Bellingham At Home

VOLUNTEER HEALTH ADVOCACY HANDBOOK

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"Listening is the oldest and perhaps the most powerful tool of healing. It is often through the quality of our listening and not the wisdom of our words that we are able to effect the most profound changes in the people around us." -*Kitchen Table Wisdom: Stories that Heal*, Rachael Naomi Remen

"A Bodhisattva understands that: what makes all the difference is the presence or absence of what is called 'healing connections.' You are a Bodhisattva!" -Anne Tojun Mikkelsen

"Loving presence is a state in which we are open-hearted and well-intentioned. It is pleasant, healthy, rewarding in and of itself." -Ron Kurtz

A number of sections of this handbook have been adapted from Capitol Hill Advocacy Program, Washington, D.C.

Volunteer Information Form

In order to facilitate the best pairing between members and advocates, we'd like to know a little more information about our advocates to start off with.

1. Name: _____ 2. Date: _____
3. Please check off any box that applies to you.

I HAVE…	
Been a caregiver to a friend or family member	
Been a healthcare provider (nurse, doctor, social worker, etc.)	
Received services through Bellingham At Home	
Volunteered with Bellingham At Home	

4. Please elaborate on any experiences you've had that would be useful in working with Bellingham At Home as a Health Advocate:

   _____

   _____

   _____

   _____

5. I can currently commit to:
   a. Meet with a member weekly in-person
   b. Meet with a member occasionally and call weekly to work on and discuss their health needs
   c. Meet with a member as needed and call 2-3 times a month to discuss their needs
   d. I am not available for an on-going commitment at this time and would like to be a substitute Health Advocate to work in the absence of another Volunteer Health Advocate
6. Please indicate any other information we should know that would help us ensure a successful pairing between you and a member:

   _____

   _____

   _____

   _____

Confidentiality

Bellingham At Home Health Advocates are required to maintain confidentiality with members. All information about members is to be kept private, including but not limited to name, age, gender, demographic information, health conditions, medical information. Private information must not leave the organization or be discussed in conversations with family or friends for any reason.

Bellingham At Home seeks to build trusting relationships between advocates and members and respects the dignity and autonomy of our members. We aim to empower our members and provide them with the means to maintain a sense of control over their lives. We recognize that we are working with a vulnerable population and that their personal experiences are not our stories to tell. By setting a high bar for confidentiality, our members can receive the support they need without fear of stigma. We encourage Volunteer Health Advocates to discuss troubling situations in VHA meetings and with the VHA Coordinator when needed.

If a Volunteer Health Advocate wishes to share details about their work with friends or family, we ask that you do so mindfully in order to maintain confidentiality. Focus on *your* feelings and experience rather than that of the member, and avoid sharing identifying information about members in the process. Use of the pronoun "they," rather than "he/she" is encouraged.

In certain cases, private details about a member should immediately be shared with the VHA Coordinator. Please do so in the event that:

1. Members threatens harm to themselves or someone else
2. You notice any indication of abuse, neglect, or exploitation of a member

Bellingham At Home staff will take the necessary actions to protect individuals involved in these situations.

I, _____, understand that I am responsible for maintaining the confidentiality of all private information disclosed to me as a Bellingham At Home Volunteer Health Advocate, whether it pertains to members or other Health Advocates. I understand that this information is not to be shared with anyone outside of Bellingham At Home, including family and friends.

_____ _____

Volunteer Health Advocate signature Date

Bellingham At Home Monthly Volunteer Health Advocate Check-in Form

The VHA Committee uses this form to determine progress with members and identify any issues you or your member may be experiencing. Please complete to the best of your ability so we can ensure the best experiences for Health Advocates and members.

1. Health Advocate name: _____
2. Date: _____
3. In a typical week during the past month, how many times did you contact your member?

Once a week	Twice a week	Three times a week	Other (specify)

4. How did you contact your member during the past month? (Select all that apply)

In person	Over the phone	Email	Other (specify)

5. What types of Volunteer Health Advocacy services have you provided over the past month for the member?

Date	**Services provided**

6. If you served as a Volunteer Health Advocate this month, please specify how and check all that apply. If not, please check "did not perform this role this month."
   ___ Did not perform
   ___ Attended doctor's appointment(s) with member (# of times: _____)
   ___ Recorded doctor's instructions
   ___ Worked with member to organize important medical documents
   ___ Pre- and post-surgery
   ___ Hospital stay
   ___ Rehabilitation and continuing care facility
   ___ Palliative care
   ___ Hospice care
   ___ Bereavement
7. In the past month, what have you learned about interaction with your member that the VHA Coordinator should know?

8. Do you have reflections/feedback on your role and experiences as a Health Advocate that you would like to share?

9. Is there anything you wish to be discussed at the next Volunteer Health Advocacy meeting?

Please be prepared to discuss the following questions at monthly check-in meetings:

1. What feelings are you hearing?
2. What concerns are clear?
3. What "red flags" could you look for?
4. Who or what are some of the member's strengths?
5. Who or what are your member's sources of support?
6. What are some tasks you can work on together to help the member be prepared for future unexpected events?
7. What BAH services would be helpful for your member?

Code of Ethics

Basic principles of ethics:

- Autonomy: Right for member to determine their own destiny/wishes
- Beneficence: Provide acts of kindness towards members
- Non-maleficence: Always working against harm/wrong-doing
- Justice: Equitable treatment for all members
- Respect

Please review the Bellingham At Home Code of Ethics, available in your volunteer handbook

Neglect

Types of neglect:

- Active neglect: Willful/interpersonal
- Passive neglect: Caregiver unable to fulfill responsibilities – financial, medical, social, sanitary, emotional
- Self-neglect: No perpetrator, refusal of care – symptoms may be distress, withdrawal, anger, resentment

Volunteer Health Advocacy

Volunteer Health Advocacy in the Bellingham At Home program is as involved as the member and volunteer wish for it to be. Each member has unique needs and each relationship has a unique dynamic, making it impossible to predict the role that any Volunteer Health Advocate will have in health advocacy.

Health Advocacy takes many forms which can range from reminding a member to make a medical appointment all the way through physically attending appointments and completing follow up with medical professionals on behalf of the member. The Volunteer Health Advocate is not to come between the member and their doctor, but to support the member/doctor relationship.

The following levels of advocacy service for members include:

1. Advocacy for medical note taking in doctor's office
2. Advocacy in pre- and post-surgical outpatient unit
3. Advocacy in Hospital stays
4. Advocacy in Rehabilitation and Care Centers, including long-term care
5. Advocacy in Palliative care
6. Advocacy in Hospice care
7. Advocacy in Bereavement period

All service levels, except advocacy for Medical Note Taking, will entail two (2) advocates for each member requiring services. Only one advocate will serve the member for a single service.

Volunteer Health Advocates have a three-month term of service, although they may extend this period if they wish. Volunteer Health Advocates will serve one member at a time, except in the case of Medical Note Taking, where advocates may serve multiple members.

Procedure

Members will contact the BAH office and request a Volunteer Health Advocate. The office will contact our coordinator, who then assigns two persons for the period of the member's needs. One person only will be assigned for the medical note taking task. We strongly emphasize volunteer continuity, especially if the member experiences continuing care in rehab or care center, palliative care and Hospice care. We still leave open the limits of volunteering as an advocate for a member over many months or even years. Therefore, we

will be on the lookout for stress or burnout of our advocates. We plan to have a monthly Health Advocacy meeting to check in and relate experiences and stress points, and continuously tweak our program to better serve our members. Advocates will also be available for one another throughout the month.

We will encourage all members who plan to use the Volunteer Health Advocacy service to complete end-of-life documents, including the POLST form with their physician. This is to enable the advocate to better understand the member's final wishes. The Health Advocate's task is to support the member so their end of life intentions are respected and followed throughout their contacts with the medical system. We also plan to have a program in place for members to find a health agent and to complete the end-of-life documents.

We are requiring all Volunteer Health Advocates, who are not currently BAH volunteers to sign up as BAH volunteers, including passing the criminal background check, before signing up for Volunteer Health Advocacy service.

Important: Volunteer Health Advocates will not be permitted to dispense medications, change a patient's clothes, perform body checks, lift or turn a patient or assist with feeding or toileting a patient. In a word, our advocacy service does not perform any medically related or other activities that duplicate services for the member.

Levels of Health Advocacy

1. **Advocacy for Medical Note Taking in a Doctor's Office**
   Medical note taking in the doctor's office involves meeting the member at the doctor's office (unless the volunteer *also* has BAH clearance as a volunteer driver). Volunteers must pass BAH volunteer requirements, as well as a two-hour training program in Medical Notetaking before assisting members. The training focuses on specific note writing skills, legal concerns, as well as appropriate decorum and interaction with medical personnel. Material for the course will be based on Northwest Neighbors Village and Capitol Hill Village, as well as other materials created by the VHA Committee.

   The primary task of the Volunteer Health Advocate is to serve as a second pair of ears and support the member emotionally. In addition, the volunteer advocate aims to enhance the member's interaction with the physician. We have an Authorization Form with the member's consent to be given to medical personnel prior to the office visit. We also have developed a

complete Medical Note Taking Handbook with pertinent sections to be brought to the medical office. At the end of the office visit, the volunteer will read the medical notes back to the M.D. before handing it over to the member. This will be especially useful, as some medical offices lack a summary sheet for the patient, leaving the patient to figure out new medicines, dosages, next appointment, and other medical recommendations.

The Medical Note Taking form will also include standard questions/probes to better assist the member in gaining information or clarifying the doctor's statements (e.g. Did you understand that the doctor recommends a higher dose this time? Do you have any more questions for the doctor?)

We foresee the Health Advocate volunteer having a conversation with the member, either by phone or in person *prior t*o meeting them at the doctor's office to answer any questions and to further support the member before the appointment. A primary consideration will be to understand the purpose of the appointment.

2. **Pre- and Post-Surgery**
   Advocates planning to serve members through the process of pre- and post-surgical periods, hospital stays and rehabilitation or long-term care centers, will be expected to sign up as a BAH volunteer, and to take a course offered by the Health Ministries Network (HMN) that includes 32 contact hours and 8 weeks online. This class includes legal, social, medical issues, as well as holistic healing, important for negotiating the medical system and serving the member.

   The next HMN course offering will be March 3-April 27, 2018. We are seeking funds to pay for the $350 training course.

   The rationale for this specialized training is to have greater access to PeaceHealth facilities and private care facilities, as the training provides a PeaceHealth Volunteer Badge, which is well respected in the medical community. Medically related services in surgical and hospital settings can be fraught with confusion and misunderstanding. Advocates receiving the HMN training will be better prepared for identifying members' needs and recognize when medical services may be inadequate or lacking altogether. Volunteers do not speak *for* the member, but once a volunteer has the member's consent, may speak on *behalf* of the member, including contacting the appropriate PeaceHealth administrator or the State Ombudsman if the

Volunteer Advocate observes abuse or neglect of a member by medical personnel.

The Health Ministries Network (HMN) offering the proposed training course is a non-denominational, faith/community based network of 139 registered nurses and other health occupations serving 81 parishes or communities in four counties: Whatcom, Skagit, San Juan and Island. The nurses and health ministers in this network have received security clearances as hospital volunteers prior to enrollment in a comprehensive training course (described above) that focuses on mind-body-spirit holistic healing. HMN has evolved out of parish nursing, and is sometimes identified as Foundations of Faith Community Nursing and Health Ministry. Importantly, this is an international movement, and includes a range of Christian denominations, as well as Jewish and Moslem faith networks.

An alternative to taking the HMN Foundation course is to sign up for the PeaceHealth St. Joseph's Medical Center Volunteer Services Orientation. Regular classes are available throughout the year.

For members who have not had time to take care of their personal affairs before their medical crisis, and now confront surgery, hospitalization or rehabilitation/long term care, we propose assisting them in a variety of tasks. These include, but are not limited to: stopping mail service, pet care, checking their advance Health Care Directives, calling their family members, contacting Meals on Wheels, or other supportive activities. Our services will not duplicate any existing services the member may be receiving. In many instances, regular BAH volunteers will be called upon for this assistance.

3. **Hospital Stay**
   The requirements for the Health Advocate for serving the member during a hospital stay will be similar to Pre-and-post Surgical periods. The two-person team will alternate during a hospital stay, unless the duration is fewer than 24 hours. Successfully completing the HMN course is a basic requirement for this service. An alternative to taking the HMN Foundation course is to sign up for the PeaceHealth St. Joseph's Medical Center Volunteer Services Orientation. Regular classes are available throughout the year.

4. **Rehabilitation and Continuing Care Facility**

The requirements for the Health Advocate at this level will be similar to Pre-and-post Surgery and Hospital Stay. The two-person team will alternate during a rehab or long-term care stay, unless the duration is fewer than 24 hours. Successfully completing the HMN course is a basic requirement for this service. An alternative to taking the HMN Foundation course is to sign up for the PeaceHealth St. Joseph's Medical Center Volunteer Services Orientation. Regular classes are available throughout the year.

5. **Palliative Care**
   Palliative care focuses on relieving the symptoms, pain and stress caused by serious or life-limiting conditions. Recoveries from a serious injury or major surgery, or support through advanced stages of a disease are examples of what might qualify for this service.

   Palliative care involves "Care without Cure," a maxim that involves a team of medical specialists—physicians, nurses, social worker, nutritionist, etc. to assist a patient through a chronic, although not a terminal disease. Palliative care, the Health Advocacy Planning committee determined, carries the same requirements as Medical Note Taking in a doctor's office. As long as the member is located at home or in a community based retirement residence, we can continue support by medical note taking and helping the member clarify treatment recommendations.

6. **Hospice Care**
   Health Advocacy at the Hospice Care level may be undertaken only by Hospice-trained volunteers. Volunteer Health Advocates may visit members as friends, especially if they have developed a personal relationship, but may not serve in the advocacy role. Currently, we have two members of our Health Advocacy Planning Committee who have Hospice training and have worked as a Hospice Volunteer.

7. **Bereavement**
   Although we provide no special training for this level of service, the Health Advocate may wish to continue as a supportive person through the post-death experience of a member or of a member's immediate family (e.g. spouse, children, parent, sibling) or intimate friend. Similarly, if the member loses a family member or friend, they may seek consolation from a Health Advocate. Such contacts are limited to phone calls, visits and empathetic listening. Health Advocates will be urged to encourage the member or the

family to seek available Grief Groups, offered by St. Joseph Hospital or their local hospital, church, synagogue, temple or spiritual center.

At all levels of care, be prepared to excuse yourself/step out of the room to preserve the member's dignity and physical privacy when/if a physical exam or some other maneuver is being done by the medical professional which might expose them. However, if a member requests that you stay in the room, you may do so if you are comfortable.

Communication

Communication is the foundation of a relationship between a Volunteer Health Advocate and a member. It is how we comfort, empathize, and establish trust. Here are some techniques for developing positive communication skills and practices:

Active Listening: Use verbal and non-verbal cues to show that you are listening to the member.

- Verbal cues example: "Uh huh," "Hmm," "Ah," "Yes."
- Non-verbal cues example: Slightly leaning in towards the speaker, head nodding, making eye contact, etc.

Open Questions vs. Closed Questions: Open questions give people permission to say more about what they are thinking and feeling. Closed questions focus on specific problems and elicit limited responses, often just a one-word answer. Closed questions rarely elicit a lot of additional information but they are appropriate when specific information is needed quickly.

- Open question examples: "What else can you tell me about…" "Can you tell me more about…" "What are some of thing things you want to talk about today?"
- Closed question examples: "Have you reviewed the doctor's discharge orders?" "What day is your next appointment?"

It can be difficult to start a conversation or get detailed information from a closed question. If you find yourself getting stuck on certain topics when communicating with members, call the VHA Coordinator or bring it up at the monthly Volunteer Health Advocacy meetings to get ideas.

Repetition: Repetition involves repeating one or two key words from the person's last sentence, which indicates one is listening. This encourages others to keep talking, and enhances their sense of being heard. For example:

- Member: "I was too tired to get out of bed yesterday."
- Volunteer Health Advocate: "I understand you were too tired to get out of bed?"

Repetition does not mean that one agrees with another; it only means the person is listening. Repetition is an important skill, but it should be mixed with other techniques to avoid sounding like a parrot.

Paraphrasing and Reflecting: Paraphrasing is when the listener repeats the person's statement in their own words to ensure that the message is understood. For example:

- Member: "I don't want to get into a living situation in which I will not be able to make choices on my own."
- Volunteer Health Advocate: "So what I hear you saying is that maintaining independence is very important to you?"

Clarifying Responses: Clarifying responses helps the listener understand the facts and the other person's feelings and attitudes.

- Examples: "Is it possible that you feel…?" "Can you give me an example of what you are talking about?"

Clarifying responses also help other people think about what they have just said, examine their choices, and look at their life patterns.

Difficult Topics: Gently exploring uncomfortable subjects, such as continued resistance, can be important in creating an open, honest relationship. Always approach uncomfortable topics with compassion and empathy. Seek supervision from the VHA team in preparation for these discussions.

- Timing: You need to have a relationship built upon trust before you approach difficult subjects.
- Delivery: Remember that communication is not just about saying something, but relies on how you deliver it. The examples below can be said in many different ways and illicit various reactions. Again, practice with compassion and empathy in your approach.

- Examples:
    - "Last week you said that you would call your doctor; is there a reason you have not contacted her?"
    - "I hear anger in your voice…"
    - "You sound sad today, is something troubling you?"

Integrating and Summarizing

- At the end of a topic or completed discussion, organize your thoughts and ensure that you and the member are on the same page by integrating and summarizing what you discussed.
- Integrating and summarizing help ensure that the main concerns are understood. They help clarify their thoughts and feelings and encourage them to further explore confusing and conflicting issues.
- For some members, it may be important to write down the summary, particularly any action points.

Boundaries

What is a boundary?

A boundary is another word for line, edge, limit, border, or margin. When setting and crossing boundaries refers to a physical line, as in a fence between properties, it is quite clear when that boundary is crossed and a response may or may not be necessary. It is a very different matter when the word boundary refers to an emotional limit or line. We live our lives in relationships, and every relationship has its boundaries.

Boundaries in relationships

In any relationship between two people, boundaries will exist within each individual. How does a person know his or her own personal boundaries?

- If someone asks you to do a task, and you are able to calmly say "no" without feeling guilty, then within that relationship you know what your own boundaries are and you are capable of articulating them.
- If someone asks you to do a task, and you cannot say "no," even when you feel uncomfortable about the request, then you may have boundaries in place, but you are not able to maintain them.

- If it is difficult for you to stop thinking about the problems of others and you feel obligated to solve these problems, then you may not have healthy boundaries in place.

Boundaries are necessary

Boundaries are necessary for a relationship to grow. Boundaries ensure that both parties feel comfortable in the relationship. A reciprocal relationship is mutually beneficial for everyone. Within the context of the Bellingham At Home Volunteer Health Advocacy program, boundary setting is vitally important for the emotional well-being of both the volunteer and member to prevent burnout.

- Some members tend to be individuals who are coping with a chronic illness, disability, or less able to tend to all their daily needs because of age or overwhelming duties of caring for a family member at home. It may be easy for a Health Advocate to become overly involved in a member's life, as he or she listens to stories and complaints. A member's list of problems – chronic illness, isolation, etc. – will cause a response in a Health Advocate. Compassion is a natural and appropriate response as well as desire to ease the burdens of a care partner, as long as it does not lead a VHA into inappropriate efforts to solve all of the member's problems.
- Conversely, VHA are people who will likely enjoy the volunteer experience. It may be easy for a member to become overly dependent or have unrealistic expectations of a VHA and breach established boundaries.
- If emotional boundaries are not set in a relationship, the danger exists that one or both of the persons will be consumed, pulled in, and sucked into situations that he or she finds uncomfortable and may not want to be involved and cannot resolve. This may result in one or both parties quitting the relationship.
- Boundary setting is both a VHA's and a member's responsibility. Both individuals in a relationship need to be candid with each other.
- If a VHA becomes concerned that he or she is overstepping a healthy boundary or that a member is infringing on the established boundaries, he or she should seek immediate consultation from the VHA Committee.
- VHA must maintain a boundary with their member that is consistent with the roles described in this manual. This is essential in managing member expectations from that specific VHA, in addition to managing expectations

of the Bellingham At Home program in general. All VHA must work within similar boundaries to ensure consistency across the program.

How to Create Healthy Boundaries

So how and when does one set healthy boundaries? Here are some tips:

- Know exactly how much time you are open to offering assistance.
- Understand your limits for services you can offer.
- Use clear and simple communication
    - *"Hello, Mrs. X, this is _____. I will be coming by at 10:00 today, but we must finish by 11:30 because my family is waiting for me."*
- If a member makes a request and a VHA is not sure it falls within the boundaries of a healthy relationship, the volunteer should consult with the Volunteer Health Advocacy Coordinator for guidance. Then, the VHA Coordinator should be certain to report back to the member with his/her decision promptly.
- Be consistent. Don't waiver when a boundary has been set.
- Be prepared to be tested and follow through on consequences if certain behavior or demands persist.
- Be prepared for a reaction when you make it clear that a boundary has been crossed. It may be a verbal attack, refusal to speak, passive aggressive behavior, or an attempt to make you feel guilty.
    - *"Mrs. Z, I am sorry that you are angry. I do not mean to hurt you but I made it clear that I would not do X, Y, or Z task for you. I am happy to help you locate someone else who can help you complete this task."*
- **Always** treat the member with dignity, respect, and empathy. Do not raise your voice or display other negative body language.

Setting and maintaining healthy boundaries allows the VHA to maintain their role as a volunteer, while being supportive and involved in a member's life. When boundaries are breached, VHA should discuss these issues with the VHA Committee or VHA Coordinator as needed. This lets the VHA Committee be aware, discuss, and decide how to proceed with the situation.

Resistance

Volunteer Health Advocates might be amazed and frustrated that prospective member matches, who could obviously benefit from Volunteer Health Advocacy services, appear to be ambivalent about or refuse the offer of support. In order to properly respond to the refusals, it is helpful to have some understanding of why people tend to refuse the kindness of others.

There are a number of societal factors that contribute to resistance to accept care and support. For many, independence and individualism are primary, if not ultimate values in American society. Growing up with these norms has fostered a system that predisposes people to not call another person for a gift of care. It is thought impolite to ask for a gift which can be seen as "begging." If care is needed and obtained, then it "should" be purchased, a sentiment captured by the comment, "I don't want charity." Thus, "care" becomes a service that one purchases.

Why resistance occurs

Personal factors may also contribute to a person's resistance or ambivalence about accepting care and support. Some of these personal factor's may include:

- People may simply minimize, not recognize, or deny their incapacities or limitations. A survey by the National Council on Aging conducted in 2000 of adults 65+ illustrates this lack of self-recognition. For example, 92% said health problens are a very or somewhat serious issue for most people 65+, but only 42% said it was for them. They said loneliness is a very or somewhat serious problem for those 84% over 65, but only 21% said it was for them. This data may not be surprising if we consider how we see ourselves with respect to our own age. We hardly think or feel that we are as old as we are or that our age does or should entail any limits on our activities.
- Pride may inhibit a person from accepting care. Admitting one has need is felt to be a personal failure. It is contrary to self-reliance and, accordingly, a sign of personal shortcoming. We live in a culture that idealizes perfection, which results in anything less being disvalued and hidden. Asking others for assistance requires one to recognize and reveal one's shortcomings. Rather than do this, people often think that it is better to accept and compensate

rather than to reveal one's loss or need. Losses are kept secret to protect oneself or a loved one from the changed opinions or pity of others.

- Embarrassment about one's circumstances or feeling ashamed in some way may add to resistance to accept care.
- Polite people tend to be reluctant to make other's uncomfortable. If it is felt that others would be uncomfortable with one's situation, people resist allowing them in.
- People are reluctant to bother, impose, disturb, burden, or intrude on others. The presence and assistance of others may be perceived to do this.
- People tend to never have learned how to ask for or accept assistance. They have had no good role models. Rather than make a blunder, they resist assistance.
- People may resist offers of care because of some anger or grudge about some past offense.
- People may minimize or underestimate a desire or willingness of others to assist. The offer of support may not be taken seriously.
- Accepting "help" may carry a social stigma (one that is not independent or self-sufficient) or feel like one is accepting "welfare," a good or service that has not been purchased.
- People may become paralyzed by negative feelings about self and one's situation, which renders on incapable of asking for or accepting assistance.

Volunteer Health Advocates can utilize several strategies to overcome resistance. The key to all attempts to combat resistance is in the relationship that the volunteer creates with their member. By fostering a supportive, empathetic relationship, the Volunteer Health Advocate will communicate that they respect the boundaries and the independence of that member.

In addition to maintaining these healthy boundaries of self-determination, the Volunteer Health Advocate should keep these tips in mind:

- Initial and subsequent conversations with members should highlight how the member is adding value to the Volunteer Health Advocate's life. This expression of gratitude may effectively reframe a member's idea that he or she is a burden to others. It may help them recognize and be proud of the gifts they have during the course of a relationship with the Volunteer Health Advocate.

- Gently and sensitively, over time, point out to members how much control over their circumstances, increased self-determination, self-esteem, dignity, and enjoyment they have gained since joining the Volunteer Health Advocacy program. Do not suggest that the program has brought these gains about; rather, highlight the achievement of the member without pointing out his or her weaknesses, losses, and adversities. If our intent and goal in a gesture of care is to be truly responsive to another's need, then we need to seek ways to meet that need in a manner acceptable to another person. It is the member's comfort we desire, not our personal comfort.

Health Issues

There are some health issues that are too advanced for us to manage within our boundaries. Bellingham At Home cannot assist with Activities of Daily Living (ADL's). These include: bathing, dressing, grooming, oral care, toileting, transferring bed/chair, walking, climbing stairs, and eating.

Some members may need assistance with Instrumental Activities of Daily Living (IADL's). These include: shopping, cooking, managing medications, using the telephone, housework, laundry, driving/public transportation, and managing finances. In this event, the member will be referred to a Bellingham At Home volunteer – the Health Advocate focuses on the member's health needs.

The following issues require assistance of a member's family member, friend, or home health worker:

- **Sundown Syndrome:** Sundown Syndrome is a term that describes the onset of confusion and agitation that generally affects people with dementia or cognitive impairment and usually strikes around sunset. Many people, though, use the term to loosely describe increased agitation and confusion that can occur anytime, but may be more noticeable in the late afternoon or early evening.
- **Dementia:** Dementia isn't a specific disease. Instead, dementia describes a group of symptoms affecting intellectual and social abilities severely enough to interfere with daily functioning. Memory loss generally occurs in dementia, but memory loss alone doesn't mean a member has dementia. Dementia indicates problems with at least two or more brain functions, such as memory loss, impaired judgment, and distorted language. Dementia can

make a member confused and unable to remember people and names. A member may also experience changes in personality and social behavior. Although Alzheimer's disease is progressive, some causes of dementia are treatable and even reversible (e.g., improper drug dosage).

- **Stroke:** Occurs when the blood supply to part of one's brain is interrupted or severely reduced, depriving the brain tissue of oxygen and food. Early action and prompt treatment can minimize brain damage and potential complications.
    - **Five signs of a stroke:** 1) Numbness or weakness on one side of the body; 2) Sudden confusion or trouble speaking/understanding; 3) Trouble seeing out of one or both eyes; 4) Dizziness or loss of balance/coordination; and 5) Headache.
- **Macular degeneration:** This is a chronic eye disease that causes vision loss in the center of a person's field of vision.
- **Diabetes:** This develops when a body's insulin levels are chronically insufficient. Older adults may not experience the typical symptoms of fatigue, increased appetite, weakness, slow healing, and frequent urination that are associated with diabetes. Symptoms for older adults are blindness and nerve damage. Untreated, it leads to kidney failure, infection, and heart damage.
- **Chronic illness:** Various health issues, such as loss of heart or lung function or other long-term illness, may not be visible, but the Health Advocate's awareness of such health limitations can be helpful for the member.

Self-Determination

With the support of healthy boundaries, the VHA and member relationship will have the framework necessary to encourage the member's self-determination. The members of Bellingham At Home are individuals with their own value systems and decision-making processes. While VHA are involved in the lives of members as an additional support, members are still independent individuals capable of making their own decisions.

Every person has the right to make bad decisions. Often, mistakes are some of the greatest opportunities for learning and growth to occur. While VHA may feel conflicted or disagree with a member's decisions, we must understand that a member's decision is their own to make. The role of a VHA is not to make

decisions for a member. VHA must be aware of the beliefs and values that influence their own decisions. These beliefs and values should not be imposed on members.

If you are concerned with a member's decision, seek guidance from the Volunteer Health Advocacy Committee or the VHA Coordinator.

Self-Care Solutions for the Health Advocate

When you sign up for a three-month commitment, it may evolve into a time-demanding commitment. It is important to take care of yourself through your Volunteer Health Advocacy experience to prevent burnout. Burnout is the gradual process by which a person, in response to prolonged stress and physical, mental, and emotional strain, detaches from work and other meaningful relationships. The result is lowered productivity, cynicism, confusion, a feeling of being drained, and having nothing more to give.

Taking time for self-care will help your volunteer relationships remain healthy and rewarding. Here are some strategies for preventing burnout.

Burnout Tip #1: PACE YOURSELF

Remember, you have a time period to fulfill your role. Most volunteer leaders commit to a role because they are passionate about the cause, and that passion can fuel a lively energy, but it is important to not over extend yourself. You will benefit the members more if you can harness that energy during the duration of your commitment. One way you can do this is by reminding yourself that you cannot (and in fact, should not) do everything immediately.

Burnout Tip #2: SET GOALS

Work with your member to establish 3-5 reasonable goals and seek feedback from the VHA team on the goals to ensure they are feasible. This will give you focus for your time, and structure for your work with your member. A way to hold yourself accountable for these goals is to assess your work-to-date for each goal while completing the monthly Health Advocate Check-in Form.

Burnout Tip #3: DELEGATE AND COLLABORATE

Some volunteer roles can feel isolating. Unfortunately, we often create that isolation ourselves because we believe leadership means doing it on your own. It is

important to remember that you are not alone. Do not hesitate to use the variety of resources that surround you. Collaborate with other volunteers in bringing action to ideas. Empower others to work with you on tasks by asking for help. Whether delegating or collaborating, it is critical to set clear expectations for both yourself and those you are working with, and then hold each other accountable to these by checking in periodically with other VHA members and the VHA Coordinator.

Burnout Tip #4: GIVE YOURSELF PERMISSION

Give yourself permission to ask for help and advice, to make mistakes during your term of service, and to acknowledge both your learning opportunities and achievements. It is important as a VHA to model positive and healthy relationships, and permission to make mistakes is critical in helping establish that.

Understanding Conflicts

Volunteer Health Advocates may encounter various conflicts in their efforts to assist members. These can include conflicts with family members, medical personnel, or other members and friends who have a stake in the member's health and welfare.

Such conflicts can be mitigated by open communication and maintaining appropriate boundaries. Volunteer Health Advocates do not serve as conflict resolution experts. Instead, Volunteer Health Advocates should seek help and advice from the VHA Coordinator or other Volunteer Health Advocates.

Working with Third Parties (e.g. Family)

When Volunteer Health Advocates start to work with members, it is important to be aware of any other people that may also be playing an important role in the member's life. These are referred to as third parties. A third party can be a caregiver, family members, a neighbor, friends, paid staff, other volunteers, etc. Just remember, third parties can be a wonderful resource for both you and the member you are working with, as long as you are all working towards improving the quality of life for the member.

Introduce yourself and explain your role: As a Volunteer Health Advocate, it is your role to serve as a point of contact between the member and Bellingham At

Home. The Volunteer Health Advocate and the member work together to determine what the needs of the member are and how the volunteer/member relationship will be structured.

Confidentiality: It is important to make sure that you speak to the member before sharing any information about the member with third parties. It would also be beneficial to speak with the member about what kinds of activities the third party participates in. There may be some areas where the Volunteer Health Advocate would be appreciated, such as following up on BAH service requests, for example.

Some insights to keep in mind when communicating or working with third parties (especially caregivers):

Third parties are often caregivers in some respect. They may not be providing traditional cooking/cleaning/personal care roles, but instead they may be providing oversight/emotional support/advocacy. When communicating with third parties and/or caregivers, here are some things to keep in mind.

- Caregivers may neglect themselves while providing services to the member. The caregiver may become so involved with caring for the member that they do not realize they also need support.
- Caregivers may resist sharing responsibility. The caregiver may not feel as if anyone else can care for the member like they do and may become filled with guilt or feel like they have abandoned the member if they take any time off.
- The caregiver may be uncomfortable with asking for and/or receiving help from outside sources, even if the member is not. There are two sets of thoughts, feelings, and values to consider.
- Caregivers are often not willing to discuss negative effects that caregiving is having or has had on their mental and physical health.

Losses for the Elderly

This is an excerpt from the book *How to Say It to Seniors* by David Solie, a highly recommended resource for Volunteer Health Advocates.

The overwhelming feeling of loss that accompanies old age creates a need to “hang on tight” to whatever one possibly can. Loss isn’t something that motivates younger generations as much, because their development drivers are compelling

them to move forward. Younger persons do experience loss – loss of a relationship, a job, a parent, or elderly colleague – but they possess the physical and psychic energy to replace those losses with something else – a new partner, a new work arrangement, a new lifestyle. Persons aware of their power and sense of control enable them to move on.

The elderly, however, find it much more difficult to cope with loss. In some areas, the losses cannot be regained or replaced. Some of the losses the elderly experience are more obvious than others.

Loss of physical strength

We know that as we age we lose strength, but before we become old, there always seems to be a quick fix available in the form of different pep pills, better nutrition and exercise, more sleep, longer vacations. No one under the age of seventy can appreciate what it's like to lose strength and not be able to get it back. The intensity with which the elderly experience the body's loss of strength has a profound impact on their sense of who they are. As Volunteer Health Advocates, we need to exercise patience and understanding, especially when a member experiences chronic illness and other physical maladies.

Imagine what it would be like if *you* developed the flu and were asked, when you're sick in bed with sweats, aches, and a fever so high you can't lift your head off the pillow, to make an important decision, such as where you'll live for the next twenty years! Many elderly people comment that making such an important decision is difficult because they don't have the strength to cope with the details. The task seems overwhelming. Yet older people may be battling the losses imposed by the chronic condition of old age and their family pushing them to downscale or move to a senior car facility can be bewildering. Such demands for a life-altering decision under such circumstances may not be reasonable.

Loss of health

It's not unusual for the seventy-plus age group to make more visits to the doctor, take more medications, and get sick more often than persons of middle age, but when they visit the doctor, they're not presenting the sore throats and colds or strained muscles from which young persons seek relief. Our members may be dealing with life-threatening conditions that must be treated, followed, and medicated on a daily basis. Just as they reach the stage of life where they have

fewer responsibilities and the time to enjoy themselves, their bodies begin to betray them in ways that they simply cannot control.

Loss of peer group

Once health begins to slip, people in their seventies begin to lose friends and members of their social groups at an alarming rate. In Germany, deaths are announced via black-bordered cards sent in the mail. An eighty-year-old woman explained that she received two or three of these cards every month. She reaches into her mailbox, pulls out a black-bordered card, and there's no mistaking that her peer group has just lost another member. Imagine what it would be like to lose even one friend with whom you've shared your life stories for decades.

Loss of consultative authority

Ours is not a culture that values the wisdom of elders. There is little chance for us to come together and use wisdom accumulated throughout their years of living as a resource that enriches our lives. We tend to segregate them into communities of other older people, so their perspective is not available. Society also tends to see older folks as diminished, high-maintenance versions of normal people. Younger persons ignore their special qualities,

Loss of identity

Cherished roles may disappear for seniors as they age. Parent, spouse, worker, and other highly valued identities may not be available, as children move away, grandchildren grow up, and retirement precludes daily contact with fellow workers. Loss of identity was painfully rendered in the movie *About Schmidt*, who once retired, tried to come back as a self-driven consultant with disastrous results.

Individuals who worked as homemakers all their lives also feel a loss of identity, usually at a somewhat later age, when their spouses die and they are no longer part of a marital team. Many older adults who survive their spouses find themselves exposed, no longer part of the comingled identity they shared when they were married. Even individuals who were not particularly happily married become quite anxious at the thought of widowhood. There was a case of one woman who moved to another part of the country because she could not adjust to being single among the social group that knew her as a married woman.

Loss of physical space

Face it: We really don't want to worry about the elderly. We want them to go someplace – assisted living, or a retirement village – where they'll be safe and well cared for and part of a community of old folks just like themselves. The house or condo that was once their sanctuary has become a safety hazard, threatening the older person's very existence. But a person's identity may be closely tied to the comforts of the physical space he or she has occupied for years. Even more important than the comfort the space provides is its role as a repository for memories. The elderly seem to be less concerned about the safety and convenience provided by something unfamiliar than they are about the risks involved in losing the familiar. They are not focusing on the safety; they are dealing with issues much larger and more important to them than convenience.

Loss of financial independence

Many seniors fear being poor, particularly widows or widowers who depend on their spouses' incomes to meet financial obligations. Combine that with the high cost of living and the fact that Americans are living such a long time, and they begin to realize they may run out of money. The financial freedom they took for granted during their high-earning years may elude them in old age when all else is failing, too. Actually, "freedom" when it comes to finances is too strong a word, for this senior group has typically been very frugal. They clearly remember the financial hardships their families experienced during the Great Depression, and how they had to scrimp and save to raise their children and put them through college.

Termination

We know that situations occur, circumstances change, and that life happens. We understand that the member or volunteer may have to terminate the Volunteer Health Advocacy relationship suddenly. Whenever possible, we appreciate as much notice as the volunteer or member can provide.

When terminating, we encourage a final meeting or visit to help the volunteer and the member experience a supported transition. It is possible to take a pause as a Volunteer Health Advocate when needed – we have trained substitutes for this reason. Please consider all options before terminating your Volunteer Health Advocacy relationship. Contact the VHA Coordinator with any issues that arise.

There may also be a time when the member would like to terminate their relationship with either the Volunteer Health Advocate or Volunteer Health Advocacy program all together. In that instance, the VHA Coordinator will meet with the member to discuss their options and will encourage the member to meet with the volunteer to discuss how they came to that decision. The VHA Coordinator will also contact the volunteer to discuss options for continuing the VHA program with a different member.

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