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Reaching Out Veterans Hospice Program *Replication Manual*

Manual Contents

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SECTION 1 - History

LINK of Hampton Roads, Inc. is the largest provider of homeless services on the Virginia Peninsula, which is defined as the Cities of Williamsburg, Newport News, Hampton and Poquoson and Counties of James City and York. LINK has been providing services since 1992. Among the services is a winter shelter program that operates for 20 weeks annually from the beginning of November until the end of March. Approximately 600 unduplicated individuals and families access the winter shelter. Each evening, the number of guests served average 100. In addition, LINK operates three permanent supportive housing programs that provide 77 units of housing and supportive services to homeless individuals and families who are willing to make the life style changes that will help them to become productive members of the community. Over the years, LINK has provided shelter and supportive housing services for many veterans.

It has not been unusual for LINK to provide assistance to individuals suffering from terminal illnesses. Rather than see them spend their last days or weeks on the streets or in a cold, vacant building with no support, LINK has creatively developed alternate shelter and hospice care by using community resources, including care by Roman Catholic Nuns, faith-based individuals opening their homes and when necessary, hotel rooms. The resources have provided critical support to homeless individuals to assure them a peaceful and dignified death.

During 2007-2008, the Executive Director of LINK opened her home and “hosted” 2 friends diagnosed with terminal cancer. Neither of the women was able to return to her home for her final months of life. A medical hospice program was brought into the home along with volunteers, family and friends to provide the services and support necessary to help the women make their final journey. Both women became members of the host’s family. Visitors to one woman became visitors and a support to both women. The women found peace, enjoying the quiet beauty of the yard and all it offered, the laughter of children and the greetings of animals. Needless to say, each woman died a peaceful death surrounded by their caregivers and enjoyed a quality of life that had not been experienced prior to their becoming part of the “family.”

This program has been dedicated to the two women as well as the homeless men and women who spent their final days in comfort rather than on the streets. They truly have been the pilots who have guided and helped craft this project.

SECTION 1 - Philosophy

A well-known adage says that death is one of the few guarantees in life. We will all experience death, but the experiences related to and conditions under which we die are determined by our culture, state of health, economic position, social standing and support system. However, one commonality is, most of us would rather complete our life's journey surrounded by family and friends than in a hospital or nursing home cared for by strangers.

While many terminally ill patients prefer to die in the familiarity and comfort of their own homes surrounded by family and friends, caring for a terminal patient in the home presents challenges that many caregivers cannot meet. The home may not adapt well to the needs of the patient, the caregiver may be in poor health or physically unable to meet the demands of the patient. Aging or terminally ill parents may live thousands of miles from family members, such that the family is unable to provide support for the patient and the caregiver.

While the choices are difficult for veterans with family support, choices are typically nonexistent for homeless veterans, who most often have jeopardized or lost their family and support systems because of behaviors or circumstances that have resulted in their living on the streets or in shelters. For them, death is frightening, lonely, and physically and emotionally painful.

Edward Ratner, MD, Center for Bioethics and Department of Medicine, University of Minnesota, presented a training on April 9, 2009 on end of life issues among the homeless population. He related that 47% of the homeless worry about the care they will/will not receive at end of life. He quoted one homeless person who participated in his study as saying, "It's definitely a concern for people, so if I die in the shelter, if I die in a ditch someplace, probably what's going to happen is that I'll go to a coroner, they'll put me in a cardboard box, and stick me in the ground someplace with my name on it. Nobody will be there."

Approximately 28% of all deaths in the United States are veterans. Of that number, 25% are homeless. Typically, veterans who die at a VA facility are homeless and die without a caregiver. With the veteran population of our nation aging, the number of deaths will increase in the near future.

LINK's Reaching Out Hospice project is designed to meet the needs of rural and/or homeless veterans who are within 6 months or less of death. It utilizes the home and family environment of private homes. Community members, "hosts," open their homes to veterans and invite them to become members of their families. The hosts become part of a team that includes hospice professionals, volunteers, other caregivers and family, dedicated to providing comfort and support for the veterans in their final stage of life.

SECTION 2 - Getting Started

So you want to begin a home hospice program that will make the final journey for homeless and/or rural veterans more comfortable, with greater quality and greater empowerment through personal choices. How can you be sure your community needs or will support such a program? If you believe, and have documentation to support your assertion, how do you start?

In order to establish that your community needs and will support such a program, you need to do some research and prepare a needs statement. Talk with homeless programs and rural services. What need do they see? Are there community hospice programs that serve homeless and rural veterans? Is the need greater than what can be met by the community programs? What is the number of homeless veterans in your community? Has your Continuum of Care completed a Point In Time Count (PIT) within the last year? The PIT is an annual count of homeless individuals and families in your community. Within the count, the special populations of homeless, such as veterans, are categorized. Are you located near a VA Medical Center? Does the Center have a hospice unit? Who is eligible to be admitted to the unit? Is there a waiting list? Is the unit willing to support your efforts? Talk with the Homeless Outreach Team at your area VA. They can provide critical information about community need.

Make a strong case, because you will need to use it to *sell* your concept in the community. You will need it when you speak publicly before community and veteran groups, get media support, and look for funding within the community or from local or national grants.

Once you get the “ground swell” moving, organize a steering committee comprised of representatives from community organizations and services whose missions and goals are compatible with yours and who are willing to partner with you. Invite your potential partners to sit around a table and share their ideas. Before the close of the meeting, be sure that those attending are on board and are willing to bring more potential partners to the next meeting.

As you read this Replication Manual, you will begin to develop your network of individuals and organizations you want to have around the partnership table. Once the interested partners are at the table and the ideas are flowing, create a list of goals you will need to achieve in order to begin your program and a time line for completion of the goals. Before the close of the meeting, designate either yourself or another impassioned individual to accept the role of being the temporary coordinator. This person may eventually become the permanent coordinator, but don’t scare anyone away by bestowing what may be perceived as a large responsibility too soon!

Develop an agenda for every meeting and stick to the agenda. Agree on the time commitment for each meeting and honor it. It goes without saying that everyone’s time is valuable. Respect that by facilitating meetings that are timely and productive. Maintain ongoing communication by distributing minutes of the meetings to all the partners. Between meetings, keep partners updated with new, important information either by telephone or email. You may consider

routing the meeting minutes to other key staff in each of the partner organizations. You can never communicate enough!

Read on! Good Luck, you will all feel proud of what you will achieve!

LINK staff, volunteers and members of the Board of Directors would like to thank the National Hospice and Palliative Care Organization (NHPCO) and the Veterans Administration for their funding and support. We are grateful for the support and guidance of the NHPCO staff, particularly Donna Bales, Kandyce Powell and Emil Zuberbueler. Thanks also to Chris Cody of the Veterans Administration and Diane Jones, consultant to the Veterans Administration for their wisdom and support.

Sincere gratitude is also extended to Sentara Hospice and Homecare, Williamsburg, VA, who have been providing quality hospice medical care and volunteer training. They have been an invaluable partner. We are grateful to the professionals at the Hampton, Virginia, VAMC. Our partners in the first replication project, Good Samaritan Hospice, Roanoke, Virginia and Hunter Holmes McGuire Richmond, Virginia, VAMC, gave us the push we needed to make the concept available for dying veterans outside the Hampton Roads area. Thanks to all the Richmond VA partners, including Brenda, Emily and Myra for your support and plenty of chocolate!

There are several web sites you may want to review as you begin your journey. They are located in Section 5 – Resources.

SECTION 2 - Community Partners

The “life-blood” of this project is the strength and diversity of the community partners. In as much as this project is focused on cost efficiency, it cannot be accomplished without the support of a variety of programs, organizations, individuals and groups within the community.

A strong relationship with a **VA Medical Center (VAMC)** is critical. It is important to identify the individuals and programs within the VAMC that work with the homeless veterans and the hospice program, including the nursing, medical and social work professionals that can identify and refer individuals who are appropriate for a hospice program. It is important to develop a relationship with an individual at the VAMC who is familiar with benefits and who can facilitate accessing benefits. Remember, every VAMC is an individual entity. Each Center operates differently. What works in one VAMC may not work in another. Do not become discouraged, it may take a while to identify the key staff members that are willing to support the project. Also remember, the staff person you contact may want to help you, but may be limited in his/her ability to help. Again, do not become discouraged, keep trying. Possibly the place to begin is with the Homeless Veterans Outreach Coordinator. That individual is particularly aware of the needs of the homeless population in the community, their needs and their access to services. Once you establish the relationship and accept veteran referrals, keep the individual or department in the loop related to the veteran’s status in the program. Be sure to advise the referral source of the death of the veteran. You should also communicate with the **Hospice Veterans Partnership**, the local **CBOC (Community Based Outpatient Clinic)** and your area **VISN (Veterans Integrated Service Network)**. Advise them of your program, your mission and your goals. They can be helpful in directing you to the appropriate staff members at your VAMC as well as referring veterans needing hospice care.

Your **state hospice association** is an invaluable resource. Among the membership are hospice programs throughout the state. Ask if you can be listed on their web site. As a member, you can be mentioned in their newsletter and perhaps have access to their data base. They are a powerful advocacy group and connected to the Veterans Administration and National Hospice and Palliative Care Organization.

Equally important is the partnership with a **community-based or hospital-based hospice** organization, particularly one that has a strong volunteer training program. The hospice program routinely trains volunteers and most likely has a procedure and curriculum in place. The hospice program must be willing to work with the VA Medical Center to develop a protocol for referring veterans to a hospice home. The program must also have in place and adhere to a strong quality assurance program. Veterans must be assured nothing less than a quality, comfortable final journey. It is entirely feasible that there may be partnerships with more than one hospice provider. Remember, we must assure that the veteran has choices. If your program is in an area that has more than one hospital with a hospice program, you may get hospice referrals from multiple hospitals. If the veteran has a relationship with a referring

hospital, it will make the transition from hospital to hospice easier by continuing with the referring hospital's hospice program.

Be sure that checking backgrounds of all volunteers and home hosts is part of the volunteer training program. You must always protect the veterans; and checking the backgrounds is an important step toward their protection. If the program that facilitates the training does not check backgrounds, you will need to find an organization that will assist.

A home hospice program is a natural fit for the **inter-faith community**. They are a rich source for volunteers, funding and donations of equipment and supplies. The inter-faith communities have their own networking and communications system. Generally one key contact can get your message or needs circulated to multitudes of members. Within each community are outreach groups or circles. For example, a men's group may be willing to take on building ramps or making minor repairs to make a host home wheel-chair accessible. A sewing circle may feel particularly called to make quilts or comforters for beds. Even youth groups, if properly prepared and supervised, can cheer up a hospice veteran by sharing conversation, laughter, books, bringing in disciplined pets, etc. The faith community is also a good source of specialized equipment such as wheel chairs, bed-side tables, etc. Some churches may have a lending program for additional specialized equipment or be willing to begin one on behalf of the hospice program.

Veteran Service Organizations seek out programs such as the home hospice so their members can provide veteran-to-veteran support. Veterans have a special and unique way of communicating their experiences, experiences that only they understand among themselves. Always give the hospice veteran the option of having a veteran provide support. The organizations will welcome a speaker at their meetings to provide awareness of the veterans' home hospice program. If there are problems identifying key staff at the VAMC, or if there is a communication problem, often a member of one of the service organizations can become the conduit to identifying staff or improving communication. It is an added plus if a member will accompany you to VA meetings or public speaking engagements. The presence of the VSO member adds credibility to your program.

Most communities have homeless programs, which may include shelters and/or medical clinics. A relationship with community **homeless service providers** is important. Remember that some homeless veterans do not have a relationship with their local VAMC and are unknown to them. This is particularly true for Vietnam era veterans. If your community has a Continuum of Care for homeless service providers, become a member. It is all about collaboration -- you can help them and they can help you; and together you help the veterans! If you receive referrals from homeless shelters, you need to be aware that many homeless veterans have not been enrolled in the VA and you will need to call your VA contact to get them enrolled. Also, if an enrolled veteran has not used the services of the VAMC in over a year, they need to re-enroll.

You need the **media**. A well-placed news article about the program is a great recruiting tool for home hosts and other volunteers. Don't limit your efforts to just print, try for an interview on

local television or radio. While the internet is not exactly considered media, it is equally important. Publicize your efforts on your web site, or create a web site for the new program. Link your web site to other web sites to maximize exposure.

Civic organizations look for speakers. Again, this is a source of volunteers, group projects, supplies and even referrals. A 30-minute presentation may be well-worth your time when a group offers to build a ramp, provide a lending-library of books or videos, transportation for a member of the veteran's support network or numerous other worthy projects that can add to the comfort and quality of life of a dying veteran.

Veterans without VA benefits, or with few benefits, may need to supplement their resources with civilian benefits. You will need to familiarize yourself with civilian benefits that are available in your community, including federal entitlement benefits. It is helpful to establish a relationship within the **Social Security Administration** and **Department of Human Services**. In most cases, benefits will be expedited for an individual with a terminal illness.

Other thoughts:

Always let your partners know how much they are appreciated. Keep them in the loop; share minutes of meetings and important updates and progress.

Define the roles and expectations of your partners.

If hospice providers are not using the Military Check List when serving veterans, encourage them to do so. A copy of the Military Check List is included in Section 5 – Forms.

Learn as much as possible about your VAMC and Veterans Service Organizations. Understand their work and their challenges. Take time to learn their "language" and use it as you communicate with them. Doing so will make communicating easier and they will appreciate that you have taken the time to speak their language.

SECTION 2 – Recruiting home hosts and volunteers

Recruiting volunteers has been, by far, the easiest part of this journey.

When the grant from NHPCO was first awarded, we were sent a PSA that was placed in our local newspaper. We received many inquiries as a result of the PSA, and it produced about 5 solid prospects for volunteers and 2 individuals inquiring about becoming home hosts. After a lengthy conversation, we thought the 2 women inquiring about becoming hosts would not work, but the other volunteer prospects were put on a list for an informational meeting.

LINK is an interfaith organization. The agency's very good friend, Sr. David Ann, is at the core of the interfaith network. She has an unbelievable database and can get the word out for volunteers or donations in a matter of minutes. Sr. David Ann is the type of person that causes people to stop and listen when she speaks. She is a tiny lady with a big heart. She often makes big men shake in their boots, and few say "no" to her easily! Needless to say, we had many responses from people wanting to be volunteers and many offers of hospice supplies. I only hope you can identify a Sr. David Ann in your community!

LINK has thousands of volunteers who come together from November to March to help run the winter homeless shelter. Many of the key volunteers are veterans. When the shelter closed for the season, a letter was sent to each volunteer thanking them for their service and letting them know about the hospice program. Again, we had many responses. The veteran volunteers went on to contact their chapters of volunteer service organizations and more volunteers were identified. They expressed great interest in providing veteran-to-veteran support.

There are times when contacts have unexpected benefits. I was meeting with the director of a community based hospice program. As I was describing the program, the director seemed disinterested. When finished, I politely thanked her for her time and left brochures on her desk. Later that day, I received calls from 2 of her nurses asking to be considered for the program as home hosts. Every time I have spoken before a civic or community group, the engagement has been followed by donations of hospice supplies or offers to become volunteers.

One of our partners is a hospital-based hospice program that routinely recruits and trains volunteers. They not only train our hospice volunteers, but have included our program as an option for community members requesting volunteer opportunities.

Our community is in an area that has an extraordinary military presence. Many military families retire and remain in the local communities. Veterans' programs are an easy sell. Who doesn't respect and care about the welfare of veterans! Like issues related to children, the community cares about veterans and are willing to provide assistance to programs that provide veteran services. To be successful, you need to take every opportunity to create the awareness and verbalize the need, while providing a variety of ways the community can help.

SECTION 2 - Home Screening Criteria

EXTERIOR

- Is the home in a neighborhood that is considered “safe?”
- Is the home in good repair?
- Is there a ramp for handicapped or wheel chair accessibility?
- Is there more than 1 exit from the home?
- Is there available parking for vehicles of professionals, family, volunteers?
- If there are pets in the home, are they healthy and are shots up to date?

INTERIOR

- Is the home clean, well-maintained, is carpet loose, are there “throw rugs” that would impede use of wheel chair or walker?
- Is there unobstructed pathway from entry to the bedroom?
- Is there a working laundry facility within the home?
- Are there working smoke detectors and fire extinguishers on each floor of the home?
- Are electrical or phone cords in good condition and placed out of the flow of traffic?
- Are exits clear and well lit?
- Are door handles in all rooms secure?
- Is flooring level and free of tripping hazards?
- Is there a working washer and drier?

Bedroom

- Is room large enough for hospital bed and hospital equipment?
- Is there a window in the room?
- Is there adequate storage for supplies and clothing?
- Are there sufficient electrical outlets to support the equipment?
- Do the electrical outlets accommodate 3-prong plugs?

Hallway

- Is the hall way wide enough for maneuverability of a wheelchair or gurney?

Bathroom

- Is it wheelchair accessible
- Are there grab bars in the tub or shower?
- Is there a night light in the bathroom?

Kitchen

- Is the kitchen clean, are all appliances in working order?
- Is there an eating area for a veteran who is ambulatory?
- Are towels, curtains and other things that may catch fire away from the stove?

SECTION 2 - Home Host Screening Criteria

1. Determine motivation for becoming a home host.

Is the motivation consistent with the philosophy and goals of the program or is it financial gain?

Has the applicant had hospice experience?

Has the applicant been in the presence of a dying individual?

2. Explain the mandatory volunteer training program including background checks and screening.

Is the applicant willing to participate, is there any reason he/she or a member of the family living in the home would not clear checks and screening?

3. Explain the role of home host.

Help applicant understand the commitment is 24/7. It is not in the best interest of the veteran to relocate, unless there are extreme circumstances that would warrant the move. It may be necessary to make home modifications for the comfort of the veteran, i.e. build a ramp, install grab bars in the bathroom, etc. The host will need to consult an insurance professional to review insurance coverage.

4. Discuss reimbursement.

What reimbursement would be expected?

How would the host react if the veteran had no funds or had applied for funds and probably would not be approved before end of life?

5. Explain that the home host is a member of the team that helps the veteran complete his/her final journey.

How does the applicant feel about professionals, family, and/or volunteers accessing the home at any time?

Are there young children, teenagers or animals in the home? Would hosting a veteran impact negatively on young children, teenagers and/or animals?

Are there health issues among family members or pets that could have a negative impact on the veteran?

6. Assess applicant's crisis management skills.

How will applicant manage/react to a health emergency or death?

SECTION 2 – Training

The 3 pages that follow outline the basic training curriculum. The training is facilitated by our partner, Sentara Home Care and Hospice Program. The program is part of the larger Sentara health system, which is the largest hospital system in the Hampton Roads area of Virginia. Needless to say, they utilize a large volunteer force and use well-defined training programs that successfully prepare community members to augment the services of their professional staff.

Prior to beginning the formal hospice training, all volunteers and home hosts attend an orientation meeting. The purpose of the meeting is to introduce community members to the hospice program for rural and homeless veterans. Discussed are the mission and goals, the expectations of volunteers and the variety of volunteer opportunities.

All volunteers must submit to background checks. The home hosts and family members living in the home must also participate in background checks. It cannot be emphasized enough that everyone having contact with the veterans must have a clean background. Many of the veterans have been exposed to trauma through their military service, and many homeless veterans live with trauma on a daily basis. Their final days must be peaceful and free of danger.

Trainees are also tested for tuberculosis and must have up-to-date tetanus shots. The testing and shots are provided free of charge by Sentara. The trainees also provide 3 references, which are checked by the training coordinator.

Once medical testing and shots have been completed and references have been checked, the formalized volunteer training is scheduled.

Hospice Home Training Agenda

Date: _____ Location: _____

At any training a Sentara Hospice professional may be present to augment any session.

Welcome and Introduction

1. Training Agenda
2. Questions and Answers

Session 1: Introduction and Hospice Philosophy / Concepts

1. What is Hospice?
2. What is the Hospice Benefit and how does it compare to the Home Health Benefit?
3. Does a hospice patient need a DNR?
4. The Hospice Circle of Care
5. Mission Statement
6. Roles and Responsibilities of the Personal Care Giver (PCG)

Session 2: Volunteering Part 1: Job Description

1. Different types of volunteers
2. Camp Lighthouse
3. Questions for a Life Review
4. Can I do the job?
5. Virginia Act of Assembly
6. Volunteer Supervision, Assignment and Evaluation
7. Hospice Volunteer Patient and Family Relations
8. Volunteer Roles and Supervision
9. Fitchett's 10 Commandments on Death and Dying

Session 3: Volunteering Part 2: Responsibilities

1. Volunteer Requirements
2. Volunteering in a LINK home
3. Confidentiality Policy
4. Health and Safety Information
5. Volunteer Agreement
6. Documentation of Volunteer Hours
7. OSHA / Regulatory Information
 - Standard Precautions for Infection Control
 - Tuberculosis
 - MRSA
 - Fire Safety
 - Electrical Safety

- Body Mechanics / Back Safety/ Transfers/ Equipment (by: Physical Therapist)
 - Violence in the Workplace
 - Cultural Diversity
 - Professional Boundaries
 - Ethical Issues
 - Medical Device Act
8. Home Care Prevention Protocol
 9. Health Screening for Sentara Hospice Volunteers
 10. I-9 Form
 11. Medication Education/ Comfort pak / Medication Routes (by: Hospice RN)

Session 4: Listening With Love

Session 5: Psychosocial Aspect of Death and Dying

1. Needs of the Terminally Ill
2. Caring for the Terminally Ill
3. What is Psychosocial Care?
4. A Dying Person's Guide to Dying
5. How to Deliver Tragic News with Compassion

Session 6: Hospice Diseases and Conditions

1. Hospice isn't just for cancer!
2. Patients with Dementia
3. Patients with Alzheimer's
4. Patients with AIDS

Session 7: Physical Care of the Dying Patient

Video: "My Gift: Myself" ***Chapter Four:***

"Physical Care of the Dying Person"

1. Symptom Control Measures
2. Body Wisdom
3. Last Days of Care at Home
4. Signs & Symptoms of Approaching Death
5. How to Know if Death Occurs

Session 8: Spiritual Work of the Dying

1. The Role of the Chaplain
2. Some Tests for Mentally Healthy Religion
3. Comparative View of World Religions
4. Transition Rituals
5. Jewish Pastoral Care

Session 9: Bereavement and Grief

1. Grief Cycle

2. Sentara Online Support and Support Group
3. Helping Those Who is Grieving
4. Basic Life Assumptions
5. Hospice Bereavement Philosophy

Session 10: In Conclusion

Video: "A Shared Experience"

1. Avoiding Volunteer Burnout – *Take Care of Yourself!*
2. Personal Bill of Rights
3. Self-Nurturing Activities
4. Signs of Health / Unhealthy Boundaries
5. Group Review Quiz
6. Fill out and turn in all required paperwork!

SECTION 3 - HOSPICE ADMISSION PROCEDURE FOR RURAL AND HOMELESS VETERANS

Activity	Responsible Party
Receive referral from VA Medical Center, Sentara Home Health, other hospital, community-based hospice, family or self.	Program Manager. PM will also ascertain if there is DNR in place, release of Information signed and if there is a Power of Attorney designated, if appropriate.
Verify Benefits.	Program Manager. PM will verify with VA Homeless Outreach staff, designated VA contact, referral Source or family member.
Provide physician orders and medical/diagnosis paperwork to hospice provider.	Program Manager will facilitate with referral source to be received ASAP by hospice provider.
Meet with veteran.	Program Manager will meet with veteran, if appropriate, to inform about the program and gather information that can be used to determine most appropriate home referral and to discuss program fee.
Contact home host.	Program Manager.
Arrange meeting between veteran and Home host.	Program Manager will arrange meeting between veteran and home host if there is time and it is appropriate.
Transport veteran to host home, provide hospital equipment.	Hospice provider in conjunction with the referral source. Hospice nurse meets with home host to advise plan of care, special needs and instructions. Advise schedule of nursing visitation.
Meet with veteran.	Program Manager. Assure veteran's needs are being met, offer support of volunteers and/or chaplain. Complete program assessment, sign releases of information as appropriate.
Engage volunteers	Program Manager will schedule volunteers based on the wishes and needs of the veteran and Host.
Continue to meet with veteran and home host.	Program Manager.

SECTION 3 - Veteran Rights

Rights

- To receive respectful and considerate treatment and care;
- To receive current information concerning diagnosis, treatment and prognosis in understandable terms;
- To receive information necessary to give informed consent to hospice treatment, with a full understanding that hospice care is not curative in purpose, but is designated to alleviate pain and discomfort and to relieve symptoms;
- Choose a hospice provider;
- To receive care provided under the direction of the hospice medical director by staff and volunteers who are qualified;
- To have my values, preferences and way of life respected and incorporated into my plan of care;
- To participate in the development and subsequent revisions of the plan of care and to have my caregivers involved in the planning and provision of care;
- To remain as comfortable as possible;
- To be provided with every consideration of privacy, security and confidentiality of information with regard to medical, personal and family matters;
- To refuse treatment to the extent permitted by law and to be informed of the medical consequences of such refusal;
- To revoke consent for hospice care;
- To voice grievances free from restraint, interference, coercion, discrimination or reprisal by or from hospice staff, home hosts, volunteers and administration;
- To be served without regard to race, ethnicity, national origin, gender, handicap, age, disease or sexual preference;
- To be included in resolving conflicts about care or service;
- To have personal property cared for securely and respectfully;
- To have reports of pain believed and responded to quickly;
- To receive information about pain and pain relief measures;
- To receive effective pain management;
- To make informed decisions about proposed and ongoing care and services;
- To formulate advance directives, as appropriate to the care and services to be provided;
- To be notified of the potential benefits, risks and effects of the care or services provided, their likelihood of success and problems;
- To involve family members, significant others, Power of Attorney and/or designated support persons in care and services to be provided.

LINK of Hampton Roads, Inc./LINK Home Hospice, will protect and promote the exercise of the veteran's rights.

- The veteran and/or responsible other will be informed of the rights verbally and in writing in advance of beginning care.
- LINK will investigate complaints made by the veteran or the veteran's family or guardian regarding treatment or care that is furnished, or fails to be furnished, or regarding lack of respect for the veteran's property by anyone furnished services on behalf of LINK and will document both the existence of the complaint and the resolution of the complaint. The complaint should be first made to the Program Director, and if not resolved satisfactorily, the level of complaint should go to the Executive Director of LINK. If at this level there is no satisfaction, a complaint should be filed with the Personnel Committee of LINK's Board of Directors. After review by the Personnel Committee, their decision will be final and in writing.

SECTION 3 - Home Host Rights and Responsibilities

Rights

- To receive respect and considerate treatment by the veteran, professional staff, volunteers and veteran's family;
- To set hours of visitation
- To not admit a visitor to the home that is under the influence of alcohol, drugs or who is demonstrating threatening or inappropriate behavior;
- To be compensated financially for care of the veteran;
- To be informed of the medical condition of the veteran and changes in the condition as they occur and interpretations of the condition.
- To determine whether smoking is or is not allowed in the home.
- LINK will investigate complaints made by the home host with respect to behavior or actions of the veteran, veteran's family, volunteers or professionals providing services to veterans. LINK will document both the existence of the complaint and the resolution of the complaint. The complaint should be first made to the Program Director, and if not resolved satisfactorily, the level of complaint should go to the Executive Director of LINK. If at this level there is no satisfaction, a complaint should be filed with the Personnel Committee of LINK's Board of Directors. After review by the Personnel Committee, their decision will be final and in writing.

Responsibilities

- Provide a clean, safe and secure environment for the provision of care of the veteran;
- Participate in and adhere to the hospice provider plan of care;
- Follow instructions given for performing a procedure or operating a piece of equipment as provided by the hospice provider;
- Report any concerns about equipment malfunction;
- Report any unexpected changes in the veteran's condition;
- Provide full care for the veteran when medical staff, aides, and/or veterans are not on site, i.e. meal preparation, laundry and bathing and diaper changing, when appropriate.

SECTION 3 - DNR (Do Not Resuscitate)

The DNR will likely have been signed through the referral source, if the source is the VA hospital or a hospital or community based hospital. If a form has not been signed, it may be that the veteran does not wish to sign the form, or it was not explained and provided through the referral source.

If there is not a signed DNR, the topic would be best addressed by the hospice nurse, who has been trained to discuss the “terminal” diagnosis and end-of-life care. If after discussion with the nurse, there is doubt or conflict within the veteran’s family, advice can be sought from an attorney who practices in this area of the law. A veteran should never be forced to sign a DNR.

It is important to assist the veteran in making critical end-of-life medical decisions before the veteran deteriorates or cannot speak for himself/herself.

The only DNR form that is legally acceptable in the State of Virginia is included in Section 5 – Forms.

SECTION 3 - Death of the Veteran

Prior to death:

During the initial training, home hosts learn to recognize symptoms and signs of impending death. The hospice provider will recognize the symptoms and be in the home, or available to be in the home when a phone call is made by the home host. The veteran's family or support network, if not already in the home, must be called. If the veteran has been receiving support from or had established a prior relationship with a chaplain, call that individual. Honor the veteran's choices of individuals who will support his/her passing.

If death is not expected at the time it occurs, a phone call to the hospice nurse must be made as quickly as possible. Then, contact the chaplain, family, friends as designated by the veteran.

It is not necessary to contact 911 or police when an individual in a hospice program dies. Under other circumstances, it is. Follow the guidance of the hospice provider.

After death:

Refer to the "after death" choices expressed by the veteran. Call the crematory or mortuary identified by the veteran. Advise the VAMC individual who made the referral to the hospice program.

The VA website contains information related to benefits available to the veteran after death, Cemetery burial and headstones – www.cem.va.gov/bbene/eligible.asp.

Burial flags – www.cem.va.gov/bbene/bflags.asp.

or, a phone call can be made to the VA referral contact.

Dependents and Survivors Benefits:

Dependents and survivors may, under certain circumstances, be entitled to death benefits.

Information can be accessed through the VA web site:

www.vba.va.gov/bln/dependents/index.htm or, a phone call can be made to the VA referral contact.

Bereavement Counseling:

The hospice provider will provide bereavement counseling for the survivors, friends and for the home host, if requested. The counseling is part of the veteran's hospice benefit.

Home hosts need to be encouraged to participate as needed. Unresolved issues related to the death of a veteran can have a negative impact on the host's opening his/her home to another veteran. A veteran should never be placed in a home with a host who has unresolved issues related to the death of a veteran. If the home host does not feel comfortable addressing

unresolved issues related to the veteran's death within the context of the hospice provider, perhaps the chaplain or the host's place of worship can make an alternate suggestion.

Assist the hospice nurse in accounting for all unused medication and hospice supplies. Gather the veteran's personal items for presentation to the family or support friendships. The hospice team will provide information about the return of hospice-related equipment, i.e. bed, tables, oxygen, etc.

SECTION 4 - Sample Budget

HOSPICE PROGRAM OPERATING EXPENSES

		Cash	Inkind
Personnel - P/T Program Manager		24,000	
Benefits		4,800	
	3,900/yr. x		
Mileage	.55	2,145	
Cell Phone		948	
Office Space			6,000
Internet			576
Fax Machine			100
Fax Line			144
Volunteer/Host Training			15,000
	Total	31,893	21,820

SECTION 5 - Forms

MILITARY HISTORY CHECKLIST

PATIENT DATA		
Patient's Name:		Date:
Address:	Hospice Medical Record #:	Last 4 SSN:
VETERAN STATUS INFORMATION		
1. Did you (or your spouse or family member) serve in the military?		
1a. Patient: <input type="checkbox"/> Yes <input type="checkbox"/> No	Did you serve on active duty?	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Did your service include combat duty?	<input type="checkbox"/> Yes <input type="checkbox"/> No
	Do you have a copy of your DD214 discharge papers?	<input type="checkbox"/> Yes <input type="checkbox"/> No
1b. Did your spouse serve on active duty?		<input type="checkbox"/> Yes <input type="checkbox"/> No
Comments:		
1c. Do you have any immediate family members that served or are serving in the military?		<input type="checkbox"/> Yes <input type="checkbox"/> No
Comments:		
MILITARY BACKGROUND		
2. In which branch of the military did you serve?		
<input type="checkbox"/> Army	<input type="checkbox"/> Marines	<input type="checkbox"/> Merchant Marines during WWII
<input type="checkbox"/> Navy	<input type="checkbox"/> Coast Guard	<input type="checkbox"/> Other _____
<input type="checkbox"/> Air Force	<input type="checkbox"/> Reservist or National Guard member	
3. In which war era or period of service did you serve?		
<input type="checkbox"/> WWI (4/6/17 to 11/11/18)	<input type="checkbox"/> Vietnam (8/5/64 to 5/7/75 and 2/28/51 for veterans who served "in country" in Vietnam) before 5/5/64	<input type="checkbox"/> Peace Time
<input type="checkbox"/> WWII (12/7/41 to 12/31/45)	<input type="checkbox"/> Gulf War (8/2/90 through a date to be set by law or presidential proclamation)	<input type="checkbox"/> Afghanistan/Iraq (OEF/OIF)
<input type="checkbox"/> Korea (6/27/50 to 1/31/55)		<input type="checkbox"/> Other _____
<input type="checkbox"/> Cold War		Note: after 9/7/80, must have completed 24 months continuous active service, or the full period for which they were called or ordered to active duty.
4. Overall, how do you view your experience in the military?		
5. If available would you like your hospice staff/volunteer to have military experience? <input type="checkbox"/> Yes <input type="checkbox"/> No		
VA BENEFITS INFORMATION		
6. Are you enrolled in VA?		<input type="checkbox"/> Yes <input type="checkbox"/> No
6a. Do you receive any VA benefits?		<input type="checkbox"/> Yes <input type="checkbox"/> No
6b. Do you have a service-connected condition?		<input type="checkbox"/> Yes <input type="checkbox"/> No
6c. Do you get your medications from VA?		<input type="checkbox"/> Yes <input type="checkbox"/> No
6d. What is the name of your VA hospital or clinic?		
6e. What is the name and contact information of your VA physician or Primary Care Provider?		
6f. Would you like to talk with someone about benefits you or your family might be eligible to receive?		<input type="checkbox"/> Yes <input type="checkbox"/> No



Durable Do Not Resuscitate Order

VIRGINIA DEPARTMENT OF HEALTH

Patient's Full Legal Name _____ Date _____

Physician's Order

I, the undersigned, state that I have a bona fide physician/patient relationship with the patient named above. I have certified in the patient's medical record that he/she or a person authorized to consent on the patient's behalf has directed that life-prolonging procedures be withheld or withdrawn in the event of cardiac or respiratory arrest.

I further certify (must check 1 or 2):

- ☐ 1. The patient is CAPABLE of making an informed decision about providing, withholding or withdrawing a specific medical treatment or course of medical treatment. (Signature of patient is required; see reverse.)
- ☐ 2. The patient is INCAPABLE of making an informed decision about providing, withholding or withdrawing a specific medical treatment or course of medical treatment because he/she is unable to understand the nature, extent or probable consequences of the proposed medical decision, or to make a rational evaluation of the risks and benefits of alternatives to that decision.

If you checked 2 above, check A, B or C below:

- ☐ A. While capable of making an informed decision, the patient has executed a written advanced directive which directs that life-prolonging procedures be withheld or withdrawn.
- ☐ B. While capable of making an informed decision, the patient has executed a written advanced directive which appoints a "Person Authorized to Consent on the Patient's Behalf" with authority to direct that life-prolonging procedures be withheld or withdrawn. (Signature of "Person Authorized to Consent on the Patient's Behalf" is required; see reverse.)
- ☐ C. The patient has not executed a written advanced directive (living will or durable power of attorney for health care). (Signature of "Person Authorized to Consent on the Patient's Behalf" is required; see reverse.)

I hereby direct any and all qualified health care personnel, commencing on the effective date noted above, to withhold cardiopulmonary resuscitation (cardiac compression, endotracheal intubation and other advanced airway management, artificial ventilation, defibrillation and related procedures) from the patient in the event of the patient's cardiac or respiratory arrest. I further direct such personnel to provide the patient other medical interventions, such as intravenous fluids, oxygen or other therapies deemed necessary to provide comfort care or alleviate pain.

Physician's Printed Name

Physician's Signature

Emergency Phone Number

Important – Emergency Medical Services Providers cannot honor copies of the Durable Do Not Resuscitate Order. They must have the original yellow form.

Patient's Signature

I, the undersigned, hereby direct that in case of my cardiac or respiratory arrest, efforts at cardiopulmonary resuscitation not be initiated and not be continued once initiated. I understand that I may revoke these directions at any time by physical cancellation or destruction of this form or by orally expressing a desire to be resuscitated to qualified health care personnel. I also understand that if qualified health care personnel have any doubts about the applicability or validity of this order, they will begin cardiopulmonary resuscitation.

Signature of Patient

Signature of Person Authorized to Consent on the Patient's Behalf

I, the undersigned, hereby certify that I am authorized to provide consent on the patient's behalf by virtue of my relationship to the patient as _____ (in order of priority: designated agent, guardian or committee, spouse, adult child, parent, adult brother or sister, other relative in descending order of blood relationship). In that capacity, I hereby direct that in case of the patient's cardiac or respiratory arrest, efforts at cardiopulmonary resuscitation not be initiated and not be continued once initiated. I understand that I may revoke these directions at any time by physical cancellation or destruction of this form or by orally expressing a desire to be resuscitated to qualified health care personnel. I also understand that if qualified health care personnel have any doubts about the applicability or validity of this order, they will begin cardiopulmonary resuscitation of the patient.

Signature of Person Authorized to Consent on the Patient's Behalf

EMS Personnel Will Look for This Order in the Following Places:

- ① On the back of the door leading to the patient's bedroom
- ② On the bedside table, beside the patient's bed
- ③ On the refrigerator
- ④ In the patient's wallet
- ⑤ On an approved alternate form of identification (bracelet or necklace)



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SECTION 5 – Resources

There are many resources available to assist with replicating the home hospice program. From the time you contemplate beginning a replication of the program until the program is implemented, you will undoubtedly need all the resources referenced here, and will develop resources you believe are important, or are unique to your community.

We ask that you share resources that are not listed in this document to facilitate the journey for others, thereby making their efforts more effective. It would also be helpful to all if you share your successes and challenges. Who doesn't want to share and support the good things that happen, they help us all move forward. Conversely, there are barriers and challenges to every project. One of the important pieces of information we have learned is that most barriers and challenges are not unique. If they are shared, perhaps assistance can be offered. Keep in mind; that ultimately, the winners, when we share are the veterans!

On-line Resources

The Veterans Administration home page, www.va.gov, will direct you to specific sites to address veteran issues. For example, health care eligibility, www.va.gov/healtheligibility, benefit payment rates, www.vba.va.gov/bln/21/rates, and burial and memorial benefits, www.cem.va.gov. It is an easy site to navigate.

The web site of your local VAMC will provide important information specific to your area and will also link to the Veterans Administration home page.

The National Hospice and Palliative Care Organization, at www.NHPCO.org has valuable information you will need when working with hospice-eligible veterans, particularly the Tool Kit 101. Go to the web site, click on "Professional Resources," then click "Access, Outreach" and scroll down to "Veterans Hospice Resources." This web site will also link you to your state hospice program for information specific to your area. Contact NHPCO at 703-837-1500.

Social Security Online, is located at www.socialsecurity.gov. The site will provide you with access to publications and other public information materials as well as links to local Social Security Offices. There is a toll-free phone number, 1-800-772-1213.

Print Resources

The Department of Veterans Affairs publishes a booklet of programs and services available to veterans. The 2010 edition, *Federal Benefits for Veterans, Dependents and Survivors*, VA Pamphlet 80-10-01 P94663, can be obtained from the U. S. Department of Veterans Affairs, Washington, DC 20420, (there is a \$5 charge) or from your local VAMC.

The Social Security Administration publishes numerous pamphlets explaining Medicare (No. 05-10043), Supplemental Security Income (No. 05-11000) and Understanding The Benefits (No. 05-10024). They can be ordered through the Social Security Administration, but are sent in bulk, 25 – 100 copies. The quickest way to access these helpful pamphlets is through your local office or the contact you have established at the local office.

Partner Resources

Your partners and potential partners can provide on-line and print resources specific to community programs and services available to veterans and to your program. It will be helpful to develop a list of the specific resources including contact information via mail, phone and internet. The list will be especially helpful to the professionals, home hosts and volunteers providing services through your program.

Mentoring

LINK of Hampton Roads, Inc., our partners and volunteers are available to mentor at any point in your journey, whether you are considering beginning a program or need to problem-solve a situation once you have begun. Lynne Finding, Executive Director of LINK of Hampton Roads, Inc., can be reached at 757-254-2424, and Joyce O'Brien, Program Director for the Reaching Out Hospice Program, can be reached at 757-903-5206. We can also be reached the program email address, linkhospice@gmail.org.

SECTION 6 - Challenges and Lessons Learned

Challenge: Finding the individual(s) at your VAMC willing to champion your project.

Lessons Learned: Most importantly, DON'T GIVE UP! Begin with the Homeless Outreach team and sell them on the project. It will be an easier sell as they work with the homeless in your community. In many VAMCs a hospital nurse is a member of their team, which means there is an awareness of the health issues of the homeless. Make contact with the Palliative and Hospice Care Unit. If your VAMC does not have an inpatient hospice facility, they usually contract with community hospices and they should be interested in your project. One of the fastest ways to reach staff that can be of assistance is to make a presentation to the VAMC's social workers. Your Homeless Outreach Team should be able to help you get on their meeting schedule for a presentation. Be sure to touch base with the VISN and CBOC programs in your area. They are also a great source of referrals.

Challenge: Impassion potential community partners so they will take an active, leadership role.

Lessons Learned: Put a face on your project. Develop a passionate needs speech about the need for hospice services for homeless and rural veterans. Include statistics that support the need in your community. Go first to programs that likely share your concerns as a result of the work they do, whether it is homeless or rural services, veteran services or a hospice program. Once you get a program on board, use that program as leveraging to get others involved. Programs will often be more receptive and agreeable once they learn what other programs have committed. When looking at partnerships don't forget faith-based communities and veterans service organizations and civic groups. Addressing community needs is generally in their charters and they are particularly sensitive to veteran projects.

Challenge: Host reimbursement. The benefits a veteran receives vary greatly.

Insight: The veteran must know upfront that the service is not free of charge. The amount of benefits a veteran receives, whether the benefits are VA or civilian, such as SSDI, vary from veteran to veteran. Additionally the schedule of payment of the benefits may be such that reimbursement may not be available at the time the veteran enters the host home. When a referral is made, you need to ascertain the amount of funding the veteran has available. As you are making a decision about placement, it is important to be upfront with the host as to the amount of funding that is available. Some hosts are willing to provide the service without reimbursement while others need to bring someone into their home to assist in the non-medical care of the veteran, in which case reimbursement would need to cover that cost. Before the veteran enters the home, an agreement to reimburse the home host should be signed. Sometimes a veteran has a bank account and is willing to reimburse from the account while waiting for a check. That is not usually the case with homeless veterans. Unless you have hosts who are not as concerned about reimbursement as they are about helping the veterans, you will need to be aware of the veteran's prognosis – if death is imminent, there will likely be no reimbursement, as benefits are not retroactive.

Challenge: Host support following the death of the veteran.

Insight: As mentioned previously, home hosts become involved in the program because they care greatly about veterans and the sacrifices they have made for our freedom. They take veterans into their homes and make them part of their families because they care deeply. Your hosts may be veterans themselves or have immediate family members who are active duty military or military veterans. So, before the veteran enters the home, there is an attachment and a kinship. While in the home, the veteran becomes a member of the host's family and a bond is formed. When the veteran passes, the same grieving process occurs that occurs with an immediate family member. The medical hospice provider will likely provide bereavement services and offer them to the host family. Encourage the family to participate in that or another community bereavement program. If a host has loss issues that have not been addressed, you should not place another veteran into the home until such time that the issues are being addressed.

Challenge: Many veterans have mental health issues, including PTSD and substance abuse that are intimately tied to their military service. As they near death, they may be reliving experiences that trigger reactions to their issues.

Insight: Deborah Grassman, ARNP, a Nurse Practitioner who has been with the Veterans Administration for 24 years, is considered an expert on issues related to hospice and palliative care of veterans. The following is an excerpt from her article "Veterans: An Underserved Population" dated January 2007. In the article she writes "Veterans have unique, often unrecognized hospice needs that complicate the dying process. For example, military culture instills stoic values that might interfere with peaceful dying. A "fight to the bitter end" attitude complicates death, requiring skillful intervention from hospice clinicians. On a battlefield, death is the enemy and "surrender" is failure; yet much of hospice work focuses on "letting go" and "surrendering." Additionally, combat veterans' last experience with death may have been filled with fear, horror, and helplessness on the battlefield. These associations may also interfere with a peaceful death. On the other hand, because death is no stranger to combat veterans, they often report that they've faced death before and are not afraid of it. To address these barriers, here are some suggestions for improving hospice care provided to dying veterans.

- Assess if patients are combat veterans or have experienced any other military trauma. (Don't assume all combat veterans sustained trauma; some had "safe" assignments. Don't assume all non-combat veterans did NOT sustain trauma; many served in dangerous assignments.)
- Anticipate that veterans may underreport pain or fear because of deeply-held stoic values.
- Remember that combat veterans may have sustained mental, emotional, social, spiritual, and moral injuries. Moral injuries especially might complicate death. Those who have not only witnessed trauma but caused it may need encouragement to touch the moral injury and engage in the work of forgiveness. Don't dismiss their guilt with platitudes; instead, create a safe emotional environment for guilt to emerge.

- For patients with Post-Traumatic Stress Disorder (PTSD), eliminate as many “triggers” as possible. Remember that coming into a hospital (especially a VA hospital) often triggers past military memories of barracks, procedures, unsafe environments, past combat hospitalizations, visiting injured comrades, etc. A government hospital and its employees may not be trusted by Vietnam vets. On the other hand, a VA hospital can be like “coming home”, supporting their soldier identity while providing camaraderie and a sense of belonging.
- Loud or unexpected sounds will startle people with PTSD. Don’t touch them without first letting them see you or calling out their name.”

Challenge: Program funding and sustainability.

Insight: If your program is a part of a nonprofit organization, you can research grants that will support the program. Hospital foundations or United Ways often look for such programs as they focus on directing funds to meet community need and community impact. The program is fairly low budget, so a Board of Directors or a civic organization that is committed to serving veterans may be willing to raise the funds in an annual fundraiser. This is also a project that a veterans’ service organization may be willing to champion, using an individual in their organization as the coordinator and in-kind services from business affiliations of their members. In today’s economic climate, raising funds is difficult, but in spite of the difficulty, veteran issues and programs generally are an easy sell.