

# *Be Loved*



HOSPICE

## Volunteer Handbook







Thank you for choosing to be a volunteer for BeLoved Hospice!

By supporting us as a volunteer, you have joined a team of individuals who regularly provide their time and skills, to enable us to provide a quality service to our patients/guests and their families during a critical time. As a volunteer you will be making a difference to patients whom have been diagnosed with a life-limiting illness, directly as a patient and family Volunteer or indirectly by serving as a volunteer in clerical, marketing, or other capacities. We are proud of the work we do and our hope is that you will be proud of being part of the team here at BeLoved Hospice.

We want to make volunteering a rewarding and enjoyable experience for you. This handbook is intended to give a brief outline of the work we do, and about your role as a volunteer. Further training may be required, dependent on your volunteer role. It is important you take the time to read through this handbook and refer to it, should you have questions. If you cannot find the information that you are looking for, or have more questions, feel free to reach out to us at (971) 236-1199.

Thank you for your compassion and commitment!

Amber Perelgut  
Administrator

# Mission, Vision, Core Values, and Goals

## BELOVED HOSPICE MISSION STATEMENT

BeLoved Hospice is committed to providing comfort, support, and dignity to patients and their loved ones on their journey through end-of-life care. BeLoved Hospice believes that valuing each patient as an individual is the most important aspect of care that we can give.

## BELOVED HOSPICE VISION STATEMENT

BeLoved Hospice strives to be an advocate and educator in the community about the benefits of hospice care both for the patient and those that love them.

## BELOVED HOSPICE CORE VALUES

- We value people and treat everyone with compassion, care, respect, and courtesy.
- We value the comfort, dignity, and safety of our patients, their loved ones, and their caregivers.
- We value integrity, honesty, and ethical behavior.
- We thrive on teamwork, open communication, and mutual respect for one another.
- We value being part of our community.

BeLoved Hospice does not discriminate on the basis of race, religion, color, national origin, ancestry, age, disability, gender or gender identity, sexual orientation, marital status, veteran status, medical condition, financial status or resources, or any other legally protected class.

## BELOVED HOSPICE GOALS

- To assist the patient to live comfortably by relieving pain and distressing symptoms,
- To support the patient, family, and their loved ones: physically, socially, and spiritually during their journey.
- To empower the patient to preserve a sense of hope by helping them to maintain autonomy, self-worth, control, and dignity.
- To aid the patient, caregiver, and loved ones in being at peace with end-of-life decisions.

# Protecting Our Patients

BeLoved Hospice has a duty to protect our patients and their families. As part of that responsibility, we must complete background checks on any volunteers who may come in contact with a patient or patient information. We complete a full background check on initial orientation and every three years for every employee, contractor, and volunteer. If you have any questions about the background check process, please feel free to reach out to us.

## YOUR AVAILABILITY AND COMMITMENT

As a volunteer, you are making a commitment to the patients and team of BeLoved Hospice. In terms of time and availability, you should decide on how much or little you want to give. Make sure to take your existing commitments into account and then volunteer with what you think you can manage. We always appreciate your help and dedication, but want you to have a healthy balance between volunteer commitments and your everyday commitments. It is better to agree to only give a little time at first, you can increase your commitment later if you feel you can cope with more.

If you are finding that you are having difficulties meeting your volunteer commitments, you may decrease or discontinue your involvement at any time. Please just let us know, preferably giving as much advance notice as possible.

## BE DRESSED PROPERLY

Discreet, comfortable, and professional. Adhere to the dress code of the hospice you serve with and utilize common sense. Also, remember that most facilities keep the temperature up pretty high, and on the same token: keep in mind that if you go in the late afternoon, there may be a temperature drop outside by the time you go home.

## BADGE

Always bring your badge, it identifies you as part of the hospice team, and patients and loved ones can see your name. They have a lot to deal with and sometimes get embarrassed if they have to keep asking.

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# What Should I Bring?

## PATIENT INFORMATION AND IMPORTANT PHONE NUMBERS

Make sure to have important contact information for the patient, in case you get lost or are running behind, and the BeLoved Hospice office. It is also wise to have the direct number to your Volunteer Coordinator and the patient's RN Case Manager, in case of emergency.

## BOTTLE OF WATER

Bring a bottle of water or something else you may want to drink. Sometimes there isn't anything available, or you may find yourself at a place where you do not necessarily WANT to make use of what is available. Just as we remind our patients to stay hydrated, we should do the same!

## HAND SANITIZER

We will cover hand hygiene later on in this handbook. But sometimes, a sink or soap is not readily available. If your hands are not visibly soiled, hand sanitizer is a suitable alternative to clean your hands. Proper use of hand sanitizer makes you come across more professional because you observe universal precautions and you come prepared. BeLoved Hospice is happy to supply you with pocket or purse-sized bottles of hand sanitizer.

## A NOTE PAD AND A PEN

Carry these just to make notes if needed. Sometimes a situation may get hectic and if you write down important things along the way, you can't forget them later. Additionally, sometimes your patient may be hard of hearing. Having a notepad and pen allows you to communicate with one another without yelling and possibly disturbing others.

## A BOOK

Sometimes volunteering activities include respite care for the caregiver. During this time, your patient may not want or be able to talk and entertain a guest. Make sure that you are prepared by having something to quietly occupy yourself. This is an excellent way to give a patient privacy while still being able to keep an eye on them by peeking over the book every now and then.

## OPEN HEART AND ENERGY

Come from loving compassion, devotion, and respect.

# General Information

## YOUR BOUNDARIES

Being a hospice team member is extremely rewarding. You are providing a priceless gift to your patients and families during a critical time in their lives. However, it is important to ask yourself some key questions before accepting your first volunteer assignment. Here is some food for thought:

- Am I comfortable with death?
- Am I comfortable being alone with someone who is dying?
- What if a patient or loved ones start proselytizing?
- Can I refrain from proselytizing myself?
- Am I capable to deal with the tears and/or stress of loved ones?
- Am I capable of not taking it personally if a patient/loved one is rude or displays inappropriate behavior?
- Am I capable of setting my personal feelings and/or preconceptions apart?

Know the boundaries set for you, as a volunteer, by BeLoved Hospice. Know what is within your scope and know what is prohibited.

It happens quite frequently that individuals assume that since you are with hospice and you are sitting with their patient, you automatically will take over all of their tasks. This is not necessarily because they are lazy, but mostly because a lot of them have never worked with hospice or simply do not know the scope of a hospice volunteer. It is advisable that you do your best to educate the facility staff or the patient's caregivers about your scope as a volunteer. The Volunteer Coordinator and the team at BeLoved Hospice will do their best to help reinforce this education.

Another important boundary is recognizing when is it time to hand over care to other staff members (know that you are capable of handling a lot of things, yet knowing when professional staff needs to be involved)

It is very important for you to ask yourself: where do I draw a line where my boundaries are concerned?

# Standards of Conduct

BeLoved Hospice believes that its patients, families, and loved ones should experience effective, safe, and appropriate support that meets their needs and protects their rights.

BeLoved Hospice has certain rules within which volunteers are expected to operate. This handbook is intended to be a helpful guide to volunteers by stating the standards which are expected and behavior that is not acceptable.

Everyone within BeLoved Hospice is committed to the same goal – to provide quality care and services for patients and their families. This can be achieved by every team member performing their role and ensuring the highest standards.

## STANDARDS OF BEHAVIOR

Volunteers are expected to be:

- Honest and trustworthy.
- Polite and helpful to others.
- A member of the team and considerate of others’ feelings and needs.
- Positive in approach with a can-do attitude.
- Flexible and willing to meet the changing demands of the role.

Volunteers are expected to:

- Abide by any specific guidelines of the role(s) in which they are involved.
- Be a reliable and dependable member of the team.
- Be honest and accountable in fulfilling commitments.
- Maintain confidentiality. Confidential information must not be disclosed to an unauthorized person at any time, during or after volunteering.
- Not to make public statements on behalf of BeLoved Hospice. Those approached for an official statement or comment should refer the request to the Administrator. Act in the best interests of patients, families, staff, and the hospice.
- Participate in training and/or group meetings as arranged/required.
- Be open to any feedback that may be given regarding their work.
- Not to give out their own personal contact details and not to contact patients outside of hospice assignments.
- Wear suitable clothing, appropriate to their role and task.
- Not to have children accompanying them whilst volunteering for the charity. Raise any concerns and discuss any area of dissatisfaction with the Volunteer Coordinator, Director of Nursing, or Administrator.
- Seek prior permission before removing any material or equipment from their place of work. Wilful damage, theft, or negligence which leads to loss or damage to property belonging to the hospice, patients, families, or other team members may result in termination of volunteering. Act within the law and not bring the charity into disrepute.
- Volunteers will not be permitted to work under the influence of alcohol or drugs.
- Volunteers are advised not to accept any gift or consideration of any kind from any patient, family, or persons with whom they are brought into contact by reason of their volunteering. Any other inducement or gift must be politely but firmly declined and reported to the Volunteer Coordinator, Director of Nursing, or Administrator.
- BeLoved Hospice can accept no liability for loss or damage to personal property by burglary, theft, fire, or otherwise. Volunteers are accordingly advised not to bring items of value to their place of volunteering.

We also ask that you abide by the following:

- Do not provide medical advice.
- Never discuss the qualifications of the interdisciplinary team assigned to the patient.

- Follow instructions carefully and only perform assigned responsibilities. When in doubt, ask.
- Do not take advantage of your association with healthcare professionals to seek free medical advice or services for yourself or friends and family.

## ABUSE, NEGLECT, AND EXPLOITATION

Victims of abuse or neglect may come to BeLoved Hospice in a variety of ways. The patient may be unable or may be reluctant to speak of the abuse, and it may not be obvious to the casual observer. Staff shall be given education during orientation to assist in their ability to identify abuse or neglect, as well as the extent and circumstances of the abuse or neglect, to give the patient appropriate care.

The team member who first becomes aware of a patient who is alleged to be abused, neglected, mistreated, and/or exploited must take all appropriate steps necessary to protect the patient. The report must be made to the Administrator or Director of Nursing within 24 hours. Before making any calls to Elder Protective Services, Adult Protective Services, or Child Protective Services, the team member must contact the Administrator directly to relay the situation necessitating reporting.

Elder Abuse or Child Abuse is a crime! Licensed independent and all other health care providers or medical practitioners who have actual knowledge that a dependent adult or an elder (age 65 or higher) whom he or she observes in his or her professional capacity, has been the victim of physical abuse, must verbally report the suspected instances to the Administrator, the Director of Nursing, and/or the Oregon Department of Human Services at 1-855-503-SAFE (7233) immediately or within 24 hours. Written reports must be made within 2 working days.

## PATIENT PRIVACY AND CONFIDENTIALITY

Never discuss patient information in public places or with those not assigned to the patient’s care team. This includes common areas of the BeLoved Hospice offices, like bathrooms, hallways, parking lots, etc., common areas of facilities, or public spaces like restaurants or coffee shops. In addition, never leave patient information in a location where unauthorized individuals may see it. All printed patient information should be returned to the BeLoved Hospice office each day at the end of your visits.

# Health Insurance Portability and Accountability Act (HIPAA)

BeLoved Hospice follows all applicable state and federal laws as related to the Health Insurance Portability and Accountability Act of 1996, Public Law 104-191.

## DEFINITIONS:

Standards for Privacy of Individually Identifiable Health Information “Privacy Rule”:

- The Standards for Privacy of Individually Identifiable Health Information (“Privacy Rule”) establishes, for the first time, a set of national standards for the protection of certain health information. The U.S. Department of Health and Human Services (“HHS”) issued the Privacy Rule to implement the requirement of the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”).<sup>1</sup> The Privacy Rule standards address the use and disclosure of individuals’ health information, called “protected health information” by organizations subject to the Privacy Rule, called “covered entities,” as well as standards for individuals’ privacy rights to understand and control how their health information is used. Within HHS, the Office for Civil Rights (“OCR”) has responsibility for implementing and enforcing the Privacy Rule with respect to voluntary compliance activities and civil money penalties. A major goal of the Privacy Rule is to assure that individuals’ health information is properly protected while allowing the flow of health information needed to provide and promote high-quality health care and to protect the public’s health and well-being. The Rule strikes a balance that permits important uses of information while protecting the privacy of people who seek care and healing. Given that the healthcare marketplace is diverse, the Rule is designed to be flexible and comprehensive to cover the variety of uses and disclosures that need to be addressed.
- The Health Insurance Portability and Accountability Act of 1996 (HIPAA), Public Law 104-191, was enacted on August 21, 1996. Sections 261 through 264 of HIPAA require the Secretary of HHS to publicize standards for the electronic exchange, privacy, and security of health information. Collectively these are known as the Administrative Simplification provisions.

## PROTECTED HEALTH INFORMATION (PHI)

- The Privacy Rule protects all “individually identifiable health information” held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral. The Privacy Rule calls this information “protected health information (PHI).”
- Individually identifiable health information is information including demographic data, that relates to:
  - the individual’s past, present, or future physical or mental health or condition;
  - the provision of health care to the individual; or
  - the past, present, or future payment for the provision of healthcare to the individual;

- and that identifies the individual, or for which there is a reasonable basis to believe can be used to identify the individual. Individually identifiable health information includes many common identifiers: name, address, birth date, and Social Security Number.
- In order to protect patient’s protected health information, which could be stored on personal cell phones and other devices, BeLoved Hospice requires that team members create a Personal Identification Number (“PIN”) or Passcode Lock for their phone and other devices when not in use.
- There are no restrictions on the use or disclosure of de-identified health information. De identified health information neither identifies nor provides a reasonable basis to identify an individual. There are two ways to de-identify information:
  - a formal determination by a qualified statistician; or
  - the removal of specified identifiers of the individual, and of the individual’s relatives, household members, and employers is required and is adequate only if the covered entity has no actual knowledge that the remaining information could be used to identify the individual.
- A covered entity is permitted, but not required, to use and disclose protected health information, without an individual’s authorization, for the following purposes or situations:
  - To the Individual (unless required for access or accounting of disclosures);
  - Treatment, Payment, and Health Care Operations;
  - Opportunity to Agree or Object;
  - Incident to an otherwise permitted use and disclosure;
  - Public Interest and Benefit Activities; and
  - Limited Data set for the purposes of research, public health, or health care operations. 18 Covered entities may rely on professional ethics and best judgments in deciding which of these permissive uses and disclosures to make.

## PROCEDURE

- Authorizations
  - All authorizations must be written, dated, and currently signed by the patient or his/her legal representative.
    - » A current authorization is one that is signed within the last year.
    - » If the authorization has not been dated, it must be returned to the sender with the statement: “The authorization, which you sent, was not dated. In order to be valid, the patient’s authorization must be dated prior to the signing of the authorization. If you wish to resubmit a properly dated and signed authorization, we will be happy to process your request.”
- Authorizations may not be accepted when they are addressed to another party, such as a hospital, physician, or third-party payor.
- Authorizations may be accepted if they are not addressed to hospice but are addressed “To Whom It May Concern.”
- Authorization must state the name of persons or entities to which medical information is to be released.
  - Persons who may sign include:
    - » The competent patient, 18 years or older.
    - » Conservator or attorney-in-fact of an incompetent adult (must produce papers of guardianship, etc.)
    - » Minors, only if they could have consented to treatment without parental consent. Parent or guardian of a minor patient (must produce letters of guardianship-step parents may not consent.)
    - » Patient’s spouse, for a limited purpose of processing an application for a health insurance plan.
    - » Parent or guardian of a minor patient (must produce letters of guardianship-step parents may not consent.)
    - » Patient’s spouse, for a limited purpose of processing an application for a health insurance plan.
    - » Executor or administrator of the estate, or an heir of a deceased patient.

- All patients or legally qualified patient representative authorizations, as well as the original requests for information, will be retained and kept in the back of the patient's clinical record.
  - Release of Information from Hospice Records of patients currently on service.
    - » Occasionally, there will be a need to provide photocopies of records of patients who are currently on service at Hospice.
      - Copy the information requested and sends it with a cover letter stating that the record has been photocopied up to the current date.
      - Use this language at the bottom of the cover letter: "Photocopies of the record consisting of \_\_\_\_ (number of) pages have been prepared up to and including \_\_\_\_ (date). Since the patient is currently on service at a hospice, the record is incomplete, and there may be additions or deletions prior to or following discharge."
  - Law Enforcement Inquiries
    - » If a request for the release of information is received from a law enforcement agency, please notify the governing body immediately and follow the directions of the office.
      - Police or investigative agencies' requests for information will not be complied with unless the patient or his/her legal representative has given specific consent for release of information or a court order or subpoena is presented.
  - Information is released as specified below:
    - » Requires patient authorization
      - Government Agencies
      - Medicare/Blue Cross/Intermediaries
      - Attorneys, Insurance Brokers, and Agents
      - Patient/family/caregiver – also requires a written request from patient
      - FBI and all law enforcement agencies
    - » Can be released without patient authorization
      - Attending Physician's Release
      - Workmen's Compensation Releases
      - Subpoenas
- FBI and all law enforcement agencies – with a court order

# Hand Hygiene

Practicing hand hygiene is a simple yet effective way to prevent infections. Cleaning your hands can prevent the spread of germs, including those that are resistant to antibiotics and are becoming difficult, if not impossible, to treat. On average, healthcare providers clean their hands less than half of the time they should. On any given day, about one in 31 hospital patients has at least one healthcare-associated infection.

## WHAT IS HAND HYGIENE?

Hand hygiene means cleaning your hands by using either handwashing (washing hands with soap and water), antiseptic hand wash, antiseptic hand rub (i.e. alcohol-based hand sanitizer including foam or gel) or surgical hand antisepsis.

## WHY PRACTICE HAND HYGIENE?

Cleaning your hands reduces:

- The spread of potentially deadly germs to patients
- The risk of healthcare provider colonization or infection caused by germs acquired from the patient

Equipment and Supplies Needed:

- Running water
- Soap
- Paper towels
- Trashcan
- An alcohol-based antimicrobial agent

## WHEN TO PERFORM HAND HYGIENE?

Multiple opportunities for hand hygiene may occur during a single care episode.

The following are the clinical indications for hand hygiene:

- Wash with Soap and Water
  - When hands are visibly soiled
  - After caring for a person with known or suspected infectious diarrhea
  - After known or suspected exposure to spores (e.g. B. anthracis, C difficile outbreaks)
- Use an Alcohol-Based Hand Sanitizer
  - Immediately before touching a patient
  - After touching a patient or the patient's immediate environment
  - Immediately after glove removal

# Things A Volunteer Should Know

## PATIENT'S FULL NAME, PHONE NUMBER, AND ADDRESS

You will need to know the patient's full name and age. Phone number and address are obviously important information to have on hand too. Other information like the type of residence, parking, and after-hours access is important as well.

## PATIENT'S DIAGNOSIS, STATUS, GENDER, AND AGE

Being knowledgeable about the patient's status/diagnosis is important so you know what to expect in terms of what the patient may look like, how he or she may act etc. and you also come across more professional and prepared to loved ones and caregivers. Obviously, the hospice will inform you if a patient carries a contagious illness such as MRSA, and preventive measures will be taken. Gender is important because names can get confusing and in certain cultures, it makes a big difference whether you are working with a male or female. The age of the patient is important for the very same reason.

## SOME OF THE PATIENT'S HISTORY

It can be very important to know some of the patient's history as this often greatly influences a patient's behavior and needs for appropriate care. Some examples are: Is the patient an Immigrant? Do they speak a different language? Are they a veteran? What are their diagnoses? Does she have any abuse in her history? Etc.

## FAMILY DYNAMICS

Family dynamics may influence people's behavior and may require careful navigation. Everything that is happening at this point concerning the patient as well as his loved ones is in the context of everybody involved.

On top of possible areas of friction in the past, comes now the journey which has led to hospice. Oftentimes, hopes of recovery have been crushed over and over and by now everybody involved may be experiencing some pretty raw emotions. Especially at the time when one has entered the stage of actively dying. A lot of times, people have still been hoping deep down inside that they will not have to lose their loved one. Now, at the end stage, where people are truly actively dying, there is no escape from reality – THIS IS IT – THIS IS REAL...

In light of having to face this painful truth, a lot of people tend to shut down, go into “survival mode” or simply lash out at others. These are all valid, common emotions, and tensions can rise pretty high. Knowing of possible frictions upfront will enable you, the volunteer, to have a better insight and understanding and allows for the ability to be of the best support that you can be. This phase on their path is where you can carefully observe for some early bereavement concerns, which you may then pass on to the Volunteer Coordinator or other appropriate staff member such as a bereavement coordinator or a Chaplain.

## WHO IS ON THE PATIENT'S CARE TEAM?

Know who is on the patient's care team, know whom to call, and in what order. It comes across a lot more professional to patients, loved ones, and caregivers when you present as knowledgeable and organized.

## WHO IS ON CALL AFTER HOURS?

For visits outside of regular business hours, be aware of who are the staff members that are on call; they may be different staff members than the ones that would be assigned to the patient during business hours! A member of the BeLoved Hospice team is always available after hours and can be reached by calling (971) 236-1199.

# Proper Introductions and Sign In Etiquette

## RECEPTION DESK/GUESTBOOK

When arriving at a facility, always check if there is a visitor's book to sign in. Some facilities will have a designated book for regular visitors and agency visitors. Make sure to use the agency visitor sign-in book if that is the case. The sign-in book is usually located at the reception desk or near the facility entrance.

Overall, you are expected to sign in your name, which hospice organization you represent, which resident you are visiting, and time in (when you arrive) and time out (when you leave). If a receptionist or host is present, he or she will gladly tell you where the patient is located. On your way there, take the chance to observe where the emergency exits are.

## NURSES' STATION

Try to introduce yourself at the nurses' station, if there is one, first, "Hi my name is ....., I am a volunteer for BeLoved Hospice and I am here to spend some time with Mr./Mrs.... I just wanted to introduce myself so that you know who I am and that I am on the premises". This is a good time to ask the facility staff if there is anything specific about the patient that you should be aware of.

As part of universal precautions; make sure you use hand sanitizer before you see the patient and/or loved ones and after you see them. It is good to do this visibly for staff members/loved ones; it shows that you are a professional and that you take their health and safety seriously. If the patient, family, or facility requires that you wear a mask or other PPE, please don your PPE before entering the patient's home or room.

## BE RESPONSIBLE FOR THE ENERGY THAT YOU BRING

Always knock – even if the door is open! It is common courtesy. Ask if this is (patient's name) room and if you may come in.

Before anything else, disinfect your hands as you walk into the room. You can say something like, “Hi, how are you? Please excuse me – I have been running around so I just want to make sure my hands are clean. Thank you”. If the patient is awake and alert make sure that you are within the patient's field of vision and make eye contact; it is respectful and you never know how a patient's hearing ability is at that point.

Greet the patient with a smile: a smile can do wonders!

Do not “tower” over a patient – this can be very intimidating for a patient – you can get down to their level, by kneeling or pulling up an available chair.

## ADDRESS THE PATIENT APPROPRIATELY

As we strive to keep a patient as comfortable as possible, try to find out upfront how to best address the patient. Do they prefer a formal use of their last name? Do they go by a nickname or their middle name? This information is usually documented in the patient's hospice medical record, on their face sheet.

For example, if a patient has Alzheimer's disease, there is a chance that this patient, in his reality is living in 1930. This patient may believe that he is six years old. Then, it could possibly be quite confusing for him to be addressed with



Mr.... In his mind he is six years old, remember? A loved one or staff member may tell you to just call him “Timmy”. In that case, just go with that; even though the patient may be your elder, you are not being disrespectful because familiarity is very important to people who are in that stage of their dementia. It really can make a big difference for the patient and loved ones, because you show that you care and that you are knowledgeable, and it often prevents or eases restlessness in a patient. This, of course, is always nicer for loved ones as well.

## USE SHORT, CLEAR SENTENCES

“Hello Mrs... I am... I am a volunteer with... I would like to spend some time with you if I may”. Use short sentences and speak in a clear voice. If a patient or loved one has hearing difficulties, it may be beneficial to speak in a lower register.

In the case of visiting a patient who has a form of dementia or is otherwise confused, it may be beneficial to introduce yourself as a friend, either a friend of the patient or a friend of their family member or loved one as the word "volunteer" may be confusing.

## INTRODUCTION TO LOVED ONES

If a patient is unresponsive, always introduce yourself to the loved ones first. Make sure that your badge is visible and introduce yourself in a professional, yet warm manner: Sometimes it is more personal to introduce yourself quietly to each person in the room than make an "announcement" that you have arrived. This presents people with the idea that you are truly there for them.

A simple, "how are you doing?" goes a long way. If somebody starts telling you how they are, genuinely take some time to hear them out. Looking people in the eye and kneeling down in front of them if they happen to be in a low chair, brings you a bit closer as well. This is an excellent manner to get a feel for “who is who”, and their relationship to the patient.

But be sincere: a lot of times a dying patient’s loved ones are intently watching what goes on with the patient. This is a mighty intense time in their lives and therefore, they can be in a heightened state of awareness and they will see right through you if you say something just because you think you “should”. It truly does work though: “Wow, your father looks so peaceful today...” or “What a beautiful picture – does your mother like flowers?” It sets a caring tone and is also really nice as a conversation starter.

## WRITE DOWN YOUR NAME

Even though you wear a badge, it is always good to legibly write down your name and post it somewhere where it is easy to find for loved ones. There is a place in the BeLoved Hospice Patient Resource Manual where you can write your name. Patients have people coming in and going all day long and it gets confusing to remember who is who and who they were.

If at any given time during your visit you have to reintroduce yourself, do so like it is the first time. Hospice introduces a lot of people to the patient and their loved ones in a short amount of time, so names might get confusing.

## ASK QUESTIONS

Ask loved ones what they remember hospice staff telling them about how the patient is doing and what is going on at this point if they care to share. Ask them how they are holding up. This is an excellent way to figure out where they are in their understanding of the patient’s status and the process of dying. This will help you to assess how to best assist them, and educate them and it is also a great way to pick up any possible early bereavement concerns to be reported

back to the Social Worker, Chaplain/Spiritual Counselor, or Bereavement Coordinator. As a hospice team member, you are an extra set of eyes and ears for us and help us provide the best patient experience possible by working with our interdisciplinary team.

If there are questions from the patient or loved ones make sure that you only answer those questions which you are knowledgeable about and the ones that you are comfortable answering. Do not guess. You may offer to find out an answer to certain questions or forward that questions to the appropriate team member, but make sure that you follow up on that offer.

Whenever you leave, ask if you may come back (if you are scheduled and/or inclined to do so). It not only is common courtesy, but it also shows that you care and that the patient/loved ones have a choice thus providing them with a sense of control.

Don't be afraid to ask questions about the patient or ask patients and family members to share funny stories and memories; loved ones often love to reminisce!

## PHYSICAL INTRODUCTIONS

When a patient is unconscious or unresponsive, always assume that they can still hear everything that you say to them but as you can never be truly certain of that, it is appropriate to briefly touch the patient in hopes that they may become physically aware of the fact that someone is by their side.

After introducing yourself verbally, state: “I will briefly touch your (right or left) arm now, so that you may be physically aware of my presence”. It is another “just in case” way of making people aware that you are with them, but it may also be comforting to the loved ones because you show that you care.

## EMOTIONS AND CARING TOUCH

It is appropriate to always ask upfront before touching or hugging a person. Usually, patients and families welcome and encourage a hug, but it is always better to err on the side of caution, read the room, and when in doubt, ask before proceeding with any physical touch.

## INTRODUCING YOURSELF TO THE PATIENT'S CARE TEAM

If the patient resides in a facility, it is professional to introduce yourself to any staff member who comes in to provide care for the patient while you or visiting and getting to know the staff members who are regularly responsible for the patient's care. It is always nice to introduce yourself and your role within the hospice and find out who the staff member is and what role they play on the patient's care team.

## EXPLAIN HOW LONG AND HOW FREQUENTLY YOU EXPECT TO BE VISITING

Staff members often like to know how long you will be with the patient. It gives them peace of mind because they know somebody is with their patient. They may also be more discreet with their check-ins so as not to interrupt the patient's valuable companionship time.

## EXPLAIN YOUR SCOPE AS A VOLUNTEER

Always explain your scope as a hospice volunteer and emphasize that you are NOT allowed to provide hands-on care to the patient.

## BE RESPECTFUL AND SHOW TACT

Remember that you may be visiting patients who have been receiving care from the same staff members for years. Naturally, a bond has formed between them. This may cause staff members to be a bit protective of the patient, especially if the staff member is not familiar with hospice.

## DO NOT MAKE ASSUMPTIONS

Many people assume that just because a doctor, nurse, social worker, or CNA has a medical education/background they automatically know everything about dying processes and death or that dealing with death and dying is easy for them. This is often not the case. Many staff members need education and reminders about what hospice is. If you are comfortable with providing this education, feel free. Otherwise, report back to your Volunteer Coordinator that this facility might need a little more education and reassurance on the hospice benefit.

## THANK STAFF MEMBERS WHEN YOUR VISIT ENDS

When you are done visiting with the patient, it is always courteous to thank the staff members for their hospitality and cooperation. It is good for business relations (remember – you represent hospice) and always nice if you ever get to work with the same staff members again.

# The Intensity of People

Try to remember that you enter people's lives at a very intense period. They are human beings just like you; volatile at times, happy, angry... They can display basically any emotion in the book. No matter how many patient assignments you have been on, every time is different for the simple fact that every patient is different, as are loved ones and every situation is absolutely unique as well.

Everybody involved may sleep and/or eat a lot less because of the stress and may therefore become irritable easier.

Death is a normal part of life – as we say – but it can be a whole different ball game when it enters one's own life!

For patients as well as loved ones death does not “just” mean having to lose someone, but it also means having to say goodbye forever to each other, goodbye to things and beloved pets, and expectations and possibilities for the future.

For patients, loved ones, and yourself, past experiences with life, illness, and death will more than likely color your perceptions and/or expectations around these issues. If a patient is rude, it more than likely has nothing to do with you as a person, rather than an issue that they possibly are working through.

For instance:

What will happen when I die?

What will happen to me after I die?

What will happen to my loved ones when I am gone?

What will happen to my pet when I'm gone?

Some patients are angry at God, their loss of independence, unfulfilled dreams/expectations, and seeming injustice. There can be multitudes of reasons for people acting/reacting a certain way; just a few are stated here. Try not to take it personally, but rather remember that everybody deals with stress in their own way.

This does not mean that dying gives a patient and/or loved ones a “free pass” to be abusive!

If at any given point, a patient's behavior (or the behavior of loved ones, for that matter) becomes too much for you, contact the Volunteer Coordinator right away.



# It's a Tough Situation for Everyone

It is a tough situation for anyone involved and it is our task to navigate it delicately.

## MANY EMOTIONS POSSIBLE

Sometimes the people involved feel that what little time they have left with the patient should be spent privately and, at first may perceive hospice coming in as an intrusion.

Sometimes both the patient and loved ones will ask you on separate occasions to not tell the other party that the patient is dying. This often happens because they want to spare one another's feelings. We encourage you to respect these requests but be sure to inform the Volunteer Coordinator if this arises so that the members of the patient's care team can delicately address the situation. Sometimes the patient has not been told for cultural or other reasons so do not take it upon yourself to inform the patient.

## SNAPSHOT

Try to remember that when we enter a patient's life, we only see a snapshot of the patient's life and the lives of loved ones. All the more reason why we need to try our best to stay away from judging the situation and status of all involved as any given situation may be more complex than we perceive.

## LIFELONG HABITS

Every person has developed lifelong habits and these may be hard to break. If it is a negative habit, it may be difficult to change. For instance, in the case of a person with lung cancer or COPD that smokes. An issue that may arise in that situation is the discussion of whether at the end of life, it is really necessary to break this habit. In a lot of situations lifelong habits that a person has developed, are difficult to deal with for loved ones.

## NO JUDGMENT

As volunteers we are not in a position to judge and even if it is difficult, we should try to refrain from judgments. If you ever find yourself judging a patient, loved ones, and/or a situation and feel that this may interfere with your ability to provide volunteer services to this patient adequately, contact the Volunteer Coordinator.

## BOUNDARIES

On that same token; as a volunteer, you are only human and you may run into a situation that is not acceptable to you that is or feels unhealthy to you. It is very important that you protect your boundaries and if you ever encounter a situation that bothers you, contact the Volunteer Coordinator.

# Signs and Symptoms of Approaching Death

**\*\*These are just examples and may not be experienced by a patient at all.**

## INCREASED SLEEPING PATTERN

Near the end of life, a patient may sleep more and may be hard to arouse at times. This is very normal. The patient may be dying but as nature dictates, the body is still fighting the disease and that costs a lot of energy causing the patient to sleep more and/or sleep deeper.

Changes in the patient's metabolism caused by the dying process may also cause a patient to sleep more.

## WITHDRAWAL

When patients start to decline, they often withdraw from everyday things and loved ones. They may become quieter, have less interest in things that once were a great passion, and eventually, they may completely withdraw.

This can be really hard on the people surrounding a patient, as they often take it personally. Hurting feelings is not the intent of the patient – oftentimes the patient has to process a lot of thoughts and feelings surrounding their illness and their own impending death; they may worry about facing the unknown (death and dying) or about losing their independence, pain, what will become of their loved ones and more...

Often times engaging with others just takes too much energy.

## CONFUSION ABOUT TIME/PLACE/PEOPLE

The awareness of a dying patient may fluctuate. Some patients are completely lucid right up until they die, while others may get confused about time, place, and the people who are surrounding them. This is absolutely normal.

A lot of people slip into a semi-coma/coma before they die. Some people believe that the patient is “checking out the other side” so to speak then “returns”, goes back again, etc., and therefore gets confused about his or her whereabouts.

Some patients may also be completely lucid right up until they die.

## DECREASED APPETITE/THIRST

As the patient moves closer to death, the triggers for thirst and hunger will diminish and eventually even disappear. Because this trigger goes away completely, the patient is not suffering from hunger or thirst. The body is shutting down its systems one by one and is no longer able to process food and water as well as it used to.

It is important that this gets explained to the patient's loved ones as they often take this process as a personal grudge that the patient may have against them. You may hear the questions “Why won't she drink for me?” or “I made his favorite meal; what did I do wrong for him to refuse this?” A clear explanation may relieve the loved ones from feeling hurt and rejected and a patient from feeling guilty. (patients sometimes will try to keep eating because they don't want to disappoint their loved ones.)

It is highly advisable to NOT force food and/or fluids on a patient as it is very uncomfortable. Besides that, in a patient with cancer, for example, the nutrition would not necessarily be dispensed for the greater good of the patient; it more than likely would just serve as fuel for the patient's cancer.

Thirst is a sensation of the mouth so it may be nice for the patient to suck on some ice chips and/or have her mouth moistened with a swab. Small bits of ice pops or popsicles can be refreshing and help take away the lingering taste of medication or dry mouth.

## DECREASED ABILITY TO SWALLOW

The patient's ability to swallow will decrease and the risk of aspiration (choking) may be very high. This is a normal physical reaction and it is one of the reasons why patients stop eating/drinking and why you should NEVER give a patient anything to eat or drink. A caregiver or staff member may do so, but do NOT do this yourself! When the patient has a severely decreased ability to swallow, the hospice nurse may decide to swap the patient's pill medications for liquid or discontinue oral medications altogether. If you see the letters NPO in a patient's chart or on their face sheet, this means that the patient can no longer take anything by mouth.

## WEIGHT LOSS/ MUSCLE WASTING

It is very normal for a patient to lose weight rapidly and intensely when getting closer to death. The body systems slow down so the patient's appetite decreases and there is no real need for food and/or water. Certain medical conditions may cause weight loss as well. You may hear the term "muscle wasting", which means that the patient's muscles have shrunk due to decreased nutritional intake and lack of use. This usually presents most commonly in the face and neck.

# Urine output, Incontinence, and Swelling

## URINE OUTPUT

As the body continues to shut down its systems, the kidneys shut down as well. As this process progresses, the patient will show significantly less urine output and the urine will become darker as decreased fluid intake causes urine output to be more concentrated.

## INCONTINENCE

Even though the patient stops eating and drinking because they are dying, the body still produces waste. Near the time of death and most certainly after death, patients may become incontinent of urine and bowels. Keep in mind that this may be a sensitive issue for the patient and/or loved ones.

## SWELLING/EDEMA

When the patient's heart and kidney function starts to deteriorate, fluids can build up in areas such as the ankles, feet, etc. The Hospice Physician may prescribe medication to help alleviate the swelling. These medications are called diuretics. While they can definitely provide the patient some much-needed relief in the swollen areas, they also cause frequent urination and frequent trips to the restroom.

When many diseases are in their final progression stages, diuretics may no longer be effective and the patient will continue to experience swelling in their extremities. Their skin may appear red, flaky, and dry in these areas. Remember that there are contraindications to lotion and massage, so even though it may seem helpful to aid the patient by applying lotion, you should leave this task to their assigned Nurse Case Manager or CNA. If the patient complains of discomfort in this area, make sure to notify the office immediately.

## TEMPERATURE

Due to changes in the brain's thermostat, a patient may alternate between hot, cold, clammy, etc. As the heartbeat becomes weaker, the patient's blood may not be pushed through the veins and arteries as efficiently as needed. The body tries to counteract the failing circulation by pooling blood around the vital organs of the body and therefore the extremities may feel much cooler to the touch than the patient's trunk. A part of the dying process causes the patient's extremities to become cold. This happens because circulated blood is prioritized by the body to provide oxygen to the major organs, which causes significantly less blood flow to the extremities.

## CONGESTION AND "DEATH RATTLE"

As patients become weaker and/or begin to lose consciousness, they begin to lose the ability to cough up the congestion that has settled in the back of their throat. When the patient breathes, the phlegm that has collected may move up and down the windpipe and/or vibrate against the vocal chords producing a gurgling sound. This sound can get pretty loud and is often referred to as the "death rattle".

Research has shown that this is not painful for the patient and it also does not mean that they have fluid building up in their lungs. Families can be very alarmed by this sound and fear that their loved one is drowning. Suggest or offer to place an extra pillow under the patient's head, which might alleviate some of the sounds. Gently explain to the family member that the patient is not in distress and offer to call the RN Case Manager to help calm their fears.



## SKIN DISCOLORATION AND "MOTTLING"

Throughout the process of actively dying, a patient's skin color may vary greatly; you may notice skin becoming pale, yellow, grey, red, and bluish – a lot of different combinations are possible and there is not necessarily a given order in which these color changes take place.

Common places to watch for discolorations are the fingernails, toenails, and lips; they may turn a bluish-grey. This is called cyanosis and it is caused by a lack of oxygen in the patient's blood supply due to diminished blood circulation. This may be a bit harder to detect in people with a darker skin tone.

As one progresses in the dying process, a very specific discoloring of the skin may appear; a blotchy, bluish-gray pattern. You may find it first at pressure points such as on the patient's heels if they are lying on their back or on the patient's toes and at the end of the extremities. This is called "Mottling".

Mottling is an irregular or patchy discoloration of the skin caused by changes in the blood vessels near the end of life and occurs when the body restricts the range of circulation by preserving the blood for the body's major organs such as the heart and lungs. Because of the specific pattern that mottling presents, it is usually very recognizable.

## TERMINAL AGITATION OR TERMINAL RESTLESSNESS

There are patients who get really agitated when death draws near. They may become restless and/or combative. Causes of terminal restlessness can include but are not limited to:

- Medication – High or long-term use of opioids, steroids, and anti-seizure medication can cause agitated delirium.
- Pain – Uncontrolled pain can cause terminal restlessness. Patients at this stage in their illness may be unable to communicate their pain, so caregivers should speak to the BeLoved Hospice clinical team to help alleviate this.
- Fever – Fevers can be a sign of infections or sepsis.
- Metabolic disturbances – A chemical imbalance caused by vital organs beginning to shut down at the end of life.
- Decreased oxygen to the brain, brain tumors, or brain swelling
- High calcium levels
- Constipation, fecal impaction, or urinary retention
- Emotional turmoil

## COMBATIVE PATIENTS

Sometimes all of these symptoms combined cause a patient to lash out or become combative. While we encourage you to do your best to speak calmly to the patient and try to diffuse the situation, we never encourage you to stay in a situation that is dangerous or uncomfortable for you. If you are alone, providing respite care, and a patient becomes combative, immediately contact the Volunteer Coordinator so that they can find a way to relieve you and not leave the patient unattended.

## NEAR DEATH AWARENESS

When getting closer to death patients may seem to be aware of people whom "we" do not necessarily see. They may start pointing and/or looking and talking at persons who have preceded them in death, sometimes they seem to be seeing Angels, Holy figures, or different entities. Patients may be talking coherently, mumbling, or sometimes just moving their lips without producing any sound. Many times, they will start "having conversations" with loved ones who have long passed. They may begin to talk to their mother or father, or even a childhood friend. This is very normal for a patient who is actively dying.

Families are not always open to this phenomenon. They may worry that the patient is delirious because of over-medication. Feel free to explain to the family that this is not the case but tread lightly. If the family is asking questions that you are uncomfortable with or unsure of, feel free to call the office at (971) 236-1199 and have a member of the patient's clinical team called to help guide the family through this process.

## THE RALLY

A lot of times a person who is getting close to death will have a few wonderful hours or even days with new energy or lucidity, The family may be thankful and feel that the patient is making a turnaround in their prognosis. While this can happen, it is usually not the case. As patients enter into the active dying phase, they often experience a "second wind". Remind loved ones to remain hopeful and enjoy these moments for as long as they last.

# Pain Management

It is good to understand that not all who are dying are in pain.

In hospice, the goal of pain management is based on trying to stay a step ahead of the patient's pain. Some patients may experience no pain, while others may to variable degrees. Remember that a patient's pain is what the patient says it is; there is no way of telling how much pain somebody really is in. Even patients with the same diagnosis will experience pain differently.

Remember, it is ***never*** your job to assess pain. If the patient complains of being in pain, that is not managed by their current medications, while you are visiting them, contact the RN Case Manager or the Volunteer Coordinator to report what the patient is saying.

As part of the hospice admission process and part of routine nursing visits, the patient will be asked what their pain level is, usually using a scale of 1 - 10, and what the highest level of pain that they can tolerate is. This answer may change as the patient's condition progresses, but it is regularly monitored by the clinical team.

The choice of pain management may be culturally influenced; in some cultures enduring pain shows a sense of strength and/or endurance. There are also patients who are worried to become addicted to pain medications. Loved ones sometimes worry that the patient may become addicted to the pain medication as well. It is very normal for the doses of pain medication to be adjusted as the patient's disease progresses. If the patient or loved ones are worried about addiction, you may point out tactfully that there is a big difference between “drug tolerance” and “drug addiction”.

**"Drug Tolerance"** is defined as a condition that occurs when the body gets used to a medicine so that either more medicine is needed or different medicine is needed.

**"Drug Addiction"** is defined as a chronic, relapsing disorder characterized by compulsive drug seeking and use despite adverse consequences.

Offer to contact the nurse to ask for an opportunity to have this explained in detail and always report these kinds of conversations to the RN Case Manager or the Volunteer Coordinator.

It is very important that the patients stick to the scheduled intervals of administering their pain medication, as prescribed by the Hospice Physician. The doses have been carefully calculated by the Hospice Physician and the interdisciplinary team to ensure that the patient receives their next dose before the first dose wears off completely. Sometimes patients need breakthrough pain medication, which is a different medication, taken at different intervals to help control breakthrough pain or pain in between doses.

***NEVER administer any form of medication to a patient!***

## DRUG DIVERSION OR HOARDING

Sometimes, for varying reasons, patients "hoard" their pain medication. They extend the amount of time between doses or skip their doses completely in order to create a stockpile of medication. Most commonly, they do this for fear that they won't have enough medication when their pain condition gets worse and their pain increases. Sometimes, there are more sinister reasons for hoarding their medication like giving them to family, selling them, or planning to take an overdose to commit suicide. Whatever the reason, it is important to immediately report any hoarding behavior to the RN Case Manager assigned to the patient.

Another risk for hospice patients is drug diversion. The patient may have a family member at home who wants or needs pain medication and takes some of the patient's medication. Sometimes, family members steal the medication to either take themselves or sell. Drug diversion is extremely dangerous as these medications are prescribed specifically for the patient and their diagnosis. Pain medications can be lethal when they are taken by individuals other than those prescribed. If you suspect drug diversion, immediately report this behavior to the RN Case Manager and/or Social Worker assigned to the patient.

## SAFE STORAGE OF MEDICATION

Medication should always be stored in childproof containers and up, out of reach of pets and children. Many medications, not just pain medications, can be harmful or fatal to children or pets! If you see that medication is stored in a place that is easily accessible by children or pets in the home, gently encourage the patient or their caregiver to store the medication somewhere safer. Regardless of whether they are accepting of this advice or not, always report medication safety issues to the RN Case Manager or Director of Nursing.

## EMOTIONAL AND SPIRITUAL PAIN

There are many different levels and types of pain. When speaking of pain, most people only think of physical pain while other kinds, such as emotional and spiritual pain seem to be forgotten.

Regardless of what kind of pain the patient is experiencing, counseling is available through BeLoved Hospice. If a patient seems to struggle with emotional pain such as regrets and/or guilt, contact the Social worker assigned to the patient. If you feel that a patient is struggling with spiritual pain such as fear of going to hell, the afterlife, penance, etc. contact the Chaplain or Spiritual Counselor assigned to the patient.

Sometimes, the patient isn't struggling with emotional or spiritual pain, but their loved one or family member is. Remember, hospice provides emotional, and spiritual care for the patient's family as well.

When in doubt, contact your Volunteer Coordinator who can guide you to the correct team member or make contact for you.



# What Can You Do For Patients?

## PROVIDE A SENSE OF CALM

Carry yourself in a calm, humble yet confident manner and most people are likely to follow your energy. If there is too much commotion going on around the patient or when people are arguing; politely ask them to take it elsewhere.

## BE **WITH** THE PATIENT, NOT **NEAR**

Anybody can be near a person, and sit with them but being **with** someone is different.

There is a distinct difference between the two so try to truly be alongside the patient where they are in life regardless of circumstance and without judgment or expectations. Remember that this time is a gift that you are giving to the patient and their family as they make this end-of-life journey together. Be genuine, be caring, be compassionate, and be a friend.

This does not mean that you have to hover over the patient or fill the room with conversation. Allow their energy and the energy of those around them to guide how you act in the moment. Sometimes, sitting in silence is all someone needs. Sometimes they need a distraction. Sometimes they just need someone to listen without interjecting their opinions or thoughts.

## OBSERVE!

What does your patient respond to best and what would be beneficial to omit?

Some patients would like their hand held while others pull away. When you hold a patient's hand; make sure that it is not in a position that may become uncomfortable for the patient and if the patient is on oxygen make sure that you, your chair or your feet are not accidentally blocking the patient's oxygen supply (this may sound obvious but it happens as the oxygen tubing is quite long sometimes).

Pay close attention to family dynamics and report early bereavement concerns to the Social Worker, Chaplain, or Bereavement Coordinator – the sooner they know what to expect the better they can prepare to help the patient's loved ones.

## ACKNOWLEDGE

Dying is no different from many other things in life when it comes to acknowledgments. Often, when people talk to you about things that are going on in their life that may be difficult and/or challenging, they don't want an answer or a solution from you; but rather an acknowledgment. Therefore, a heartfelt “yes, I can see that that would pose a challenge” often goes a long way...

## SING OR PLAY MUSIC FOR THE PATIENT

Some patients love it when you softly sing for them – there are such sweet songs out there... Sometimes music anchors them back to their past, a time that they remember fondly. We have often seen non-communicative patients tap their foot or leg and sing along with songs that they fondly remember. If you are shy or embarrassed about singing, ask the patient or their loved ones if you can bring music and a player to softly play for them.

## READ TO THE PATIENT

Some patients like to be read to and sometimes loved ones may ask you to do so. It is important that you ask what exactly one would like for you to read for the following reasons: you would want to read something to the patient that he or she may enjoy and obviously something that would not be offensive to the patient.

On that same token: you should only read something to a patient that is within your own boundaries i.e. don't read anything that would pose offense to you.

## BRUSH THE PATIENT'S HAIR

If the patient would appreciate that you do so, it may be soothing to brush their hair. It also maintains one's dignity and showing that you care about that is greatly appreciated by patients as well as loved ones. Be very gentle and only use a patient's own brush; never one you brought yourself.

## MOISTEN THE PATIENT'S LIPS WITH A SWAB

Because some patients do not drink any fluids or wet their lips, they may become cracked and dry. If permitted by the plan of care, the patient, and loved ones, you may use one of the swabs provided by BeLoved Hospice to moisten the patient's lips to make them feel better.

Volunteers are not allowed to provide care within the mouth, so only moisten their lips or apply a bit of approved lip balm to them. ***Never use Vaseline on a patient wearing oxygen.***

## COMMUNICATING WITH THE NON-VERBAL PATIENT

Just because a patient is non-verbal does not mean that they don't enjoy interacting with others. Many non-verbal patients will smile and nod as you tell them stories or ask them about their day. Sometimes they will respond with yes or no answers and sometimes they will gesture to indicate what they are talking about. It is best to have some background information on a non-verbal patient before you start working with them so that you will know the best way to communicate.

## TALKING TO AN UNRESPONSIVE PATIENT

The fact that a patient is unresponsive is irrelevant. It is important to treat unresponsive patients exactly like responsive people.

Volunteers are not qualified to assess what the patient's capabilities are or are not. But as a volunteer, you are aware of the fact that no matter a patient's declining status, research has shown that hearing is the last of the senses to be lost. Therefore it is very important to communicate verbally with a patient even if they are unresponsive.

Share this information with the patient's loved ones, they overall truly appreciate that you treat their loved one with respect, and a lot of times, they are confused and/or embarrassed about what is the right thing to do. By setting this example, you can possibly help them with that and make them more comfortable about talking to an unresponsive loved one.

## ACKNOWLEDGE AND REASSURE

Reassure loved ones that it is okay to lament and show their sadness about losing the patient soon and allow them to cry, talk, or whatever else their needs may be.

Remind caregivers to take care of themselves by taking a nap, taking a walk with a friend, or just sitting and enjoying a cup of coffee while they read a book. Remind them that by doing so they are not being selfish but that they are replenishing themselves so that they can continue to be the best caregiver possible.

A gentle reaffirmation of all that they have already been doing for the patient, how well they are doing, and the fact that you are there to watch over the patient and will come to get them if something were to happen may help loved ones to take an often much-needed break.

## ALLOW FOR SILENCE

There are people for whom silence evokes feelings of awkwardness but it can absolutely serve a purpose. It may give people some time to contemplate or close their eyes for a bit. Sitting in silence with patients and/or loved ones can be just as powerful as any other support offered.

Leave a note for loved ones if you happen to leave before they arrive.

# When Children Are Present

When children are involved the atmosphere at the residence may be completely different.

Patients like to have children around because children are very matter-of-fact and practical and also because they can lighten the atmosphere with their silly antics and laughter.

Children are naturally curious so you may get questions from them. It is important to look to an adult caregiver or the parent to understand how to answer questions and how much information to give the child. Children are usually satisfied with a brief but honest answer or a redirection.

Children may display anticipatory anxiety. For instance: if a child's parent or sibling is terminally ill, the child may be afraid that when this person dies a parent or grandparent will die as well because of the shock of this significant loss.

Children are sometimes angry at the patient for being sick, getting all the attention, leaving them, and a whole lot of other reasons. This, in turn, can make them feel guilty for having these feelings. It is important to let them know that these are very normal feelings to have and that everyone has those at times. Depending on the age of the child, it is sometimes hard for children to express these feelings and communicate their fears. Therefore, children may act out in a rude or mean manner, with tantrums, crying, yelling, etc. Never assume that the child is spoiled or misbehaved because this behavior is likely just a reaction to the stress of their environment.

Sometimes you can help the patient and/or the caregiver(s) by being a distraction for the child, even if it is just for a brief amount of time. Get on their level and play with them, ask them about their toys, color or draw with them, watch tv with them, sing with them, or just listen to them. BeLoved Hospice maintains a small supply of toys, coloring books, and books that you may bring if you know children will be in the home during your visit.

# Reminders

The following statements/actions may cause people to shut down:

- “Don't worry, it'll be okay, don't be ridiculous/ that is ridiculous, whatever, forget about them, who cares.”
- Do not argue or add fuel to people's anger:
- “Oh no! How terrible! How could they do that!”
- Don't make assumptions: “I know how you feel, been there-done that”
- Dismissals: “you don't mean that, don't be silly, you know better than that, don't say that.” Clichés: “she's in a better place, at least he won't have any more pain, at least you had some time with her, luckily you still have other children.”
- Negation: “should, shouldn't, can't and may not” may take away a person's sense of control. Body language: don't cross your arms, don't roll your eyes, don't daydream when you are supposed to be engaged in a conversation, don't allow your phone to be a distraction, don't make yourself a distraction, and try not to slouch.

Reminders of platitudes NOT to be used:

- That happened a long time ago.
- I'm sure they have forgiven you/understand.
- You were just following orders.
- Just forget about them.
- You were just a child.
- She is in a better place now.
- It was his time.
- It was God's will.
- You can always have another child.
- I know what you are feeling.
- At least you didn't get to know this baby first and got attached to it.
- Whatever.
- Who needs them?

Reminders of more diplomatic statements:

- I know about grief, but I don't know about your grief.
- Sounds like you have a lot of love in your heart for...
- I wish I had something profound to tell you, but I don't.
- It seems like things are really mounting up for you.
- I can imagine that would feel overwhelming/frustrating/difficult/scary.
- I am not sure how I can be of help, but I am willing to listen.
- Is there anything that I can do to make things easier for you?
- May I make a suggestion?
- One moment, please.
- How can I help?
- Excuse me.

# Things To Avoid

**Never give an estimate of how long the patient may still be alive.** Dying is truly a very personal journey and a lot of times pretty unpredictable. Volunteers are not qualified to make an assessment of when a patient will die.

**No proselytizing in any way.** Even if you mean well; it is important to meet a patient and loved ones at the place in life where they are and accept that that is the appropriate place for them to be just as it is perfectly fine for you to be at the place in life where you are. If a patient or loved one initiates the topic of religion or spirituality, make sure that the conversation remains about that and the patient – If you are asked about your own views be brief and if your views don't align, stay gracious and gentle – NO arguing!

**Do not argue with a patient about time, place, or circumstance.** Sometimes patients get confused. If it is not upsetting to them or it does not create disturbing behavior – let them be, it is their reality. Sometimes it really benefits a patient if you go along with their story. If a patient is agitated, you can try to explain where they are but only in a very gentle, loving way – imagine how scary it must be to feel like things are completely out of place/time...

**Do not take it upon yourself to correct denial.** Sometimes the patient and/or loved ones may be in denial about the fact that the patient is truly dying even when a patient has entered the process of actively dying. Denial is often in place for a reason – it is a biological defense mechanism. If you have grave concerns for a person who is in denial, contact the Volunteer Coordinator as soon as possible.

**Do not generalize.** People from similar beliefs and backgrounds and ethnicities or cultures are not automatically all the same and are not automatically all on the same page. One also cannot compare grief.

**Do not judge.** It is best to try to be in the moment with a patient and/or loved ones, at the place where they are – not where one should be in society's eyes. If you find yourself judging and something is bothering you, call the Volunteer Coordinator so you can discuss these feelings. Volunteering has to be comfortable for you as well. Do not use clichés. You enter people's lives in a very stressful time and they may react to certain things more strongly than they would on average. Even if meant well: clichés can truly hurt someone's feelings.

**NEVER move or reposition a patient.** Never reposition or move a patient; this is not within the scope of a volunteer. You can do some serious damage to the patient or yourself. Always alert facility staff members, the patient's loved ones, or someone from the hospice clinical team if the patient needs moving or repositioning. Do not wear too much cologne/perfume. Make sure your cologne/perfume isn't too strong, especially when being around patients and/or loved ones who already have trouble breathing comfortably.

**Never promise a patient and/or loved ones total confidentiality.** It is just not a good idea. In many situations, you are obligated (sometimes by law!) to share certain information with your Volunteer Coordinator or other team members.

**Avoid depersonalization.** Try to remember that you are dealing with a human being. A lot of times people act impersonal around patients (especially those who are unresponsive) and just go about their business when being in the patient's room, not acknowledging the patient.

Make sure that when saying something about a patient, to do so in terms of "Bill" or "your mother" rather than "him", "her", or "the patient".

**Do not take or make personal phone calls and keep your phone on vibrate or silent.** It is highly inappropriate to make personal calls while with a patient. If you truly have to answer a call, excuse yourself and step out of the room for a while. A loud ring from a cell phone can be disturbing to the patient and loved ones so put your phone on vibrate or silent.

**Do not accept gifts.** It is unethical and against the policies of BeLoved Hospice to accept gifts from patients and/or loved ones unless it is something minor like a "thank you" note or a meal. If they insist point out that it was a privilege for you to be allowed to lend them support and suggest that they make a donation to a charity or the BeLoved Foundation instead. If they absolutely refuse to allow you to leave without taking a gift, immediately bring the item to the Volunteer Coordinator who will confer with the Governing Board about how to handle this gift.

**Stick to the plan of care!** Do not provide care that is not specifically requested for a patient; it can land the hospice and you into a lot of trouble!

## Respect the patient's right to privacy and always follow HIPAA

We spoke about HIPAA earlier in this manual. In addition, be sensitive to a patient's privacy – step out of a patient's room whenever personal care is provided.

**Do NOT visit if you are sick!** You don't want to infect the patient and/or loved ones with anything. Patients are in a highly immunocompromised state and their loved ones often are exhausted from the journey that the patient and they have been on. Adding an illness is just cruel.



# When The Patient Dies

While volunteering for the patient, you may have gotten close to their family or friends. This is natural. However, when a patient dies, your assignment and thus your relationship with the patient's family and friends come to an end.

You may want to express your condolences and that is acceptable. BeLoved Hospice often circulates a sympathy card for the team members to sign. Make sure to tell the Volunteer Coordinator that you would like to include your message in that card. It is also acceptable to send a card of your own, but allow the Bereavement Team of BeLoved Hospice to be the one to address and send it.

Families often invite the hospice team to attend any funeral or memorial service. BeLoved Hospice would be honored to have you attend the memorial services as one of the members of the hospice team. Make sure to dress appropriately and remain professional as you are still representing the hospice at this time.

BeLoved Hospice has a wonderful grief and bereavement program for the family and loved ones left behind after the patient passes. If you wish, you may volunteer to work on the Bereavement Team and send out letters and mailings to those who have lost their loved ones.

## THE IMPORTANCE OF SELF-CARE FOR VOLUNTEERS

It is often said that those who work in hospice have been blessed with a gift. A gift to help those who are taking their end-of-life journey. While this position can be extremely rewarding, it is not without stress and heartache. It is natural to become attached to patients and feel like you have lost a friend yourself. It is natural to take on the pain and grief of the patient's family and loved ones.

It is important to provide self-care to yourself, just as you offer that advice to caregivers. Volunteers often experience burnout from the emotional exhaustion of helping a patient as their life comes to a close. Remember to maintain hobbies and activities that bring you joy. Focus on your own health and bask in the love of those who surround you. Take your pets for a walk, read a good book, take a long bath, cook a new recipe, or take a vacation. All of these things, and more, are vital to self-preservation while working in this industry.

If you ever feel that you are taking on too much or that the stress of an assignment has gotten to be too heavy, immediately inform your Volunteer Coordinator so that they can adjust your hours or temporarily remove you from your assignments. BeLoved Hospice is here to support you as you support our patients!

*Thank you*

***We at Beloved Hospice thank you for all that you do and we are excited to share in this journey with you!***



We at BeLoved Hospice are honored  
that you are a part of our care team.



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