to greater acceptance of self

-Being warm, non-possessive caring

-Demonstrating acceptance

Obstacles to Unconditional Positive Regard

-Unable to overcome one's own judgments, biases, or prejudices

-A need to correct, fix, teach, or preach

-Lack of awareness of one's own boundaries, values, and assumptions

Use of Music in Care for the Dying

Music, integrated into supportive care of the dying, is becoming more common in health care settings that focus on end-of-life care, such as hospice and palliative care.

Offering music at the bedside of the ill or dying can often help to release an individual's blocked or painful feelings, and stimulate positive ones such as hope, love, forgiveness, and gratitude. Music seems to reach a deep, non-rational part of the human spirit and is thus ideally suited to help alleviate feelings such as fear, anxiety, grief, depression, sadness, and anger that can perhaps stand in the way of a person's clear passage into death.

Often, we tend to forget the fact that the dying are losing their entire world, their body, their relationships with family and friends, and even their own identity.

These losses can be overwhelming at times. A music "vigil" at the bedside, using live voice or harp, or a combination of the two, can be very beneficial for both patient and loved ones. The music can often convey a sense of serenity and consolation that can be profoundly soothing, helping the ill or dying to find deep rest and peace.

People have traditionally used music and song to comfort one another.
During medieval times, Christian monks in France developed a tradition of monastic chants for the sick and dying to bring what they called a "blessed death". The Greeks and Celts practiced this custom also, but the practice was nearly forgotten in modern times as societies have become more disconnected from the spiritual significance of death.

Now, musical medicine is experiencing a revival. The practice of playing harps for the ailing, called music-thanatology, has become more common in health care settings across the country.

The term "*thanatology*" is derived from "*Thanatos*", the Greek term for death. In the field called music-*thanatology*, the practitioner provides musical comfort using live harp or voice at the bedside of patients nearing the end of life. The service at the bedside is called a *music vigil*; the purpose is to serve the needs of the dying and their loved ones with prescriptive music. The term *prescriptive music* is live music that changes by the moment in response to physiological changes in the patient. Music vigils may ease respiratory distress, reduce anxiety and fear, allow deeper rest, and decrease pain for terminally ill people. A *music-thanatologist* who performs the music vigil, is formally trained in changes to respiration or circulation. The music-thanatologist does not try to control *what the patient is experiencing,* but rather *support the patient in whatever they are experiencing.* The goal is to create a musical passage for the person without intruding on their final moments. Music-thanatologists are part of the interdisciplinary team for the patient, working with hospital staff to plan the best course of care, and tailoring each music vigil to the individual patient.

In the absence of a live music vigil, the use of recorded music has been found to be very comforting and soothing for persons nearing the end of life.

Harp, recorder, and guitar are some of the more common instruments used for these arrangements. Purely vocal music that is sung or chanted without accompanying musical instruments and natural sounds such as chimes, bells, bird songs, rain, and wind have also been incorporated into musical compositions. The music is always of a soothing, relaxing, and uplifting nature, perhaps drawn from existing hymns, songs, and lullabies.

Music touches us in ways that words cannot reach, creating a safe, sacred space to find peace in the midst of loss while helping free emotions locked within the body. Music is safe, gentle, and comforting. It helps us to access a whole range of feelings we may be unable to articulate.

A few suggestions on using recorded music at the bedside

Several music selections on the iPad are provided in the NODA Comfort Care Cart for use at the bedside of patients and residents. Always ask the person if they like music and would like some provided before turning the iPad music player on. Some may prefer classical over harp and voice, so be sure to ask! If the person is unable to respond, simply select some music and attempt to discover what he/she finds the most comforting. The person will usually let you know by their body language if you have the right selection.

When beginning with a music selection, observe the person closely. Start with a quiet volume and turn it up gradually as you do not want to "shock" patients who are near death or semi-comatose. If the tempo is too fast or too slow, or there are too many instruments or voices, it may agitate the patient. Also, be aware of the volume and how this may be having an effect. Other sounds in the room may be adding layers of white noise, such as medical equipment or exterior sounds. Attempt to limit the "sound environment" to a calming space.

References: "Sacred Harmonies"- home.earthlink.net; "The Invisible Guest: Sacred Flight" by Heather Maharry- www.sacreflight.org; "Use of Music in Care for the Dying" – www.growthhouse.org

…in the Silence that Goes Beyond Words

Those who have the strength and the love to sit with
A dying patient in the *silence that goes beyond words*
Will know that this moment is neither
Frightening nor painful, but a peaceful cessation of
The functioning of the body.

Watching a peaceful death of a human being reminds
Us of a falling star; one of a million lights in a vast
Sky that flares up for a brief moment only to
Disappear into the endless night forever.

To be a companion to a dying patient
Makes us aware of the uniqueness of each individual in this
Vast sea of humanity.

It makes us aware of our finiteness, our limited lifespan.

Few of us live beyond our three score and ten years
And yet in that brief time most of us create and live
A unique biography
And weave ourselves into the fabric of human history.

Excerpt from On Death and Dying, page 276, by Elizabeth Kubler-Ross, M.D. Scribner. 1969


FIVE THINGS THAT MATTER MOST
Please forgive me
I forgive you
Thank you
I love you
Goodbye
-Ira Byock

The Kindness of Strangers

Not everyone goes to their deathbed surrounded by loved ones— which is why an Oregon nurse enlisted an entire hospital (everyone from kitchen workers to carpenters) to make sure that no one dies alone.

At a large medical center in the Northwest, while making her rounds, a veteran nurse checks on a frail, elderly man who is near death. "Will you stay with me?" the man asks, his voice barely audible. "Of course," she says, meaning it. "As soon as I check on my other patients."

But tending to others takes the next hour and a half, and by the time the nurse returns to the man's room, he is dead. She consoles herself with the knowledge that he was very old and obviously failing, that there were orders to not resuscitate him, that even if she had returned more quickly, she could have done nothing. Still, she is troubled. She feels that she has failed, not just as a nurse, but as a human being. It was okay for him to die, she thinks—it was his time—but it was not okay for him to die alone.

Looking back on that night, the nurse, whose name is Sandra Clarke, says, "I was overcome with guilt and frustration. I didn't know what to do. I just knew something had to be done."

Meeting Clarke, it's hard to imagine that anything could unsettle her for long. Almost exhaustingly energetic, she has an animated face framed by dazzling silver hair, the tips of which she dyes jet-black. She is the kind of person who makes her own weather, a category-defier who quotes Mother Teresa one minute and recounts the plot of a B-grade horror movie the next. The kind of woman who turns a wrenching moment into an ambitious, life-altering plan.

That plan is a program called No One Dies Alone (NODA). Almost single-handedly created by Clarke, it is today radicalizing end-of-life care in hospitals by making volunteers available to comfort dying patients in their final hours. The program enlists hospital employees from every department—from kitchen workers to carpenters, medical transcriptionists to maintenance men—to sit with dying patients who are on their own.

Launched in November 2001 at Sacred Heart Medical Center in Eugene, Oregon (where as many as 200 volunteers are routinely on call, dispatched to the hospital at all hours by a rotating group of phone coordinators), Clarke's program now operates in hospitals from Alaska to New York, as well as in Singapore and Japan. Clarke, who won a Circle of Excellence Award from a national nursing association in 2004, has written a No One Dies Alone manual and distributed it to more than 400 hospitals, hospices, and AIDS care facilities worldwide. Her all-volunteer program operates with no funding except a small grant to subsidize the printing of the manual.

Although many dying patients have family or friends available, a significant number do not— from "elder orphans" (Clarke's term for those who have outlived their families), to people whose geographically or emotionally distant relatives are not able to be present, to the occasional stricken traveler. One 40-year-old man did not want to die in the presence of his wife and young children—but also did not want to die alone.

NODA's compassionate companions, as the volunteers are called, sit at the bedside of the dying, holding a hand or stroking an arm. Some talk or read aloud—everything from essays in *Chicken Soup for the Soul* to articles in *Field & Stream*. Others play CDs. The shared time is intense but not always somber. During one NODA vigil, a volunteer found herself singing along, at 3 A.M., to Gilbert and Sullivan operettas. Another volunteer traded fishing stories with a 96-year-old man during the last hours of his life. Whatever the volunteers do in these hours, they offer the most valuable gift: a dignified death. In return, they sometimes experience something profound.

Jim Clark (no relation to Sandra) is a 61-year-old maintenance man at Sacred Heart whose work ranges from repairing beds to unclogging toilets; he's an amateur gunsmith and an NRA-certified pistol instructor. He heard about NODA from a coworker not long after his own father died, with Clark by his side. "It matters how you go," Clark says. "I would never have wanted my father to go alone." Since he put his name on the list, Clark has participated in more than two dozen vigils and has been with six people at the moment of their deaths. He remembers sitting in a chair by one woman's bedside listening to her labored end-of-life breathing. "I told her there were friends waiting for her on the other side. I told her to relax. And I think she did. I think I helped." Clark pauses and swallows. "You have no idea what that means to me."

Another volunteer, a 50-year-old receptionist named Vicki Wiederhold, recalls being able to calm an agitated patient. "After a while, she seemed to fall asleep or slip into a coma," Wiederhold remembers. "Then at one point, she opened her eyes, looked at me, and said, 'Thank you, Vicki.'" Four minutes later, the patient was dead. "To know that I can help bring a moment of peace like that is everything," Wiederhold says.

Seven years ago, when she roughed out a proposal at her kitchen table, Sandra Clarke had no idea her modest plan would become an international program—and little inkling that NODA would have such an effect on volunteers. "It is all so simple," she says. "Anyone with a heart can do it."

Lauren Kessler's latest book is "Dancing with Rose: Finding Life in the Land of Alzheimer's" *(Viking)*. *For more about No One Dies Alone, go to www.peacehealth.org/oregon/noonediesalone.htm.*

Let Me Die Laughing

We are all dying, our lives always moving toward completion.

We need to learn to live with death, and to understand

That death is not the worst of all events

We need to fear not death, but life-

Empty lives,

Loveless lives,

Lives that do not build upon the gifts that each of us has been given,

Lives that are like living deaths,

Lives which we never take the time to savor and appreciate,

Lives in which we never pause to breathe deeply.

What we need to fear is not death, but squandering the lives we have been miraculously given.

So let me die laughing, savoring life's crazy moments.

Let me die holding the hand of one I love, and recalling that I try to love and was loved in return.

Let me die remembering that life has been good, and that I did what I could.

But today, just remind me that I am dying, so that I can live, savor and love with all my heart.

By: Mark Morrison- Reed

The Ship

I am standing upon the seashore. A ship at my side spreads her white sails to the morning breeze and starts for the blue ocean.

She is an object of beauty and strength, and I stand and watch her until at length she is only a speck of white cloud just where the sea and sky meet and mingle with each other. Then someone at my side exclaims, "There, she's gone!"

Gone where? Gone from my sight, that is all. She is just as large in hull and mast and spar as she was when she left my side, and just as able to bear her load of living freight to the place of her destination. Her diminished size is in me, not in her.

And just at the moment when someone at my side says "She's gone," and there are other eyes watching out for her coming and other voices ready to take up the glad shout, "There, she comes!"

And that is dying.

-Author unknown