MISSION HOSPICE
& HOME CARE
it's about life

Direct Care Volunteer
Training Manual

PENINSULA OFFICE 66 Bovet Road, Suite 100, San Mateo, CA 94402
SOUTH BAY OFFICE 1688 Willow Street, Suite A-2, San Jose, CA 95125
650.554.1000 | Nurse available 24 hours/day
www.MissionHospice.org

Direct Care Volunteer Training Manual
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February 2023

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***"We thought hospice meant she was going to die.
Now, I realize it means she's living with more
people caring for her."***
– Kay, patient family member

Welcome!

We're so happy to have you as part of the Mission Hospice family. Please feel free to contact me at any time with questions, concerns, or ideas.

Craig Schroeder, Director of Volunteer Services

Office: 650.532.2323
Cell: 650.773.4641
cschroeder@MissionHospice.org

Mission Hospice offices

Peninsula office

66 Bovet Road, Suite 100, San Mateo, CA 94402
650.554.1000 (nurse on call 24/hours a day)

South Bay office

1688 Willow Street, Suite A-2, San Jose, CA 95125
408.554.2434 (nurse on call 24/hours a day)

Volunteer web portal

Log in to our Volunteer Resources Portal to find all kinds of information for our Direct Care Volunteers, including forms, competency training materials, volunteer training videos, and continuing education.

Volunteer portal:
www.MissionHospice.org/volunteer/volunteer-resources

Login: **mhvolunteer** / password: **compassion**

Competency training and quizzes (must NOT be logged in for these):
www.missionhospice.org/volunteer/competency-training-materials/

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Job Description: Direct Care Volunteer

Background

Mission Hospice provides professional, compassionate end-of-life care, bereavement support, and education for the San Francisco Peninsula and South Bay community. Working as a team, specially trained nurses, doctors, Social Workers, Spiritual Counselors, and volunteers address the physical, emotional, and spiritual needs of patients and families.

We tailor a care plan especially for each patient, with sensitivities to cultural, spiritual, and personal preferences. Our continuum of care allows patients (and, importantly, their families) to remain with the same support team throughout their journey.

We are dedicated to helping people throughout the challenges of a terminal diagnosis. Donations from the community support our exceptional care and educational programs and help us serve people regardless of their medical coverage or ability to pay.

Volunteer role

Our Direct Care Volunteers provide important emotional and social support to our patients and their families. Whether it's reading a book, running an errand, taking a short walk, or listening to stories about grandchildren and days of old, your time will make a very special difference in the lives of your patients and their families.

As a Direct Care Volunteer, you will

- Provide companionship
- Provide a calm, non-anxious presence
- Listen impartially and without judgment
- Help the patient with storytelling
- Identify activities that define quality of life
- Strengthen the patient's sense of being in control
- Share observations with staff regarding the patient's care plan
- Help the family by listening to them to understand their experience of losing a loved one
- Report the patient's pain level
- Report possible abuse and/or falls to the Director of Volunteer Services
- Help feed the patient
- Join the patient on outings

- Provide transportation to the patient
- Run errands
- Help with other tasks as assigned or needed

Qualifications

No experience is required. Volunteers must be emotionally and physically able to serve and be available to volunteer 4 hours/week (as needed). Your volunteer hours will be flexible, depending on the needs of your patient's family and your own schedule.

We ask that volunteers commit to a minimum of 12 months of service after completing training.

Direct Care Volunteers report to, and are annually evaluated by, the Director of Volunteer Services.

Our experienced volunteers offer mentoring and other support. We will never ask you to do anything that takes you out of your physical or emotional comfort zone.

Application process

- Complete a volunteer application.
- Have a confidential interview.
- Upon acceptance into the program, prospective volunteers must:
    - Provide required documentation (including Driver's License and proof of auto insurance)
    - Consent to criminal background check and TB screening
    - Provide proof of Covid vaccination and at least one booster shot.
    - Complete 26 hours of training

Training, continuing education, and evaluation

Mission Hospice provides volunteers with 26 hours of required training to prepare for visiting patients. Training is four Saturdays from 9:30 – 3, and two Thursdays from 6 – 8pm.

In addition, Continuing Education / Support Meetings are provided on the third Thursdays of each month. These are recommended but not required unless otherwise announced.

February 2023

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Copy 1:
Mission Hospice

Disclosure to Volunteer Applicant Regarding Procurement of a Consumer Report and/or Investigative Consumer Report and Authorization to Obtain Report

January 2018

In connection with your volunteer application, we may procure a consumer report and/or investigative consumer report (jointly referred to as Consumer Report), on you as part of the process of considering your candidacy as a volunteer and/or at any time during your time as a volunteer with us. When we request a Consumer Report, it will be obtained from Sterling Volunteers (855)326-1860, Fort Collins, CO, sterlingvolunteers.com.

The Consumer Report may contain information about your character, general reputation, personal characteristics and mode of living. The report may include, but is not limited to, criminal and other public records and history; public court records; motor vehicle and driving records; educational and employment history, including professional disciplinary actions; drug/alcohol test results; and Social Security verification and address history, subject to any limitations imposed by applicable federal and state law. This information may be obtained from public record and private sources, including government agencies and judicial records, former employers and educational institutions, and other sources.

[ ] Check this box if you would like to receive a free copy of any Consumer Report obtained by us.

The Federal Fair Credit Reporting Act (FCRA) and the California Investigative Consumer Reporting Agencies Act (ICRAA) give you specific rights in dealing with consumer reporting agencies. Attached are summaries of your rights under these laws.

Authorization

By your signature below, you authorize us to obtain a consumer report and/or an investigative consumer report for volunteer purposes as part of our pre-volunteer background investigation, and/or at any time during your time as a volunteer.

By signing below, you also authorize Mission Hospice & Home Care to obtain a driver's license report on an annual basis if you are serving as a Mission Hospice & Home Care volunteer.

Volunteer Applicant's Full Name: ______________________________

Address: ______________________________

City/State/Zip: ______________________________

Social Security Number: ______________________ Date of Birth: ______________

Driver's License Number: ______________________ State of License: ______________

Signature: ______________________ Date: ______________

Attached: Summary of Your Rights Under the FCRA and ICRAA

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**Copy 2:
Volunteer**

Disclosure to Volunteer Applicant Regarding Procurement of a Consumer Report and/or Investigative Consumer Report and Authorization to Obtain Report

January 2018

In connection with your volunteer application, we may procure a consumer report and/or investigative consumer report (jointly referred to as Consumer Report), on you as part of the process of considering your candidacy as a volunteer and/or at any time during your time as a volunteer with us. When we request a Consumer Report, it will be obtained from Sterling Volunteers (855)326-1860, Fort Collins, CO, sterlingvolunteers.com.

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Volunteer Applicant's Full Name: ____________________

Address: ____________________

City/State/Zip: ____________________

Social Security Number: ____________________ Date of Birth: ____________

Driver's License Number: ____________________ State of License: ____________

Signature: ____________________ Date: ____________

Attached: Summary of Your Rights Under the FCRA and ICRAA

Para informacion en espanol, visite www.ftc.gov/credit o escribe a la FTC Consumer Response Center, Room 130-A 600 Pennsylvania Ave. N.W., Washington, D.C. 20580.

A Summary of Your Rights Under the Fair Credit Reporting Act

The federal Fair Credit Reporting Act (FCRA) promotes the accuracy, fairness, and privacy of information in the files of consumer reporting agencies. There are many types of consumer reporting agencies, including credit bureaus and specialty agencies (such as agencies that sell information about check writing histories, medical records, and rental history records). Here is a summary of your major rights under the FCRA. **For more information, including information about additional rights, go to www.ftc.gov/credit or write to: Consumer Response Center, Room 130-A, Federal Trade Commission, 600 Pennsylvania Ave. N.W., Washington, D.C. 20580.**

- **You must be told if information in your file has been used against you.** Anyone who uses a credit report or another type of consumer report to deny your application for credit, insurance, or employment – or to take another adverse action against you – must tell you, and must give you the name, address, and phone number of the agency that provided the information.
- **You have the right to know what is in your file.** You may request and obtain all the information about you in the files of a consumer reporting agency (your “file disclosure”). You will be required to provide proper identification, which may include your Social Security number. In many cases, the disclosure will be free. You are entitled to a free file disclosure if:
    - a person has taken adverse action against you because of information in your credit report;
    - you are the victim of identify theft and place a fraud alert in your file;
    - your file contains inaccurate information as a result of fraud;
    - you are on public assistance;
    - you are unemployed but expect to apply for employment within 60 days.

  In addition, by September 2005 all consumers will be entitled to one free disclosure every 12 months upon request from each nationwide credit bureau and from nationwide specialty consumer reporting agencies. See www.ftc.gov/credit for additional information.
- **You have the right to ask for a credit score.** Credit scores are numerical summaries of your credit-worthiness based on information from credit bureaus. You may request a credit score from consumer reporting agencies that create scores or distribute scores used in residential real property loans, but you will have to pay for it. In some mortgage transactions, you will receive credit score information for free from the mortgage lender.
- **You have the right to dispute incomplete or inaccurate information.** If you identify information in your file that is incomplete or inaccurate, and report it to the consumer reporting agency, the agency must investigate unless your dispute is frivolous. See www.ftc.gov/credit for an explanation of dispute procedures.
- **Consumer reporting agencies must correct or delete inaccurate, incomplete, or unverifiable information.** Inaccurate, incomplete or unverifiable information must be removed or corrected, usually within 30 days. However, a consumer reporting agency may continue to report information it has verified as accurate.

A Summary of Your Rights
Under the California Investigative Consumer Reporting Agencies Act

The California Investigative Consumer Reporting Agencies Act (ICRA) provides you rights to review your files that are maintained by Consumer Reporting Agencies (CRAs). Following is a summary of your rights regarding these files:

- CRAs must provide requested files to you during normal business hours after reasonable notice by you.

- CRAs must make files available for your visual inspection either in person, or by certified mail upon receipt of a written request by you.

- CRAs must provide a summary of file information to you by telephone upon receipt of a written request by you. You will be responsible for any telephone charges relating to the call.

- You must provide CRAs proper identification before they release any files or information to you. Identification may be based on information from your driver's license, social security card, military identification card, or credit cards.

- You may obtain a copy of your file for a fee no more than the CRAs' actual copying costs.

- CRAs must provide you trained personnel to explain file information to you.

- CRAs must provide you written explanations of any coded information contained in your file.

- You will be permitted to be accompanied by one other person of your choosing when you inspect your file. CRAs may require you to give a written statement granting them permission to discuss your file in such person's presence.

Jan 2018

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Last Approved	03/2020	Area	Compliance
Effective	03/2020		
Last Revised	03/2020		
Next Review	03/2023		

Confidentiality of Information

PURPOSE

To ensure that the patient's right to privacy is protected by following the policies and procedures regarding confidentiality and use and disclosure of protected health information (PHI), as necessary.

POLICY

Mission Hospice and Home Care and its personnel will maintain as confidential all patient-protected health information. Protected health information will be used and disclosed in accordance with the hospice organization's policies and procedures. (See "Uses and Disclosures of PHI" Policy No. 5-017.)

PROCEDURE

1. During the orientation process, this Confidentiality Policy will be reviewed by hospice personnel.
2. All hospice personnel will be required to sign a Confidentiality Agreement at the time of hire.
3. Hospice personnel will have access to the minimum necessary protected health information of patients needed to carry out their duties.
4. Use and disclosure of protected health information will be carried out according to accepted policies and procedures. (See "Uses and Disclosures of PHI" Policy No 5-017.)
5. Patients will not be discussed by clinical or nonclinical personnel outside of the context of professional conversation regarding those patients' conditions and care.
6. Comments and conversations relating to patients made by physicians, nurses, or other hospice personnel will be made in confidential settings. It will be standard, acceptable, and necessary practice to share information with other members of the care team. The decision to share information can be aided by considering the intent of the discussion.

7. An agreement and consent for services form will be signed by the patient upon admission.
8. Valid authorizations for use and disclosure of information will be obtained, as required. (See "Authorizations for Use or Disclosure of PHI" Policy No. 5-018.)
9. Copies of clinical records, or excerpts of same, cannot be removed from hospice except by subpoena, where statutory law requires it, or on written authorization of hospice. This confidential information will only be mailed in an envelope designated "confidential."
10. Patients will be allowed access to their protected health information. (See "Patient Requests for Access to PHI" Policy No 5-022.)
11. The organization respects the safety and security of patients and their property.
12. All clinical records will be kept in a locked cabinet/room when not being utilized. The Clinical Supervisor/Nursing Supervisor or designee will be responsible for the key. No unauthorized individual will be allowed access to clinical records.
13. The following patient information will be secured after business hours:
    A. Clinical records
    B. Field clinical records
    C. Patient intake information
    D. Minutes of patient care meetings
    E. Performance improvement data
    F. Clinical notes prior to filing in clinical record
    G. Signed physician (or other authorized licensed independent practitioner) orders
14. Information contained in performance improvement reports will not contain individual patient or personnel information.
15. Mission Hospice and Home Care will apply appropriate sanctions against any hospice personnel who fail to comply with its privacy policies and procedures.

Approval Signatures

Step Description	Approver	Date

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Confidentiality of Information Agreement

Name____

Email ____

Position
☐ Employee
☐ Contractor/vendor
☐ Volunteer
☐ Intern

☐ I have reviewed the "Confidentiality of Information" policy and understand that I have a legal and ethical responsibility to maintain the confidentiality, privacy, and security of information pertaining to any patient or family serviced by Mission Hospice & Home Care.

☐ I agree to comply with this policy in all of my daily work activities.

☐ I agree to immediately report any privacy or confidentiality violations to my supervisor or to the Chief Compliance Officer.

Signature____ **Date** _________________________

Patient privacy: HIPAA basics

The **Health Insurance Portability and Accountability Act** of 1996 (**HIPAA**) is a series of national standards that health care organizations must have in place to safeguard the privacy and security of patients' health data, in all forms. It defines and covers **protected health information (PHI)**, which includes any demographic individually identifiable information that can be used to identify a patient, such as name, address, phone number, and facial photos.

Every health care provider, regardless of size, who electronically transmits any health information is considered to be a **covered entity (CE)** and must comply with HIPAA policies.

HIPAA has two main parts. ⍰⍰⍰ **HIPAA Privacy Rule** sets national standards for the privacy, integrity, and availability of PHI. The rule outlines safeguards that must be in place to ensure that PHI is kept private. The Rule also establishes guidelines for patients' rights to access their medical records, in addition to uses, disclosures, and authorizations that CEs must have in place. The Privacy Rule applies to all forms of PHI – electronic, written, or oral.

The **HIPAA Security Rule** sets national standards for maintaining the security of PHI through a series of technical, physical, and administrative safeguards.

HIPAA protects all information about patient care, including:

- All information in a patient's medical record
- Conversations the health care provider has about the patient's care or treatment
- Information about the patient in the insurer's and provider's computer systems
- Billing information and most other patient information kept by covered entities

What is the responsibility of the covered entity?

- The covered entity must have safeguards to protect patients' PHI.
- The covered entity must reasonably limit uses and disclosures.
- The covered entity must ensure that their contractors appropriately safeguard PHI.
- The covered entity must have procedures in place to limit who can view and access PHI.
- The covered entity must implement training programs for employees, volunteers, and interns about protecting PHI.

Who can look at or receive a patient's PHI?

Health information is protected in a way that does not interfere with patient health care.
It can be used or shared:

- For patient treatment and care coordination
- To pay health care providers for patient health care and to help run CE businesses
- With relatives, friends, or others patient identifies who are involved with patient's health care or health care bills, unless the patient objects
- To make sure health care providers give quality care
- To make required reports to the police (for example, if abuse is suspected)

Unless specifically allowed by HIPAA, Private Health Information (PHI) cannot be used or shared without the patient's written permission. Without patient authorization, covered entities generally cannot:

- Give PHI to the patient's employer
- Use or share PHI for marketing or advertising purposes
- Share private notes about patient's health care

What rights do patients have over their PHI?

Health insurers and providers who are covered entities must comply with a patient's right to:

- Ask to see and get a copy of their health records
- Have corrections made to their health information
- Receive a notice describing how their PHI may be used and shared
- Decide whether to give permission to share PHI for certain purposes, such as marketing
- Get a report on when and why their PHI was shared for certain purposes

If a patient believes their rights are being denied or their PHI isn't protected, they have the right to file complaints with the provider or with the federal government.

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Health Insurance Portability and Accountability Act (HIPAA) Confidentiality Agreement

Name____

Title ____

Email ____

Position
☐ Employee
☐ Contractor/vendor
☐ Volunteer
☐ Intern

☐ I understand that I have a legal and ethical responsibility to comply with all requirements of the Health Insurance Portability and Accountability Act (HIPAA).

☐ I will maintain the confidentiality, privacy, and security of Mission Hospice & Home Care patients and families.

☐ I also agree not to disclose any confidential information about the organization.

Signature______________________________________ **Date** __________________

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Auto Insurance Acknowledgement

Mission Hospice & Home Care requires volunteers who drive as part of their work with the agency to maintain auto insurance that meets the minimum requirements of the State of California. Mission Hospice & Home Care does not provide insurance.

By signing this form, I acknowledge this responsibility, declare that I will maintain the auto insurance policy listed below, and that I will notify Mission Hospice if my insurance provider changes.

Volunteer name: ____

Auto insurance provider: ______________________________________

Policy number: ____

Signature:____

Date: ______________________

Conflicts of Interest

Employees (contract and direct) and volunteers have a duty of loyalty to Mission Hospice & Home Care and should always act in the best interest of Mission Hospice & Home Care. Moreover, employees and volunteers are expected to use good judgment, to adhere to high ethical standards, and to avoid situations that create an actual or potential conflict between their personal interests and the legitimate business interests of Mission Hospice & Home Care.

A conflict of interest exists when the employee's or volunteer's loyalties or actions are divided between Mission Hospice & Home Care's interests and those of another, such as a competitor, supplier, contractor or patient. Both the fact and the appearance of a conflict of interest should be avoided. Employees and volunteers who are unsure as to whether a certain transaction, activity, or relationship constitutes a conflict of interest should discuss it with their immediate supervisor or the Director of Compliance & Education for clarification. Any exceptions to this policy must be approved in writing by the Chief Executive Officer.

While it is not feasible to describe all possible conflicts of interest that could develop, some of the more common conflicts that employees should avoid include the following:

1. Involvement in another hospice program such as in an owning, managing, operating, or consulting capacity.

2. Employment by or volunteering with a hospice in Mission Hospice & Home Care's service area. Exceptions may be made for nurses, social workers, volunteers and chaplains with prior written approval by their immediate supervisor or director <u>and</u> compliance.

3. Having a direct or indirect ownership or financial interest in any entity that services hospice patients such as:

    - Durable medical equipment
    - Medical supplies
    - Laboratory
    - Pharmacy
    - Any other business association that services hospice patients with which the employee or volunteer has a personal or financial involvement.

4. Making business referrals to patients and their family members that involve personal or business associates such as:

    - Attorneys
    - Private duty or hired caregivers
    - Funeral homes or mortuaries
    - Any other business association with which the employee has a personal or financial involvement.

5. Performing work or rendering services for any contractor, association of contractors, a current or previous patient or other organizations with which Mission Hospice & Home Care does, has done, business or which seek to do business with Mission Hospice & Home Care. This includes

accepting current or former agency patients or their family members as customers/clients of any kind for an employee's own business (e.g., private duty, counseling/therapy),

6. Receiving any monies, gifts or other compensation for referring a business or individual to a hospice patient or family member for the provision of services.

7. Using Mission Hospice & Home Care property or labor for personal use.

8. Using Mission Hospice & Home Care's proprietary or confidential information for personal gain or to the detriment of Mission Hospice & Home Care.

9. Developing a personal relationship with a subordinate employee of Mission Hospice & Home Care or with an employee of a competitor, supplier, or patient that might interfere with the exercise of impartial judgment in decisions affecting Mission Hospice & Home Care, any employee of Mission Hospice & Home Care or any patient.

Any employee or volunteer who becomes aware of a potential or actual conflict of interest must promptly disclose it to his or her immediate supervisor or director, and compliance.

Failure to adhere to this policy including failure to disclose any conflicts or to seek an exception, may result in disciplinary action, up to and including termination of employment.

Printed Name____ Date_________________

Signature ____

☐ Staff member Job Title ____

☐ Volunteer

1• About Mission Hospice

"We thought hospice meant that she was going to die.
Now I realize it just means she's living
with more people caring for her."
– Kay

The history of the hospice concept

The word "hospice" was used during the Middle Ages to refer to a lodging place where weary and sick travelers could stop and refresh themselves. The term was first applied to specialized care for dying patients in 1967 when Dr. Cicely Saunders established St. Christopher's Hospice in a residential suburb of London.

Inspired by Dr. Saunders' work, a group of people from Yale University, New Haven hospitals and the New Haven community, in 1974 began to develop the first hospice program in the United States – Connecticut Hospice, Inc. Marin's Hospice (now Hospice By the Bay) came into being late in November of 1975 when a small group of individuals made the decision to offer their professional services free of charge to dying members of the community and their families.

About hospice care

Considered to be the model for quality, compassionate care for people facing an end-of-life illness or injury, hospice care involves a team-oriented, holistic approach. Expert medical care, pain management, and emotional and spiritual support are expressly tailored to the patient's needs and wishes. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow this to occur.

Patients with terminal diagnoses of six months or less and who wish to maintain quality of life are ready for hospice care. The patient, with the consent of the primary care physician, chooses hospice. Our professional staff helps each patient and family find the best place for care, whether that is in a private home, nursing home or other facility, or in our hospice house.

Entering hospice care is not giving up – it is an opportunity for patients to truly live the last months of their lives. By addressing the possibility of hospice soon after a terminal diagnosis, the patient benefits from the physical, emotional, and spiritual care needed to ease his or her transition.

San Mateo County's first hospice program

In the late 1970s, our visionary founders Helen Lagen and Marguerite "Mac" Nash saw the need for compassionate end-of-life care in San Mateo County. The pair were drawn to hospice service from different directions. Nash, known as "Mac" to her friends, was a cancer patient. In 1977, doctors told her she had two months to live. In fact, she lived for another two years, long enough to meet Lagen who had just suffered through the death of a close friend. In August of 1978, Nash and Lagen, not acquainted with one another, began discussing with friends the possibility of developing a hospice program in San Mateo County.

With the help of community members Dr. Pierre Salmon, Evelyn Grant, Edith Morris, and Helen Campbell, they incorporated Mission Hospice as a community-based, independent nonprofit organization – and the county's first hospice program – in March 1979.

Their vision, dedication, and commitment to community created an ongoing tradition of compassionate care that continues to this day at Mission Hospice.

Mission Hospice & Home Care

Today, Mission Hospice is the leading provider of end-of-life services in the San Francisco Peninsula and South Bay. Since our founding in 1979, we have provided thousands of patients and their families with physical, emotional, and spiritual support throughout the journey from a life-threatening diagnosis through death and bereavement.

We believe that everyone deserves care that is aligned with their beliefs, wishes, and values. Our staff and volunteers represent and appreciate the diversity of our community, and we are committed to providing compassionate and personalized care to all patients and families, regardless of their race, age, religion, ability, marital or financial status, sexual orientation, or gender identity.

Our hospice house in Redwood City, **Mission House,** offers professional, 24-hour hospice care and family support in a peaceful, homelike setting. Mission House is designed for patients at the end of life who need intensive, round-the-clock symptom management that cannot be provided at home. The house also offers a safety net for patients whose caregivers need a few days of respite. Patients typically stay in the hospice house a few days to a few weeks.

Both Medicare and Medicaid, along with most private insurance plans, pay for hospice care. Mission Hospice is a Medicare-certified agency. Recognizing our commitment to providing the very best care, The Joint Commission awarded our agency the Gold Seal of Approval® for Home Care Accreditation, as well as Community-Based Palliative Care Certification.

Mission Statement

Mission Hospice honors and supports people's wishes for the last phase of life by providing our community with exceptional end-of-life care and education.

Our care – It's about life!

Mission Hospice helps patients with serious illness live life to the fullest. As a nonprofit organization, we put patients over profits, offering personalized, compassionate care. Working as a team, our specially trained nurses, doctors, social workers, spiritual counselors, and volunteers help patients and families throughout the stages of a life-limiting illness, working to address physical, emotional, and spiritual needs to give patients and their loved ones the opportunity to cherish their time together.

Our programs together provide a **Continuum of Care** designed to serve patients – and their families – at every stage of a life-limiting illness, from Community Education about advance care planning, to Bereavement Support services for those who are grieving a loss.

Hospice provides compassionate comfort care – medical care, pain management, emotional, and spiritual support – to patients with a terminal diagnosis estimated to be six months or less. Entering hospice care is a personal decision, and one that is always the patient's to make or change.

Palliative Care provides an extra level of physical, emotional, and spiritual support to improve quality of life for people with serious, life-limiting illness who are not ready for hospice. Our team makes home visits for pain and symptom management, spiritual and emotional support, education, and referral to community resources.

Transitions helps patients and families adapt to the changes that accompany living with a serious illness – changes that can be difficult and confusing. Transitions offers supportive services to patients with life-limiting illness who are not yet physically or emotionally ready for hospice. This includes evaluation by an RN, emotional support and education, and volunteer companionship and respite. This care is not reimbursed by insurance, but thanks to our community donors, it is provided at no cost to the patient.

In each program, we create a personalized a care plan especially for each patient, with sensitivities to cultural, spiritual, and personal preferences. Our continuum of care allows patients (and, importantly, their families) to remain with the same support team throughout their journey. We are dedicated to helping people throughout the challenges of a terminal diagnosis.

Most of our patients receive care in their own homes. We also care for people in assisted living, board and care, skilled nursing facilities, and elsewhere. Our hospice house offers a peaceful, homelike option for those at the very end of life whose symptoms cannot be managed at home.

We offer **Bereavement Support** to patient families and the wider community through a combination of support groups and individual grief counseling for those who are grieving or facing the death of a loved one.

Our **Educational Programs** for community members and health providers are designed to help people understand and discuss their options for end-of-life care in advance of critical need, through a series of community forums, clinical staff presentations and in-service/continuing education support for clinical staff.

The story of Mission Hospice

By Mission Hospice co-founder Helen Lagen, March 2006

The spirit of Mission Hospice was first manifested in a room at Pavilion East, an extension of Mills Hospital, where a dear friend of some thirty years, Bernice Johnson Gray, RN, had become a patient, dying where she had nursed. Mary Kemmerle, RN, the head nurse, had noticed that several friends were visiting Bernice daily. One morning she asked me if we could cover those periods of the day when members of the nursing staff were their busiest, as "Bernice shouldn't be alone." We did not realize at the time that we were creating a mini-hospice in that room.

The second bed was never occupied by a patient. It was reserved for one of her two young adult sons, Brewster and Bob Gray, who took it in turn to be with their mother at night. I credit Mary Kemmerle with having taken the first step toward hospice care. In April of 1978 when Bernice lost her struggle for life against cancer of the pancreas, Karolina Soley, MD, and I turned our attention toward finding an appropriate way to memorialize our friend.

The Hospice Movement: A Better Way of Caring for the Dying, a newly-published book by Sandol Stoddard, became a primary resource that we circulated among friends as an introduction to the history and precepts of this new revival of an old concept of care. The author had written: "We must begin to honor the labor of those pilgrims who journey before us, in being present during the part of their lives we call dying, we must learn better to honor Life itself."

Bernice had taught us so much about the needs of a patient living through the last days of life, for an advocate, for the comfort of companionship and the relief from pain. How could we better honor the memory of our friend than by bringing hospice care to our community?

Warren Dale, the Chaplain at Mills Hospital, put me in touch with Marguerite (Mac) Nash, a beautiful young woman who was a cancer patient in remission. When we became active partners in purpose, she called us the chair-pair. The poignancy of her condition was an impetus for those who had formed the Interim Hospice Group in the fall of 1978. One day during a planning session we were discussing names for the future hospice. Emily Brown, a dear woman, spoke up: "We have a name. In 1840, there was a hospice in San Mateo located between what is now Crystal Springs Road and Baywood Avenue. It was called Mission Hospice. They served weary travelers on El Camino Real. So there is an historic precedent for the name, and we each feel a mission to establish this hospice." It was immediately obvious that Mission Hospice would be revived. Working diligently with capable assistance, we became incorporated in March 1979.

From the very beginning, we realized the importance of proceeding slowly to ensure that this effort would be well-grounded, based on sound medical protocols as formulated by Pierre Salmon and the Medical Advisory Committee of his confreres. This maintained a necessary balance between my deliberate approach and the urgency felt by Mac, my lovely co-founder whose concern was that we would be ready to meet her needs when the time came.

Mac said: "I'll probably be the first patient" … and she was. We were ready with Pierre Salmon, MD, as Medical Director, Marilyn Stone RN, PHN, as Executive Director/Patient Care Coordinator, and a corps of Direct Care Givers whom they had trained. Carol Gray, RN, was included in the first group of Volunteer Nurses, also Joanne Rovno, RN, who cared for our beloved Mac, "The woman Full of Love" who died on 15 October 1979.

It was my privilege to serve for the first three years as president of the Board of Directors; then the leadership passed to Marjorie (Midge) Bolton. Initially, we were funded by a grant of $30,000 from the San Mateo Foundation. Now our income is augmented by philanthropic contributions from the community at large, by memorial gifts, and by the fundraising projects of the hard-working dedicated volunteers of our Auxiliary.

When the work became too heavy for one person to handle the dual role, Marilyn brought Carol Gray onto the staff as Patient Care Coordinator, a post she held until Marilyn's retirement in 1988. Then it was a natural for Carol Gray, RN, MPA to be appointed Executive Director, a position in which she served with distinction for 16 years. It was the culmination of 25 years of her dedicated service to Mission Hospice.

Our first office was in a medical compound on El Camino in Burlingame. As we outgrew that small space and progressed to larger offices, we finally settled in a separate building in San Mateo at 151 West 20th Avenue. On February 11, 1999, we celebrated with a gala Open House, introducing the Pierre Salmon Gallery. The new situation afforded wall space with excellent overhead lighting. Marilyn Stone and I were inspired to start a gallery in memory of our first Medical Director. Dr. Salmon was a Renaissance man, a traveler with an interest in History and The Arts, and a fine photographer. We hung a small representative group of his work as a permanent collection. This has provided a venue for local artists to show their work, bringing people into our office who become acquainted with the program of Mission Hospice, and creating a pleasant ambience in the workplace for our staff.

Despite the many changes in the delivery of medical care that have occurred during the several decades since its inception, Mission Hospice has endured autonomously. In essence, it has remained true to the ideals and goals as envisioned and affirmed by our original founders in their Statement of Purpose:

"To provide, facilitate, and coordinate physical, emotional, and spiritual care for terminally ill patients and their families in San Mateo County, and to educate professionals, those who give hospice care and the public in the methods most effective in providing that care."

To learn more about the history of Mission Hospice,
visit www.missionhospice.org/events-news/history

Mission Hospice care team members

For each Mission Hospice patient, a care team works closely with the patient's physicians and family members to develop a comprehensive, personalized plan of care. Our emphasis is on quality of life, with special attention paid to pain control and symptom management. Teams also assist families with the emotional and spiritual aspects of dying, and provide needed medicines, medical supplies, and equipment.

Physician/ nurse practitioner: Our physicians/nurse practitioners oversee all patient care and will confer with patients' personal physicians when necessary. Our physicians/nurse practitioners are specialists in hospice care, pain control, and symptom management.

Nurse case manager: A nurse case manager oversees patient care under the auspices of the Mission Hospice physician/nurse practitioners and is in direct contact with the patient's physician. The nurse case manager or the on-call/weekend nurse is always available by phone. Our nurses are specially trained in hospice care, pain control, and symptom management.

Medical social worker: Our social workers provide patients and families with emotional and practical support, anticipatory grief counseling, and information about local resources such as attendant care and Lifeline services. Social workers can help families understand hospice philosophy and Medicare insurance benefits, and will regularly assess practical and psychosocial-spiritual needs to help patients and their families cope better. Medical social workers specialize in working with family systems, conflict resolution, and can help with Advance Medical Directives, funeral and/or memorial planning, and general problem-solving.

Home health aide: Our licensed home health aides provide personal care, including bathing, showering, bed baths, changing bed linens, changing bed clothes, shaving, and hair washing.

Spiritual counselor: Mission Hospice spiritual counselors offer unbiased support to people of all faiths, as well as to those who describe themselves as being spiritual, agnostic, or atheist. Spiritual care at the end of life includes storytelling and life review, deep listening, music, guided meditation, hand massages with scented oils, exploration of the meaning and mysteries of life, blessings and prayers, rituals, and sacraments. Our spiritual counselors may also be available to officiate at funeral, memorial, or graveside services.

Bereavement counselor: Specialized social workers, our bereavement counselors can assist with the challenges and feelings of loss. Counselors offer group and private counseling for families and individuals in a warm, supportive, confidential atmosphere.

Volunteers: Direct care volunteers assist patients and families with respite and patient care. Volunteers are available so the primary caregiver can go to the grocery store, take a nap, or attend to their own personal concerns. Our volunteers can also do errands, help around the household, write letters, organize family photos, listen to the patient share memories, or just sit with the patient and family members for quiet companionship and support.

Five precepts of accompanying the dying

By Frank Ostaseski, Founder, Metta Institute (mettainstitute.org)

A while back, I developed five precepts as companions on the journey of accompanying the dying. Perhaps they have relevance in other dimensions of life and can offer some inspiration and guidance. I think of these as five bottomless practices that can be continually explored and deepened. They are not linear and have no value as theories or concepts. To be understood and realized, they have to be lived into and communicated through action.

The First Precept: Welcome Everything. Push Away Nothing.

In welcoming everything, we don't have to like what's arising. It's actually not our job to approve or disapprove. It's our task to trust, to listen, and to pay careful attention to the changing experience. At the deepest level, we are being asked to cultivate a kind of fearless receptivity.

The Second Precept: Bring Your Whole Self to the Experience.

In the process of healing others and ourselves we open to both our joy and fear. In the service of this healing we draw on our strength and helplessness, our wounds and passion to discover a meeting place with the other. Professional warmth doesn't heal. It is not our expertise but the exploration of our own suffering that enables us to be of real assistance. That's what allows us to touch another human being's pain with compassion instead of with fear and pity. We have to invite it all in. We can't travel with others in territory that we haven't explored ourselves. It is the exploration of our own inner life that enables us to form an empathetic bridge to the other person.

The Third Precept: Don't Wait.

Patience is different than waiting. When we wait, we are full of expectations. When we're waiting, we miss what this moment has to offer. Worrying or strategizing about what the future holds for us, we miss the opportunities that are right in front of us. Waiting for the moment of death, we miss so many moments of living. Don't wait. If there's someone you love, tell him or her that you love them. Allow the precarious nature of this life to show you what's most important then enter fully.

The Fourth Precept: Find a Place of Rest in the Middle of Things.

We often think of rest as something that will come when everything else is complete, like when we go on a holiday or when our work is done. We imagine that we can only find rest by changing the conditions of our life. But it is possible to discover rest right in the middle of chaos. It is experienced when we bring our full attention, without distraction, to this moment, to this activity. This place of rest is always available. We need only turn toward it. It's an aspect of us that's never sick, is not born, and does not die.

The Fifth Precept: Cultivate Don’t-Know Mind.

This describes a mind that’s open and receptive. A mind that’s not limited by agendas, roles, and expectations. The Zen teacher Suzuki Roshi was fond of saying, “In the beginner’s mind there are many possibilities, but in the expert’s there are few.”

From this vantage point we realize that “not knowing is most intimate.” Understanding this we stay very close to the experience allowing the situation itself to inform our actions. We listen carefully to our own inner voice, sensing our urges, trusting our intuition. We learn to look with fresh eyes.

2 • Communication & listening

Communication skills in caregiving

Adapted from Home Hospice of Sonoma County

The first visit is always hard. “Will they like me?” “Will I be able to help?” “What will I do?” These questions are natural. Just remember at these times that you have been selected to serve as a team member because people experienced in the field have confidence in you. Just plunge in, taking with you an attitude of openness and receptivity to the needs of the patient and family to whom you have been assigned. They will let you know what they need, and you, in turn, will let them know what you can offer. The relationship unfolds step by step in a very natural way. The following are some guidelines that may help:

Genuineness

Be yourself! Say what you mean, mean what you say, be who you are, let your words and the way you act and how you feel all match, and respect your own and the other person's right to be unique, different, and human.

Value openness. Respect privacy. People who are ill appreciate being treated naturally, and in this way are reassured that their illness has not set them apart any more than in the obvious ways. Relate to the person, not the illness.

This holds true for family members as well. The volunteer's role is that of friend and supporter, not expert or authority. You are not expected to know all the answers. It does not take long to clarify for the family that medical and technical questions can be best answered by the nurse and physician, and that the non-medical volunteer is there to facilitate this communication and to provide other, less technical support. This role definition comes about most easily when the volunteer feels comfortable from the beginning just being himself or herself.

Dependability

To people in crisis, whose lives are subject to so much unpredictability, it is essential to know that they can count on someone or something. It is your responsibility to state clearly to the family what you can and cannot offer in terms of time and availability.

Never offer more than you know you can deliver. It is helpful to ask the patient and family to outline their needs and expectations at the beginning (with the stated understanding that these may change as the patient's condition changes), and to indicate how you can help fill these needs, given your own life pattern. Regular phone calls to “check in” are often appreciated, and sometimes result in meaningful and substantive conversations.

Listening

Always remember that your function as a volunteer is to first meet the needs of your patient and family, rather than your own. In most instances this means listening more than talking.

It may mean listening to the same stories over and over again – stories that, for whatever reason, satisfy a need of the patient or the family member in the telling. It may mean listening non-judgmentally to outbursts of anger, frustration and resentment that serve to release tension.

You may even be the target for some of these negative feelings. Don't take it personally. Don't return anger. It may be appropriate to let the patient know that you would be angry too if you had a life-threatening illness.

Be tolerant of behavior that seems inappropriate or may be difficult for you to handle. Remember that this behavior may be adaptive responses to severe emotional strain.

Allow the person to talk about his or her dying and illness if desired. If not, don't push. Be alert to verbal and non-verbal cues. Expect that the patient will not always want to talk about dying even if very close to death. Don't put your agenda onto the patient and family.

Communication

Stay with NOW and HERE instead of talking about another time or a different place. Don't say “it” when you mean “I” or “you” when you mean “me.”

Own your feelings. Take responsibility for what you are doing, saying, and feeling, and allow your real self to be known. WHAT and HOW are more important questions than WHY. Talk to people, not about them. Address people by name.

Pay attention to your language. Use whole sentences instead of starting in the middle or leaving them unfinished. Recognize that “yes, but” means “no”; that “trying” means “not doing or not succeeding,” that there is a difference between what you feel and what you think.

You are real and the other person you are talking with is real. Don't turn yourself or the other person into a thing or an object. Respect your reality and your humanity and get as close as you dare.

Physical contact

Some people like to touch and be touched. Others don't.

It is helpful if you can be flexible with this issue yourself, so that you can cue in on the needs of those you are serving. In most instances, patients welcome handholding and other appropriate physical gestures as means of communication, caring and connection without necessity for tiring conversation. Family members, too, often respond to a hand on the arm or across the shoulders as a gesture of “I'm here. I care.”

It goes without saying that this dimension of the relationship evolves naturally with the passage of time and the intensity of events. Be open. Do what feels right. Again, your comfort or discomfort will communicate itself clearly, so it is important to be yourself.

Meet them where they are

Over and over again in volunteer training, the concept of tuning in to the family and meeting them in terms of their own values and life patterns is stressed. Regardless of how much you may disagree with a family's way of dealing with their situation, it is never appropriate to give unsolicited advice.

Patterns of interaction between family members, no matter how counterproductive they may seem to you, have been formed over years of association, and are rooted in a history of which you are not a part. Your responsibility is to work as helpfully and harmoniously as possible within the given structure, not to try to change it.

Initiative

At the outset of a relationship, the family will usually look to the volunteer to set the pattern of interaction. Regular phone calls and brief visits to see how things are going are usually appreciated and serve to break the ice.

Don't assume that someone doesn't need to talk to you just because they haven't called you. On the other hand, be sensitive to the possibility that you may not be needed, and never prolong a conversation in which you are doing most of the talking.

Sharing

Allow for the creative expression of feelings through paintings, drawings, music, stories, dramatic play, etc.

Details

Your personal grooming and manner of dress can affect a patient's mood. Color and attractiveness can help lift the spirit. Noisy, jangling jewelry, however, may be annoying, and large earrings, brooches and necklaces may hurt the patient in a hug.

Never wear perfume, cologne, or other scented materials in the office or in the presence of a patient. Perfume or aftershave can be unpleasant to people on medication.

A positive attitude and pleasant expression mean a lot. This does not mean phony cheerfulness or overly bright chattiness, but merely a clear message of caring and attention.

Silence

Sometimes not talking but just sitting with a patient and letting him or her know you care by being there is the greatest gift of all. Sometimes there is nothing “to do” to or for the patient except give your quiet presence.

Non-verbal communication

Be aware of non-verbal language – your own as well as those of your peers, patients, and families.

For example, if you walk into your patient’s room and stand at the foot of the bed and glance at your watch frequently, you may communicate to your patient either discomfort with him or her, or lack of time. They probably will not feel comfortable and confident in talking with you during the visit. If you give them this same message each time you see them, they eventually will know not to share on an intimate level with you. They may even protect you by always seeming happy and “well adjusted.”

Symbolic language

People with life-threatening illnesses frequently use a symbolic approach to deal with some of the heavier issues of death and dying.

It is sometimes less threatening to talk in parables. If a person talks to you in symbolic language, respond in the same symbolism. Don't interpret the symbolic language unless the person asks you if you understand what they are really saying. It's better not to interpret: your interpretation could be wrong, and the other person would probably have been more direct with you if they were ready for that. You might scare them off by pushing.

Belief systems

Be aware of religious beliefs, and see to it that patients and families get the appropriate support, priest, minister, rabbi, etc. Don't impose your belief system onto the patient and family. Allow the patient and family their beliefs – they can have powerful positive effects on healing.

Personal reactions

The relationship a volunteer has with a patient and family can be deeply personal. Often the volunteer is involved in helping to support the family members immediately following the patient's death.

The volunteer may feel the same grief that would be expected in the death of a friend or any other important person in his or her life. Sometimes these reactions are immediate and easily identified. Others may be delayed for some time, perhaps making it more difficult to identify the source.

It is important to understand that these reactions are normal and to realize that the Mission Hospice team stands ready to support you through the grieving process.

Frustrations

Becoming involved as a volunteer may present unexpected frustrations for some people. The team approach is delicately balanced, and it depends more on the needs of the patient and family than it does on the relationship of the individual caregivers.

In some cases, the nurse assumes the primary support role in the team. This may be because the patient sees no need for a non-medical volunteer or does not wish to share his or her personal life except in a professional way. In other cases, the patient might need a friend more than professional nursing. Bear in mind that the nurse's role is more defined, and often more easily accepted, particularly in the beginning of a case.

Availability

Sometimes the family will emotionally withdraw from the patient as they approach death. At this time, you can be most helpful by increasing your time with the patient. They will appreciate your being able to share in their pain and loneliness.

Expectations

Remember that death acceptance and the lack of it are both valid. Seeing the acceptance of death as a virtue is a value judgment. We each choose to die as uniquely as we live. Leave your expectations of the patient with a life-threatening illness at home.

Conflicts

Another area that may cause frustration is personality conflict. There might be a conflict between the patient and/or family and the volunteer. Remember, this is OK – we are all human. The conflict might be temporary, as the family or patient might resent needing anybody. In time, the initial rejection can turn into deep friendship. In truth, you will become very involved with some patients, and remain relatively untouched by others.

Listening to others: Person-to-person listening

Stop talking. You can't listen while you are talking.

Empathize with the other person. Try to put yourself in the patient's place so that you can see what they are trying to get at.

Ask questions. When you don't understand, when you need further clarification; be careful not to ask questions that might threaten or embarrass the patient.

Don't give up too soon. Don't interrupt the other person; allow time for the patient to say what they have to say.

Concentrate on what the patient is saying. Actively focus your attention on the words, ideas, and feelings related to the subject.

Look at the other person. A patient's face, mouth, eyes, hands, all help to communicate; they help you concentrate, too; this will reassure the patient that you are truly listening and are interested.

Share your own reactions, such as smiling or crying, when it's appropriate for you.

Leave your emotions behind (if you can). Try to push your worries, your fears, your problems, outside the room – they may prevent you from listening well.

Be aware of your feelings of anger. They may arise when listening to another person; understand your own anger, rather than judging the patient's; your anger may prevent you from understanding the patient's meaning.

Get rid of distractions. Put down any papers, pencils, etc.; they may distract your attention.

Get the main points. Concentrate on the main ideas and not the illustrative material: examples, stories, statistics, etc., are important, but are usually not the main points; examine them only to see if they prove, support, define the main ideas.

Share responsibility for communication. Only part of the responsibility rests with the speaker; you as the listener have an important part; try to understand and, if you don't, ask for clarification.

React to the content, not the person. Don't let any reactions you personally may have to the patient interfere with what is being said; be aware of your own biases.

Don't argue mentally. When you are trying to understand the other person, it is a handicap to argue mentally as they are speaking; this sets up a barrier between you and the speaker.

Use the difference in rate. You can listen faster than the person can talk, so use the rate difference to your advantage by trying to stay on the right track; anticipate what is going to be said; think back over what they have said. The rate of speech is about 100 to 150 words per minute; the rate of thinking is about 250 to 500 words per minute.

Reflections

Try to use many different reflections. The following examples from Hospice of Buffalo may be helpful:

Sounds like…

Seems as if…

I hear what you're saying…

I wonder if…

I get a sense that…

I imagine…

I think I hear…

What I seem to be hearing…

I get the feeling…

It feels as though…

Sounds to me like…

Am I right in thinking…

You seem to be…

So you're feeling…

So it's…

> ***"It gives me joy to spend time with a person who is willing to share their life experiences. I'm getting more than I'm giving – I'm seeing life through their eyes."***
>
> *– Ida Young*
> *Mission Hospice Direct Care Volunteer*

Helpful phrases

Establishing your willingness to listen

- I’m listening.
- I’m here.
- Would you like to talk about that? Do you feel like talking about that?
- Yes-s-s?
- Could say more about that?
- That (listening) is what I’m here for.
- Sounds like talking about that will be hard for you. It’s going to be hard to get started (talking) ...

Recognizing the person behind the words, hearing and acknowledging feelings

- It sounds like you are angry about that.
- How did you feel when that happened?
- What kinds of feelings are you having right now? You must have felt very hurt.
- I can’t tell you how you feel about that...
- Are you still upset when you think about that?
- Have you had these feelings at other times? Are you feeling a little confused by all of that? You sound very lonely...
- You wish things could be different?
- You feel things are pretty hopeless right now? Do you have a trapped feeling?

Helping the person think, discovering what they already know or feel, and what is going on

- What ideas have you already considered?
- You seem to have several ideas about what would help.
- You’ve tried ideas that didn’t work?
- Can you tell me what you have already done about that situation?
- Has this type of thing happened to you before? ... What did you do then?
- Have you talked to anyone else about this? ... What did they think?
- How long has this been happening to you?
- Have you thought about why this happened to you? What thoughts did you have? Sometimes it’s hard to decide on these things ...
- Can you think back to when this began and tell me about that?
- I don’t understand what you mean exactly ...
- Do I hear you saying that ... ? (summarize)
- A minute ago you said,” ... “ Would you explain more about that?
- Can you tell me when all this began?
- How do you act when that happens?
- Where do all those feelings go? What do you do with them?
- What part of that problem is really yours — something you can control?

Roadblocks to communication

Directing, ordering, commanding

You must...

You have to...

You will...

Warning, threatening, admonishing

You had better...

If you don’t, then...

Moralizing, preaching, obliging

You should...

You ought…

It is your duty…

It is your responsibility…

You are required…

Persuading with logic, arguing, instructing, lecturing

Do you realize…

Here is why you are wrong…

That is not right…

The facts are…

Yes, but…

Advising, recommending, providing answers or solutions

What I would do is…

Why don’t you…

Let me suggest…

It would be best for you…

Evaluating, judging negatively, disapproving, blaming, name-calling, criticizing

You are bad…

You are lazy…

You are not thinking straight…

You are acting foolishly…

Your hair is too long…

Praising, judging or evaluating positively, approving

You're a good boy…

You've done a good job…

That's a good drawing…

I approve of…

That's a nice thing to do…

Supporting, reassuring, excusing, sympathizing

It's not so bad…

Don't worry…

You'll feel better…

That's too bad…

Diagnosing, psychoanalyzing, interpreting, reading-in, offering insights

What you need is…

What's wrong with you is…

You're just trying to get attention…

You don't really mean that…

I know what you need…

Your problem is…

Questioning, probing, cross-examining, prying, interrogating

Why…Who…Where…

What... How… When…

Diverting, avoiding, by-passing, digressing, shifting

Let's not talk about it right now…

Not at the dinner table…

Forget it…

That reminds me…

We can discuss it later…

Kidding, teasing, making light of, joking, using sarcasm

Why don't you burn the hospital down?

When did you read a newspaper last?

Get up on the wrong side of the bed?

When did they make you President?

Snapshot

By Mission Hospice staff Gabrielle Elise Jimenez, LVN, CHPLN and Gary Pasternak, MD, MPH

By the time someone comes to us, they have lived their entire lives; we come in at the very end and only get a snapshot. We hear a lifetime of stories condensed into a short amount of time, like the *CliffsNotes* of a life. We may feel as if we've known them intimately for a long time. We take the bits and pieces that they generously share with us and using our imagination we create a tableau of the patient and family; the landscape of a life lived.

The telling of these stories is often an essential element of the dying experience.

> " 'Remember on this one thing,' said Badger," in the children's book *Crow and Weasel* by Barry Lopez. " 'The stories people tell have a way of taking care of them. If stories come to you, care for them. And learn to give them away where they are needed. Sometimes a person needs a story more than food to stay alive. That is why we put these stories in each other's memories. This is how people care for themselves.' "

Because of the way a couple is holding hands as those last breaths are taken, we assume the 70+ years together were full of so much love – without a moment of struggle, arguments, betrayals, or disappointments. We leave thinking, "I want a love like that", and "when I die, I want someone at my bedside who will have loved me that much, and will miss me that much." It becomes quite easy to create a life they may or may not have ever lived, simply with the glimpses we are given. We are humbled by how much we actually don't know about them.

Our understanding of people can be immediate and intimate, but it can also be influenced by the circumstances, their sickness, stress, our own biases and transference and the untamed wildness of our own imaginations. In the short time we have together, we must quickly build mutual trust and respect. And as psychologist Carl Rogers said, holding people with unconditional positive regard and accepting and respecting others as they are, without judgment or evaluation, is an essential element of all healing professions.

This is one of the main tasks of all hospice workers: to approach patients with objective empathy and compassion, without pitying, romanticizing, or judging. Being present for – and receiving – a life story is one of the great gifts of this work. We often call this active listening, but it is really another example of relationship-centered care. We are not passive receivers because we have a part, large or small, in creating the end-of-life experience for this patient and family. Simply sitting silently in a room with a dying person is an intimate relational act.

We took an oath to not pass judgment, to not refuse to care for someone because of choices they made and things they've done, despite how dark their past might have been. When we start to care for someone, those secrets may be shared with us, or we may only have a sliver of a story to give us a window into the person's life. At the end of the day, that doesn't matter to us, because we have learned to have respect for every human life when they are dying—all humans should be cared for kindly regardless of their past personal history. That is a right everyone should possess.

But often our snapshots do contain rich and helpful stories. Human beings are interesting, especially when there are dynamics within the family and people have stopped talking to one another, perhaps for something that happened many years ago. And when we are alone with a family member or significant other, they may share something hurtful or awful the patient has said or done. We try to remind them that at this moment, if they are receptive to our suggestion, they have an opportunity to find a way to come together to provide comfort and support to the person lying in the bed, perhaps even forgive and comfort despite a difficult and hurtful past.

Human beings can be lovely and beautiful, and cruel and selfish. We are all only human with our imperfections and our emotions, and feelings have a tendency to get the best of us. However, one opportunity at end of life is the possibility for reconciliation of long- held challenging relationship issues and emotions. Grudges, hatred, slights, regrets as well as expressions of love long withheld are so often heard in these stories we witness. Often in the telling and facilitating of communication among family members we witness the transformation of the suffering from long held painful patterns into a more peaceful and graceful state. Not necessarily a perfect or "good death" but perhaps a better one. This often allows for a death that is not necessarily without grief but that is experienced with more peace and less anguish. This doesn't always happen but often does.

A terminal diagnosis removes the luxury of time, which reminds us of things we didn't say or do, or wishing we had let something go. We often see people wishing desperately that they had let go of their grudge or anger. A husband recently said, "I took advantage of the time we had together, I always thought we would have more time". He and his wife did have a wonderful love, but it was shorter than they had hoped, and both wished they made more of the time they had together. We can all learn from that.

In these "snapshots" we may see much about a person's essential nature and unique core qualities and we can experience their "nectar", the concentrated essence of the person in their wholeness. When we are witnesses with presence and clarity (when our own lens is not clouded by judgment and bias) these snapshots and stories become gifts to us and create opportunities for healing and the experience of a more peaceful dying. Mostly we feel lucky to be able to do this work

How to listen

By Rachel Naomi Remen, MD

Just listen

I suspect that the most basic and powerful way to connect to another person is to listen. Just listen. Perhaps the most important thing we ever give each other is our attention. And especially if it's given from the heart. When people are talking, there's no need to do anything but receive them. Just take them in. Listen to what they're saying. Care about it. Most times caring about it is even more important than understanding it. Most of us don't value ourselves or our love enough to know this. It has taken me a long time to believe in the power of simply saying, "I'm so sorry," when someone is in pain. And meaning it.

One of my patients told me that when she tried to tell her story people often interrupted her to tell her that they once had something just like that happen to them. Subtly her pain became a story about themselves. Eventually she stopped talking to most people. It was just too lonely. We connect through listening. When we interrupt what someone is saying to let them know that we understand, we move the focus of attention to ourselves. When we listen, they know we care. Many people with cancer talk about the relief of having someone just listen.

I have even learned to respond to someone crying by just listening. In the old days I used to reach for the tissues, until I realized that passing a person a tissue may be just another way to shut them down, to take them out of their experience of sadness and grief. Now I just listen. When they have cried all they need to cry, they find me there with them.

This simple thing has not been that easy to learn. It certainly went against everything I had been taught since I was very young. I thought people listened only because they were too timid to speak or did not know the answer. A loving silence often has far more power to heal and to connect than the most well-intentioned words.

Generous listening

Generous listening means listening without deciding whether you agree or disagree with what is being said, or whether you like or dislike what is being said. It means listening without comparing the speaker to yourself: are they more or less highly trained, smarter, more or less competent than I am? It means listening without trying to 'fix' the person speaking or to offer advice. It even means listening without trying to understand why the speaker feels the way that they do.

Generous listening is listening simply to know what is true for another person at the time that they are speaking to others. When we listen this way, we offer a place of profound safety that allows for genuine connection and the open sharing and transformation of ideas.

Listening creates a holy silence. When you listen generously to people, they can hear truth in themselves, often for the first time. And in the silence of listening, you can know yourself in everyone. Eventually, you may be able to hear, in everyone and beyond everyone, the unseen singing softly to itself and to you.

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 affect the most profound changes in the people around us. When we listen, we offer with our attention an opportunity for wholeness. Our listening creates sanctuary for the homeless parts within the other person. That which has been denied, unloved, devalued by themselves and others. That which is hidden.

When we haven't the time to listen to each other's stories we seek out experts to tell us how to live. The less time we spend together at the kitchen table, the more how-to books appear in the stores and on our bookshelves. But reading such books is a very different thing than listening to someone's lived experience. Because we have stopped listening to each other we may even have forgotten how to listen, stopped learning how to recognize meaning and fill ourselves from the ordinary events of our lives. We have become solitary – readers and watchers rather than sharers and participants.

Perhaps the most important thing we bring to another person is the silence in us, not the sort of silence that is filled with unspoken criticism or hard withdrawal. The sort of silence that is a place of refuge, of rest, of acceptance of someone as they are. We are all hungry for this other silence. It is hard to find. In its presence we can remember something beyond the moment, a strength on which to build a life. Silence is a place of great power and healing.

Helping, fixing, and serving represent three different ways of seeing life. When you help, you see life as weak. When you fix, you see life as broken. When you serve, you see life as whole. Fixing and helping may be the work of the ego, and service the work of the soul.

Please Listen

By Leo Buscaglia

When I ask you to listen to me
and you start giving advice,
you have not done what I asked.

When I ask you to listen to me
and you begin to tell me why
I shouldn't feel that way
you are trampling on my feelings.

When I ask you to listen to me
and you feel you have to do something
to solve my problem
you have failed me,
strange as that may seem.

Listen! All I asked was that you listen.
Don't talk or do – just hear me.

Advice is cheap; 20 cents will get
you both Dear Abby and Billy Graham
in the same newspaper.

And I can do for myself; I'm not helpless.
Maybe discouraged and faltering,
but not helpless.

When you do something for me that I can
and need to do for myself,
you contribute to my fear and
inadequacy.

But when you accept as a simple fact
That I feel what I feel,
no matter how irrational,
then I can quit trying to convince
you and can get about this business
of understanding what's behind
this irrational feeling.

And, when that's clear, the answers are obvious and I don't need advice.
Irrational feelings make sense when we
understand what's behind them.

Perhaps that's why prayer works – God
is always there, LISTENING.

So, please listen, and just hear me.
And if you want to talk, wait a minute
for your turn – and I'll listen to you.

3 • Opportunities at the end of life

The art of being a healing presence

By Gary Pasternak, MD, Mission Hospice Associate Medical Director

1. When you're a healing presence, you're an artist. Healing is more art than science, and it takes practice.
2. Being present is simple, but that doesn't mean it's easy. Quieting the mind's noise to hear another takes practice and discipline.
3. Healing is about something much larger than curing. Healing is to make whole.
4. As you move toward being a healing presence, there is only one place to begin – with yourself. Calibrate your instrument by being self-aware, experiencing self-compassion, acknowledging judgments and biases, being open and curious about the workings of our own hearts and minds, and honoring and learning from imperfections.
5. It helps to prepare a space if you're to be a healing presence. Clear the physical and psychic space and be mindful of the energy you bring. Consider what helps you maintain an aura of calmness and equanimity.
6. The most important space you prepare is not around you but within you. Prepare yourself: centering, grounding, touching into your intention, prayer mindfulness, silence, letting go of outcomes. Bring yourself with wholeheartedness.
7. The other person is your equal in every way that matters. Hold the other with unconditional positive regard; noticing our biases and judgments and how they separate us from the other. I could be that person. Honor common humanity.
8. Your healing presence can take many forms. Every encounter is improvisational. Who knows what will serve? Being in the moment and being yourself. Being more than your role. Many possible tools but often listening, being receptive and present in your body, talking, holding, serving in myriad ways.
9. One of the most powerful things you can do for someone as a healing presence is simply to believe – having faith or trust that healing can take place, holding a vision of wholeness, touching in with your intention to relieve suffering. Remember times when you've experienced deep healing.
10. A healing presence is most effective when it is least active. Less is more. Helping is the sunny side of control. Resist the temptation to fix or give advice.
11. Healing presence involves being connected while maintaining separateness. Healing evolves from relationship-centered care. Remain wholeheartedly objective (not detached or dispassionate). Don’t get swallowed up in sympathy, but practice empathy.
12. You cannot be a healing presence entirely on your own. You need support and nurture. Do what keeps you healthy and supports body, mind, and soul. It takes a village. Share your joys and sorrows.

13. Being a healing presence can bring considerable joy as well as its share of discomfort. Don't push anything away. Lean into painful or troubling situations. Don't ignore the elephant in the room. Compassion can transform suffering into healing. Allow the waves of joy and sadness to come and go.
14. As a healing presence, you won't receive as much as you give. You're likely to receive even more. The dying are our teachers. Fundamentally, there is no separation between giver and receiver. Equitable reciprocity. There are many gifts of this work.
15. A healing presence is filled with sacredness. What is your sense of the divine or spiritual aspects of being a healing presence? Be present for the "full catastrophe."

Be present with willingness, simplicity, and gratitude.

Keep a strong back and a soft front.

"Being part of the Mission Hospice team feels like coming home. There is no greater feeling than knowing you play an important role in something far greater than yourself."

– Mary Santana
Chief Clinical Officer

Why we love this work

By Gabrielle Jimenez, LVN, CHPLN

I went to nursing school in my late forties specifically to become a hospice nurse. I was caring for a friend of mine who was dying and felt a sense of peace at his bedside, as though it were a chair that had been saved for me until I finally found it. This work is intimate, private, personal, powerful, and lovely. No matter how many last breaths I witness, it always feels like the first. It is such an honor to be present at the bedside for someone who is dying, as well as for those who are saying goodbye.

Each first hello, and last goodbye is a reminder to me that life is fragile, and our time here is unpredictable. I want to be the last kind word someone hears, I want to be the kind of person that makes a difference for others, that inspires them, that reduces their fears, and that reminds them they are not alone. I appreciate life in a way I never have before, and I savor it all... I am pleased when I can start seeing someone early in their diagnosis, because it allows me to get to know them, find out what they want and what their wishes are, and how they want to be cared for as they start to decline. If I am lucky, I meet their families and hear their stories.

Human beings deserve to be cared for well when they are dying; to be heard, to have their thoughts and wishes, and even their fears validated.

I put their needs first. I focus on listening, because I think all human beings deserve to be heard, but also because if we listen, if we lean in and truly hear what people need, we can honor their wishes and care for them well. Each person I meet along my path, teaches me about life, love, kindness, and compassion, all of which are beautiful gems I keep safely tucked inside me.

Meeting them where they are, not where I want them to be, is something I didn't quite understand early on. This was something I learned after realizing their experience is not about me. Meeting someone where they are means putting aside our wants for them, whether those wants are in service to them or not and endeavoring to under-stand where they are in their journey… not where you think they should be. It begins by listening without judgment, asking questions openly and honestly, and above all recognizing that they are human.

It is so easy to project what we think someone else needs, and to push our own wants and wishes onto them, but what I think is more respectful, is truly meeting them where they are and honoring their needs.

I have learned that I don't always have to be there for the last breath, as long as I make the time that I am there valuable for the patient and their family, and that has to be enough for me. When you work in end-of-life care you are constantly caught between feeling sad that they are gone, but happy they let go. This is an emotional seesaw we are all continuously learning to find balance on. Do we get attached? Sometimes, yes. I think that is why self-care is that much more important for us to practice. If we stop having an emotional reaction to the end of a life, and the ache people feel when they say goodbye, we should stop doing this work.

When we are at the bedside of someone who is dying, our presence is not always just about them… it is also for those who are preparing to say goodbye. The partner of the person in the bed has two roles – partner and caregiver – and the lines between them can become blurry. They need our support the minute they take on that second role. And our role (because we have one too) is to reach out and offer them a break, or to make a meal, or pick up groceries. There are so many things we can do for them that won’t take up too much time or money. Imagine the difference you can make for them.

The moment you start providing care for another human being, a bond is created, and you become emotionally connected and tied to this person. All the time you spend with them, caring for them, and focusing on their needs, the more you forget your own. YOU need care too and it is essential that you find a way to practice self-care and honor the needs of your own body. And when that time comes when you have to say goodbye to them, this loss will be big and your grief will be real; you cannot do this alone. Please reach out to someone; let them know you need support.

For a long time, I think I felt like if I admitted how hard it was, or how fragile I was feel-ing, it would mean I was not up to the task of taking on this job, and that perhaps I was too weak to do it. But that is not the case at all, I am fragile, but I am not weak. Weak would be not admitting you have tough days, weak would be not honoring what your body says to you, and weak would be not accepting that you are a human being doing a job that many could never even attempt, which is hard, and sad, and can take its toll... but it is also beautiful and fills my soul, and I wouldn't have it any other way.

At the end of every single day, I ask myself, “what did I do well, what could I have done better, and what did I learn.” My reason for this is to keep finding the balance between the blurry lines of end-of-life care, to accept my emotional reaction as the reminder of how truly precious life is, and to always stay focused on what matters most of all, which is that a human being was cared for well, and that is always my goal. Death has taught me to pay closer attention to life. Each last breath that I am present for shocks me because I realize the finality of it, as well as how truly fragile we are as humans, and how blessed we are to have breath, and life.

When you work in this field and experience your own personal losses, you find your-self in between standing so still you are afraid to move and moving forward swiftly, as though it never happened. Neither are healthy. I have found that facing all my feelings head on, really feeling them, honoring them, and wiping the sticky off them, helps. I call it “sticky,” because that is what grief feels like to me… like it’s stuck to me, which then becomes stuck to everything I touch. To work in a field where you have to be strong enough to witness difficult moments, and comfort others who are trying to navigate them, you have to take care of yourself and find a self-care routine that can fit nicely into your daily life. Journaling, blogging, meditation, yoga, running, walking, hiking, cooking, time with family and time with friends… all of this can center and ground you. This work is beautiful, but it cannot be everything you are or do.

I cry easily and often, and there was a time early on that I felt I needed to hold it in. I spoke to one of the hospice doctors about it, and he looked right at me, into my eyes, and he told me to feel whatever I was feeling. He gave me permission to ache for this loss, which was mine too. He told me that to be able to do this work well, we have to remember that we are bearing witness to the end of a life. He said that if I should ever stop feeling a sense of sadness witnessing a last goodbye, only then should I be concerned about whether I am capable of continuing to do this work. Their experience is not about us and projecting what we think they might need is not helpful. If we meet them where they are, if we truly listen to what they want or need, imagine how that makes them feel. When someone is nearing the end of their life, what I want most of all is for them to feel as though they were cared for well.

One thing it is always important to remember, is that THIS IS NOT ABOUT US. We should not project what we think someone else needs or wants, whether they have a voice or not. It is not for us to say he should or should not be alone when he dies…… I was reminded that it does not matter who someone prays to, kisses, votes for, or how they live ... this is their choice, and it is not for us to judge, insult, ridicule or verbalize any unkind words or energies in their direction.

I am often asked why someone is taking so long to let go, or an even harder question, is why do they have to die? What I have come to realize is that there is no real answer to the why, and there is nothing I can possibly say that would or could change the circumstances of everything that was happening at the time the questions are being asked. Life happens, and then death happens and in between is the space where memories are made, so it reminds us to make the very best of that time. Sometimes we are reminded too late. And when a diagnosis is given, or a life is cut short, the questions we need to ask are, did we live our life well, did we make lasting memories, do the people in our lives know just how loved they are?

For me, at the end of the day, what matters most… is that all human beings are cared for well when they are dying, despite their choices, their lifestyle or anything else that we might not support, agree with, or understand.

I found this quote by Colin Powell, which I believe says it all:

> “Don’t just show kindness in passing or to be courteous. Show it in depth, show it with passion, and expect nothing in return. Kindness is not just about being nice; it’s about recognizing another human being who deserves care and respect.”

As a hospice volunteer, you need to know what a difference you will bring to the life of someone who is dying. When you are at the bedside, you offer peace and you offer trust, and in some cases more so than anyone else in their lives. I have witnessed many times the patient sharing things they had never told anyone else, which is usual-ly about their fears and worries about death and dying. Sometimes, patients are afraid to be open with their loved ones, they don’t want to add to the pain they are already going through, that is why this role is so important, your role is so important. The ad-vice I gift most often, is to listen, not to fix, not to share your thoughts or your opinions, but to hear them and to validate their words. By doing this, you are building trust. And that is a beautiful gift.

When you meet someone who is dying, always remember what this means to them, and what they might be going through. Time suddenly takes on a whole new meaning when yours has been cut short, and it is at this time when you realize you have wasted a lot of time. There might be regret, anger, guilt, sadness, and pain, which can be physical but is often mental or spiritual as well. There is a lot that needs to be worked through before those last breaths are taken, and your role might just be the safe place for them to share.

Being present for someone who is dying, is an honor, one that should never be taken lightly or for granted. When you first meet them, try not to ask them how they are – we know how they are. Instead, let them know you are pleased to meet them, and that you are there for them in whatever way brings them the most comfort. At the time of that first visit, they may not know what they want or need, they might not know what a gift you are to them, so this is your opportunity to start building that trust. Lean in, and simply say, “it is an honor to meet you.” And let the conversation go from there. You are going to make a difference in their life.

4 • Body mechanics & safe transfers

Body mechanics

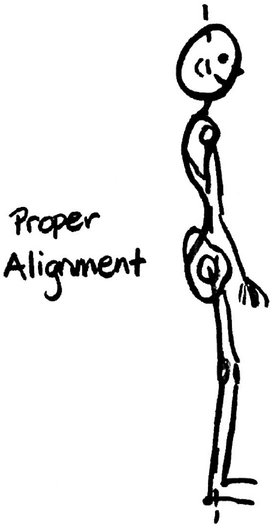
Understanding body mechanics and how to transfer someone safely will help you protect your back and other parts of your body, keeping both you and your patient safe.

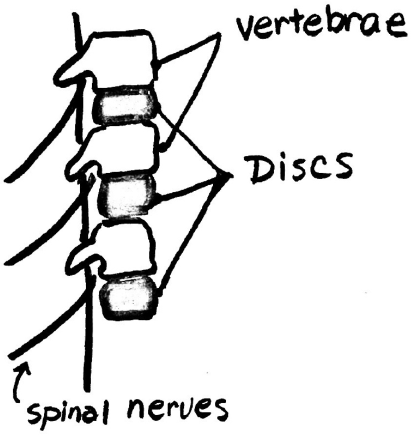
Three basic body mechanics rules when lifting:

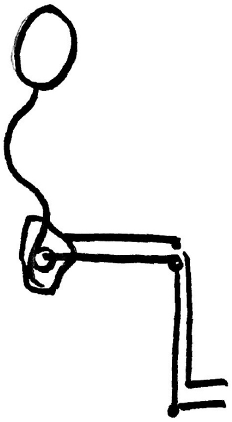
1. Maintain your natural spinal curves
2. Bend at your hips and knees
3. Do NOT twist

Spinal alignment

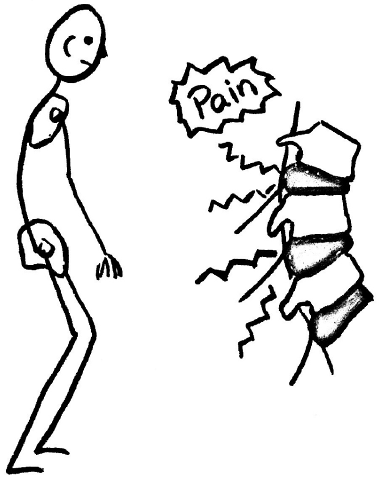
- Spinal alignment occurs when your head is balanced over your shoulders, your shoulders are balanced over your hips, and your hips are balanced over your knees and feet. Think about dropping a plumb line from your ear and having it drop straight down to your feet.
- When your spine is aligned, the vertebral bodies, discs, and nerves can function optimally.

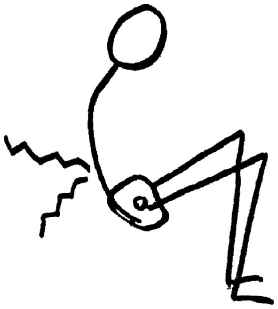






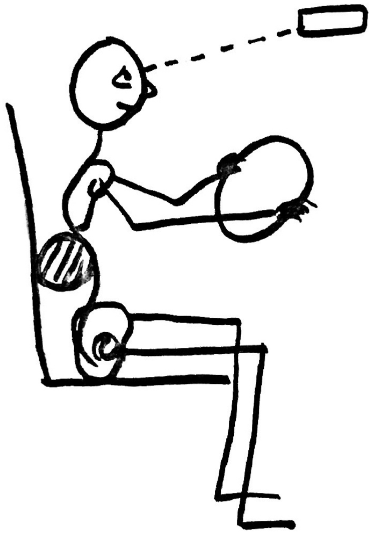
- A misaligned spine causes compression of the spinal discs, which can impinge on the spinal nerves and cause pain down our arms, back, or legs.

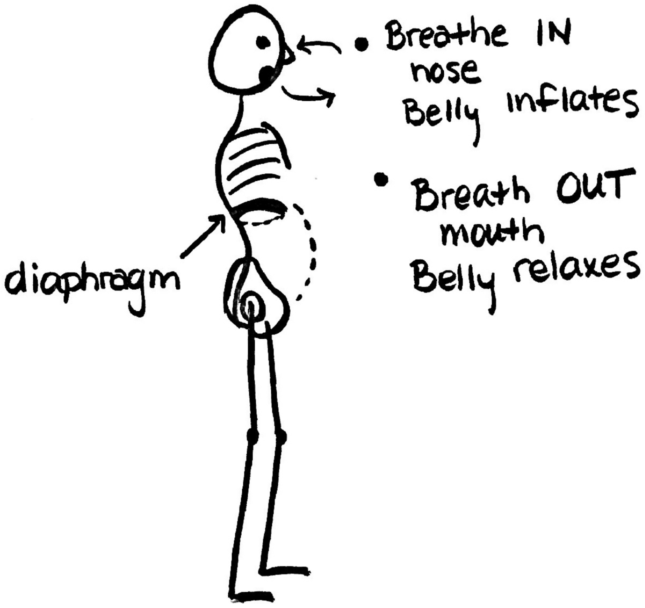




Ways to improve spinal alignment

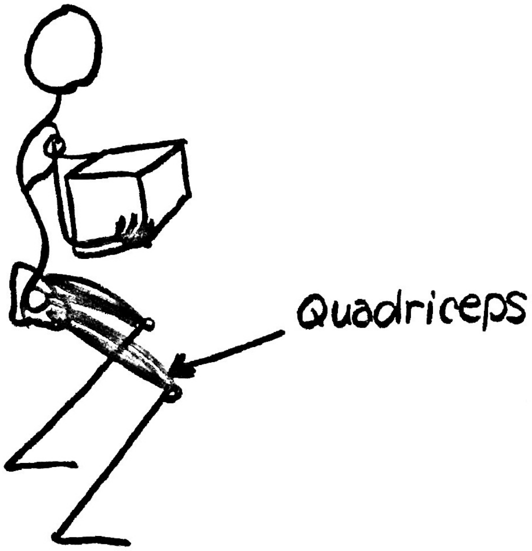
- Adjust chair height, use lumbar supports, adjust the mirror in your car, bring present-moment awareness to breathing and posture.





When lifting, or when helping a person to sit or stand:

- Use the largest leg muscles – the quadriceps – not the small, thin back muscles
- Maintain your lumbar curve to keep the spine aligned
- Use a large base of support
- Keep the load close to your body



For a healthy back

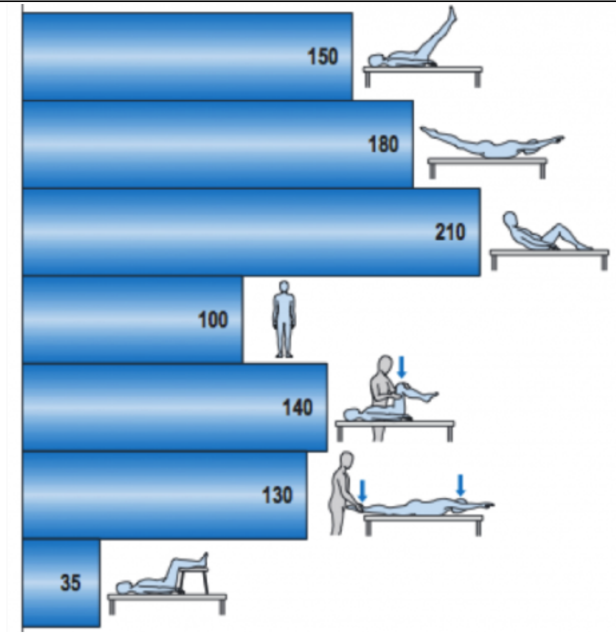
- Exercise regularly
- Limit reaching when working
- Wear good shoes
- Ask for help

First aid for your back

- Rest/lie flat with knees up
- Ice for 10-15 minutes

Lumbar intradiscal pressures

These diagrams show the intradiscal (L2-L3) lumbar pressure in various positions, relative to the pressure when standing. Higher pressures are more stressful.



Pressures are relative to that of the standing position.

Transfers

When transferring a client from sit to stand, hold their hands while you stand anteriorly and gently rock the client in a rhythmical fashion forward and back. This will make them more comfortable with leaning forward and assisting with the transfer of weight.

When preparing for sit-to-stand transfers:

1. Tell the client the plan.
2. Scoot client to the edge.
3. Gently rock forward and back.
4. Do on the count of three.
5. Ask the client to bring their nose over his or her toes.

When transferring between chair/bed and wheelchair, place the foot that is closest to the direction of the transfer slightly forward.

When preparing for supine to sit transfers:

1. Bend both knees as much as is comfortable.
2. Encourage the client to scoot away from the edge of the bed, or use a draw sheet to pull the client.
3. Roll towards the side closest to the edge of the bed.
4. Bring the legs off the edge while assisting the head up.

Bed mobility

1. Rolling patients from supine to side-lying

a. If able, have patient bend knees or assist patient in bending knees.
b. Have patient cross arms over chest or reach in the direction they are rolling. Patient can grab the edge of the bed or bed rail to assist if necessary.
c. Place one hand on patient's back at shoulder level and place other hand on back of patient's pelvis. Remember to stand facing the bed with hips positioned midway between their knees and shoulders. Assist patient with rolling by shifting your weight.
d. If the patient has a back condition, be sure to "log roll" patient, avoiding twisting the low back.

2. Moving from side-lying to sitting EOB (edge of bed)

a. Encourage the client to scoot away from the edge of the bed you want to sit up towards, (or use a draw sheet to pull client.)
b. Roll towards the direction of the transfer.
c. If patient is able to help, have them actively slide feet off bed while you assist trunk.
d. The patient can assist by pushing against the bed with his arms.
e. Avoid this technique for patients with these medical conditions: total hip replacement, open heart surgery, and upper extremity fractures.

3. Scooting sideways

a. If able, have patient bend knees or assist patient in bending knees.
b. Have patient push down into bed with feet in order to lift hips into "bridge" and scoot sideways.
c. Assist patient with movement of trunk if necessary (do not assist at head or neck).
d. Move in small steps and slowly to prevent injury.
e. If patient is unable to assist, then use draw sheet, bed rails, or trapeze.

4. Scooting to head of bed

a. If able, have patient bend knees or assist patient in bending knees.
b. Have patient push down into bed with feet in order to lift hips into "bridge" and scoot sideways.
c. Assist patient with movement of trunk if necessary (do not assist at head or neck).
d. If bed can be moved, go to the head of bed to assist.
e. If patient is able to grasp headboard, have patient assist with movement.
f. If patient is in a hospital bed, then lower head of bed; raise foot of bed.
g. Use a draw sheet to assist.
h. If patient is hemiplegic, do NOT pull on affected arm.

5. Supine to sit (no side-lying)

a. Assist patient to scooting to edge of bed unless they are very tall.
b. Position yourself close to the bed next to the patient's hips so you can prevent patient from sliding off the bed.
c. Assist patient to raise up on elbows.
d. Use with patients with the following medical conditions: total hip replacement, open heart surgery, and upper extremity fractures.
e. Have patient begin to lower legs off edge of bed as you assist in raising trunk so that patient can sit at edge of bed.

6. Toileting using bedpan

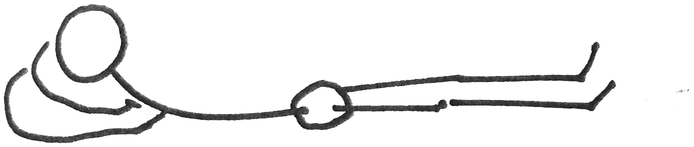
a. If able have patient bridge and place bedpan under buttocks.
b. If patient unable to bridge, assist patient in rolling to side, place bedpan under buttocks and assist patient to roll back onto bedpan.
c. Utilize same method to remove.

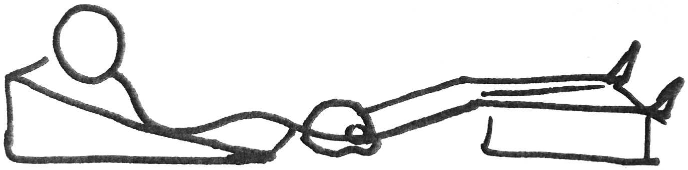
7. Occupied bed change

a. Assist patient to roll side to side.
b. Roll dirty linen underneath patient. Place clean linen on bed and tuck in bottom sheet.
c. Tuck clean linen under patient.
d. Roll over linen to other side; remove dirty linen and secure clean linen.

Proper positioning in bed

- Keep spinal alignment
- Gentle bend in knees
- Float heels





5 • Spiritual care

About spiritual care

A terminal illness leads us to grapple with a range of emotions, questions, and insights. Many of these feelings – including fear, anger, powerlessness, and despair – are signs of spiritual distress. Yet, even when facing death, we can find solace in feeling appreciated, sharing our life stories, and expressing gratitude and hope. Spiritual care encourages reflection on successes and failures, hopes and sorrows, and values, goals, and wishes.

Mission Hospice's spiritual counselors offer care to those from a broad range of cultural and religious traditions, as well as those with no religious or spiritual beliefs. Knowing we are more alike than different, our spiritual counselors and their calming presence create an environment in which spiritual healing can occur.

Spiritual care at the end of life

Few of us are comfortable facing death, so by its very nature, admission into hospice care can create a spiritual crisis for patients and families. Spiritual counselors are there to identify spiritual strengths and concerns, and guide the clinical team by adding relevant problems, issues, opportunities, goals, and interventions into the patient's Plan of Care.

A comprehensive spiritual assessment is not a one-time event but an ongoing process. Therefore, when newly admitted patients decline Spiritual Counselor support at admission, the clinical team and volunteers involved should informally assess the need for spiritual care throughout the patient's hospice care. When the needs become apparent, as a volunteer you should notify the Volunteer Services Director.

Research evidence shows that spiritual care is essential to patients' and families' sense of well-being. People with life-limiting illnesses consider that their quality of life improves when their spiritual needs are addressed. In addition, they value spiritual beliefs and practices, often using them as a way to cope with their fears or to strengthen their hope.

As a Direct Care Volunteer, you might notice spiritual pain and suffering arising during this tender, vulnerable time for both patients and their families. This overview of spiritual care will help you:

- Understand compassionate service
- Learn the difference between religion and spirituality
- Define spiritual pain and suffering
- Recognize signs of spiritual pain and suffering
- Identify interventions hospice spiritual counselors use to address spiritual needs
- Know when to report spiritual issues to the Director of Volunteer Services

1 • Compassionate service

Just as birth and death are spiritual acts, giving one’s time and talent through compassionate service to others is a spiritual act, as well. At the center of these acts are mystery and awe.

At their core lies a deep connection to that which is greater than we are – the Ground of Being, the Great Mystery, God, or any of the many names given for The Divine. When we give of ourselves from this place in consciousness, all that we give is sacred; all that we receive is holy.

Understanding the differences between “fixing,” “helping,” and “serving” allows us to approach patients and families with compassion and genuine warmth, rather than with pity and professional warmth. As clinicians and volunteers, we are not their personal friends; we are their “anam cara” – their soul friends – accompanying each one on this final part of his or her earthly journey. Blending our education and training with compassionate hearts, we aim to create spaces where their pain and suffering are minimized and their sense of peace increased.

Differences between fixing, helping, and serving

Fixing

Fixing is a mechanistic model for objects. We fix or discard broken things. Dying is a natural process that all of us will experience one day. Because nothing is broken when one is dying, nothing requires fixing. Death is not the enemy. Although slowly improving, the medical system has, for decades, been incongruent with human needs, especially with those of the dying. Hospice and palliative care movements have led the way in correcting this by joining warmth and compassion with clinical skills and practices.

Helping

Helping is the “follow me” model. “I am the professional. I know the way.” Helping is characterized by separation and difference, by one being superior and the other subordinate.

Difference hurts when one is vulnerable, and the dying and their families are always vulnerable. Eliminating a sense of separation between ‘them’ and ‘us’ fosters a healthy, caring relationship.

Serving

Serving brings our whole and authentic selves to the encounter – our strengths and limitations. This authenticity moves us closer to the sufferer with empathy. In a sense, we become gardeners rather than mechanics. Mechanics fix things. Gardeners enable the garden to bloom under good conditions. In this kind of compassionate service, we encourage deeper, more meaningful connections with and between patients and families, fostering wholeness and growth.

Compassion vs. pity

“Compassion is the spontaneous response of love; pity, the involuntary reflux of fear” (from “How Can I Help?” by Ram Dass). Patients and their families respond well to compassion but are put off – if not repulsed – by pity. Often we equate the word “pity” with “sympathy.” The American Heritage Dictionary shows them as synonyms. Still, they differ. Pity often leads to a sense of superiority, where the “pitier” stands above the pitied. Sympathy, however, is a social affinity in which one person stands with another person, closely understanding his or her feelings. It is an accompaniment, a companionship.

How can we avoid pitying the dying? We must ask ourselves these questions: “Does my understanding scare me or aid me in being with suffering?” “Can I sit with my own fears?” If we as clinicians and volunteers cannot sit with our own suffering, we will be unable to sit with the dying in theirs. When families are suffering, they often find it difficult to ask for or accept support. If they do accept, they may do so grudgingly. And if we ourselves cannot accept support, we cannot really give it. The more conscious we are of dealing with our own suffering, the more sensitive we will be to the needs of others in their own difficult places.

Roshi Joan Halifax, Founder of Upaya Zen Center in Santa Fe, NM, and world-renowned author and speaker, says the following about compassion:

> *“Compassion may be defined as the capacity to be attentive to the experience of others, to wish the best for others, and to sense what will truly serve others. Ironically, in a time when we hear the phrase ‘compassion fatigue’ with increasing frequency, compassion as we are defining it does not lead to fatigue. In fact, it can actually become a wellspring of resilience as we allow our natural impulse to care for another to become a source of nourishment rather than depletion.*
>
> *Developing our capacity for compassion makes it possible for us to help others in a more skillful and effective way. And compassion helps us as well. Findings from recent studies suggest that compassion plays a significant role in reducing physiological stress and promoting physical and emotional well-being.”*

2 • Religion and spirituality

Variety of faiths & belief systems in patients

Our Spiritual Counselors have cared for patients and families of many faith beliefs, including:

- Roman Catholicism
- Byzantine Catholicism
- Greek Orthodox
- Russian Orthodox
- Protestantism
- Judaism
- Islam
- Hinduism
- Buddhism
- Shinto
- Church of the Latter-Day Saints of Jesus Christ (Mormon)
- Jehovah’s Witnesses
- Seventh-Day Adventists
- Unity
- Gnostics
- Agnostics
- Atheists
- “Spiritual but not religious”

Definitions from the Health Care Chaplaincy Network

Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.

Religion is defined as a subset of spirituality encompassing a system of belief and practices observed by a community, supported by ritual that acknowledge worship, communicate with or approach the Sacred, the Divine, God (Western cultures) or Ultimate Truth, Reality, or Nirvana (Eastern cultures.)

> ***"To live is to suffer; to survive is to find some meaning in the suffering."***
>
> *– Friedrich Nietzsche*

Pain and suffering in spiritual matters

Problem-centered	**Existential/transcendental**
Fear of dying/death	Philosophy of life
Fear of abandonment	Expressions of spirituality
Hopelessness	Important past or current events
Spiritual emptiness	Feelings about a higher power and self
Guilt, shame	Disbelief or doubt about an afterlife
Unresolved grief	Existential meaningfulness
Loss of meaning in life	Loss of faith
Loss of identity	Desire to forgive or to be forgiven
Unfinished business	Desire for comfort and peace
Unresolved conflicts	Desire to be loved
Confusion or doubts about spiritual beliefs	
Reconciliation	

Pain and suffering in religious matters

Rituals	**Problems and barriers**
Anointing	Alienation from faith community or God/Higher Power
Baptism	Religious concerns about hospice or palliative care
Confession and penance	Unanswered prayers
Expressed feelings toward God/Higher Power	Confusion or doubts about religious beliefs
Meditation and guided imagery for the emotionally healthy	Difficulties carrying out religious practices
Prayers and blessings	Desire for stronger faith or beliefs
Sacraments	Desire to resolve feelings of guilt & shame
Religious/scriptural readings	Desire to forgive or to be forgiven
Worship service	Religious differences that create family conflict
Weddings/vow renewal	

3 • Spiritual pain

Spiritual pain is “any unpleasant sensation occurring in varying degrees of severity as a consequence of injury, disease, or emotional disorder.” (From *The American Book of Living and Dying: Lessons in Healing Spiritual Pain*.)

It is not optional but it is purposeful, in that it allows us to identify the source of the pain and to find ways (interventions) to address it. Left untreated, spiritual pain can exacerbate physical pain and lead to spiritual/existential suffering.

Spiritual suffering is an optional response to the pain of disease, old age, and dying because it is often a choice that one makes for the good of others – for family, friends, beliefs, or patriotism. Suffering can worsen physical pain and prevent effective pain and symptom management. Often, pain causes us to feel helpless and motivates us to end the suffering. Supporting the patient and family in using their spiritual strengths as coping tools can alleviate suffering.

Still, sometimes patients and families choose not to address their suffering, which often creates challenges for their hospice team. At these times, we must remember that this is their process, their journey, which requires that we meet them where they are and be with them in their suffering as compassionate, empathic companions, secure in our understanding that accompaniment can be comforting, if only for brief moments.

Assessment of spiritual pain

from the Sacred Art of Living Center, www.sacredartofliving.org

Meaning Pain

In the dying, Meaning Pain leads to the questions, “Who am I now?” “Who am I becoming?” “What has my life meant?” “How do I make sense out of my illness and death?” A crisis in meaning creates even more questions, such as those pertaining to The Mystery, ambiguity, purpose, and transcendence.

Forgiveness Pain

Forgiveness Pain results from our inability to forgive. It is not condoning the hurt and suffering that resulted from the sense of betrayal. It is not denying that the insult ever occurred. It is not inviting reconciliation with the offender or forgetting that emotional scars remain. Instead, it is “releasing our hold on the other person’s jugular,” letting go of negative emotions that no longer serve us. It is freeing us from remaining the victim. Often the most challenging person to forgive before death is not another, but ourselves.

Relatedness Pain

Relatedness Pain results from resisting the reality that the seasons of life are natural cycles, as we learn in *Ecclesiastes* 3:1-2, “To everything there is a season, and a time to every purpose under the heaven: A time to be born, and a time to die….” It is the inability to accept life as it comes. It is the unwillingness or fear of making the best of difficult situations, by turning away from them rather than *leaning into* them.

Hopelessness Pain

As described in *The American Book of Living and Dying: Lessons in Spiritual Healing,* Hopelessness Pain is the terminal illness of the human spirit. It results from a fear of letting go of the familiar, and it is an inability to imagine what could be life-giving. Even as one is dying, Hopelessness Pain is a loss of the will to live as well as one can for as long as one can, and the resistance to adapting and adjusting to the ongoing physical, emotional, and spiritual changes occurring as the illness progresses. Most distressing can be our discomfort in living with the ambiguity that dying brings.

Signs of spiritual pain and suffering

In addition to the religious and spiritual issues shown in the two previous tables, the following signs may also warrant intervention from a Spiritual Counselor:

- Family's moral conflict when patient stops eating and drinking
- Fear of patient dying in the home (concern that the spirit will linger, or the home will not sell, or the seller will not receive a fair price)
- "Am I being punished?" Or, "What did I do to deserve this?"
- Guilt or shame (sexuality, addictions, abortions, criminal convictions, etc.)
- Fear of dying or suffering while dying
- Reflection on losses, failures
- A great expectancy of secular and/or religious miracles, healing
- A desire for euthanasia
- Sense of purposelessness
- Family's guilt about wishing the patient would not linger and suffer
- Loss of identity
- Ready to meet God
- Inability of family to discuss death/dying
- Patient/family conflicts
- Visions of religious figures, or of deceased relatives, friends, or pets
- "Is there an afterlife?"
- "Have I lived a good life?"
- Unexplained agitation, restlessness, or anxiety, despite use of appropriate medications (existential pain)
- Frequent statements that the patient long ago stopped attending religious services
- Sorrow over and a desire to heal broken relationships or estrangements
- "Does hospice care meaning 'giving up'?" Or, "Is hospice care the right thing to do?"
- Unfulfilled hopes
- Suicide ideation
- Sense of meaninglessness
- Not ready to die
- Religious conflict with clergy or others representing their faith tradition
- Family's instruction not to use the "H" word with patient
- Sadness or grief over past, current, and future losses (anticipatory grief)

Knowing when a spiritual counselor is needed

If a patient declined spiritual counselor support at admission, but you as the volunteer are seeing spiritual issues shown in this guide, OR if you notice any one the situations below, please notify the Director of Volunteer Services.

Patient requests

- A spiritual counselor, minister, priest, rabbi, imam, or other clergy
- Prayer, meditation, or readings from religious or spiritual texts
- Sacraments and/or rituals
- Honoring of religious observances (such as Ash Wednesday or Rosh Hashanah)

Change in patient's condition

- Patient or family are anxious, distressed, overwhelmed, or angry
- Patient states they will commit suicide or asks us to hasten death
- Patient desires reconciliation with the Divine or others

Moral, ethical, religious, or spiritual issues

- Patient, family, or hospice team member is concerned about any of these issues
- Patient/family's existential suffering or religious beliefs prevent effective symptom management
- Patient/family wonder aloud about the mysterious and the transcendent
- The medical diagnosis has complex emotional and spiritual dimensions, such as HIV/AIDS, body image, history of substance abuse or incarceration, abortion, prisoner of war, or PTSD
- The hospice referral itself has created deep grief and suffering

Religious delusions, obsessions, aversions

- Patient may feel "chosen," "persecuted," or "possessed"
- Patient's expression of anti-religious sentiments may be a cry for help (i.e., "If there is a God, then why is the world such a mess?")

Patient is actively dying, or patient has died

- Families are overwhelmed
- Families seek spiritual support as patient is actively dying or after the patient has died

Spiritual counselor interventions

After a spiritual counselor completes comprehensive and ongoing spiritual assessments, they add the pertinent problems, issues, and opportunities to the patient's Plans of Care. These include spiritual strengths and issues assessed, goals set for resolving them, and interventions used to achieve those goals. Spiritual counselors update the Plan of Care after each visit and discuss the patient and family's progress in the weekly Interdisciplinary Group (IDG) meetings.

Spiritual counselors align their support with the patient and family's beliefs, not with their own beliefs. Spiritual counselors never proselytize, condemn, or judge. They do not manipulate or push, but sensitively accompany patients and families through this most sacred and mysterious part of their journey. Below are a few interventions spiritual counselors use with patients and families:

- Identify sources of spiritual nourishment and pain
- Support their culture and beliefs
- Explore the meaning and purpose of their lives
- Assist with healing relationships, facing fears, and overcoming regrets
- Guide them through the mystery and awe enfolding them; offer spiritual direction
- Offer or provide prayers, blessings, communion, sacred or scriptural texts, and music to soothe the soul
- Arrange for religious rites and sacraments
- Officiate funeral, memorial, and graveside services
- Lead guided meditation and imagery
- Offer or provide complementary therapies, such as Healing Touch, Reiki, and The Threshold Choir
- Provide a loving presence
- Provide pastoral presence, counseling, and support
- Lead patient or family in life review
- Enhance understanding of Divine compassion and forgiveness
- Provide empathy, deep listening, and positive reinforcement
- Collaborate with the other hospice team members about the patient and family's spiritual care issues

Helping, fixing, or serving?

By Rachel Naomi Remen, MD

"Fixing and helping create a distance between people, but we cannot serve at a distance. We can only serve that to which we are profoundly connected."

Helping, fixing, and serving represent three different ways of seeing life. When you help, you see life as weak. When you fix, you see life as broken. When you serve, you see life as whole. Fixing and helping may be the work of the ego, and service the work of the soul.

Service rests on the premise that the nature of life is sacred, that life is a holy mystery which has an unknown purpose. When we serve, we know that we belong to life and to that purpose. From the perspective of service, we are all connected: All suffering is like my suffering and all joy is like my joy. The impulse to serve emerges naturally and inevitably from this way of seeing.

Serving is different from helping. Helping is not a relationship between equals. A helper may see others as weaker than they are, needier than they are, and people often feel this inequality. The danger in helping is that we may inadvertently take away from people more than we could ever give them; we may diminish their self-esteem, their sense of worth, integrity or even wholeness.

When we help, we become aware of our own strength. But when we serve, we don't serve with our strength; we serve with ourselves, and we draw from all of our experiences. Our limitations serve; our wounds serve; even our darkness can serve. My pain is the source of my compassion; my woundedness is the key to my empathy.

Serving makes us aware of our wholeness and its power. The wholeness in us serves the wholeness in others and the wholeness in life. The wholeness in you is the same as the wholeness in me. Service is a relationship between equals: our service strengthens us as well as others. Fixing and helping are draining, and over time we may burn out, but service is renewing. When we serve, our work itself will renew us. In helping we may find a sense of satisfaction; in serving we find a sense of gratitude.

Harry, an emergency physician, tells a story about discovering this. One evening on his shift in a busy emergency room, a woman was brought in about to give birth. When he examined her, Harry realized immediately that her obstetrician would not be able to get there in time and he was going to deliver this baby himself. Harry likes the technical challenge of delivering babies, and he was pleased. The team swung into action, one nurse hastily opening the instrument packs and two others standing at the foot of the table on either side of Harry, supporting the woman's legs on their shoulders and murmuring reassurance. The baby was born almost immediately.

While the infant was still attached to her mother, Harry laid her along his left forearm. Holding the back of her head in his left hand, he took a suction bulb in his right and began to clear her mouth and nose of mucous. Suddenly, the baby opened her eyes and looked directly at him. In that instant, Harry stepped past all of his training and realized a very simple thing: that he was the first human being this baby girl had ever seen. He felt his heart go out to her in welcome from all people everywhere, and tears came to his eyes.

Harry has delivered hundreds of babies, and has always enjoyed the excitement of making rapid decisions and testing his own competency. But he says that he had never let himself experience the meaning of what he was doing before, or recognize what he was serving with his expertise. In that flash of recognition he felt years of cynicism and fatigue fall away and remembered why he had chosen this work in the first place. All his hard work and personal sacrifice suddenly seemed to him to be worth it.

He feels now that, in a certain sense, this was the first baby he ever delivered. In the past he had been preoccupied with his expertise, assessing and responding to needs and dangers. He had been there many times as an expert, but never before as a human being. He wonders how many other such moments of connection to life he has missed. He suspects there have been many.

As Harry discovered, serving is different from fixing. In fixing, we see others as broken, and respond to this perception with our expertise. Fixers trust their own expertise but may not see the wholeness in another person or trust the integrity of the life in them. When we serve we see and trust that wholeness. We respond to it and collaborate with it. And when we see the wholeness in another, we strengthen it. They may then be able to see it for themselves for the first time.

One woman who served me profoundly is probably unaware of the difference she made in my life. In fact, I do not even know her last name and I am sure she has long forgotten mine. At 29, because of Crohn’s Disease, much of my intestine was removed surgically and I was left with an ileostomy. A loop of bowel opens on my abdomen and an ingeniously designed plastic appliance which I remove and replace every few days covers it. Not an easy thing for a young woman to live with, and I was not at all sure that I would be able to do this. While this surgery had given me back much of my vitality, the appliance and the profound change in my body made me feel hopelessly different, permanently shut out of the world of femininity and elegance.

At the beginning, before I could change my appliance myself, it was changed for me by nurse specialists called enterostomal therapists. These white-coated experts were women my own age. They would enter my hospital room, put on an apron, a mask and gloves, and then remove and replace my appliance. The task completed, they would strip off all their protective clothing. Then they would carefully wash their hands. This elaborate ritual made it harder for me. I felt shamed.

One day a woman I had never met before came to do this task. It was late in the day and she was dressed not in a white coat but in a silk dress, heels and stockings. She looked as if she was about to meet someone for dinner. In a friendly way she told me her first name and asked if I wished to have my ileostomy changed. When I nodded, she pulled back my covers, produced a new appliance, and in the most simple and natural way imaginable removed my old one and replaced it, without putting on gloves. I remember watching her hands. She had washed them carefully before she touched me. They were soft and gentle and beautifully cared for. She was wearing a pale pink nail polish and her delicate rings were gold.

At first, I was stunned by this break in professional procedure. But as she laughed and spoke with me in the most ordinary and easy way, I suddenly felt a great wave of unsuspected strength come up from someplace deep in me, and I knew without the slightest doubt that I could do this. I could find a way. It was going to be all right.

I doubt that she ever knew what her willingness to touch me in such a natural way meant to me. In ten minutes she not only tended my body, but healed my wounds. What is most professional is not always what best serves and strengthens the wholeness in others. Fixing and helping create a distance between people, an experience of difference. We cannot serve at a distance. We can only serve that to which we are profoundly connected, that which we are willing to touch. Fixing and helping are strategies to repair life. We serve life not because it is broken but because it is holy.

Serving requires us to know that our humanity is more powerful than our expertise. In 45 years of chronic illness I have been helped by a great number of people, and fixed by a great many others who did not recognize my wholeness. All that fixing and helping left me wounded in some important and fundamental ways. Only service heals.

Service is not an experience of strength or expertise; service is an experience of mystery, surrender and awe. Helpers and fixers feel causal. Servers may experience from time to time a sense of being used by larger unknown forces. Those who serve have traded a sense of mastery for an experience of mystery, and in doing so have transformed their work and their lives into practice.

Rachel Naomi Remen, MD, is Associate Clinical Professor of Family and Community Medicine at UCSF Medical School and co-founder and medical director of the Commonweal Cancer Help Program. She is author of the bestseller *Kitchen Table Wisdom: Stories That Heal*.

Helping, Fixing, or Serving? was published in the *Shambhala Sun,* September 1999.

6 • Nursing

The role of the nurse case manager

Together with the Mission Hospice physician/nurse practitioner, the nurse case manager oversees patient care and is in direct contact with the patient's primary doctor. The nurse visits hospice patients at least once a week and perhaps more often, depending on the patient's condition. Our nurses are specially trained in hospice care, pain control, and symptom management.

The focus of hospice care is the comfort of the patient. The nurse case manager will work with the patient, the patient's doctor, and the rest of the Mission Hospice team to determine the severity of the patient's pain, and to develop a pain care regimen to keep the patient comfortable.

A nurse is on call for patients 24/7. After hours, the caller is connected to a triage nurse who reviews the patient's records and works to relieve the patient's symptoms. If the triage nurse needs help, s/he will contact a senior clinical officer from Mission Hospice (the Administrator On Call, or AOC) to help troubleshoot. If the patient's care cannot be managed over the phone, Mission Hospice will send an after-hours nurse.

The nurse case manager coordinates all care:

Management of patient/family caseload

- Scheduling visits
- Phone calls
- Medication delivery and refills

Physical assessment and care

- Pain management
- Bowel care (preventing constipation)
- Skin care and preventing pressure ulcers (bedsores)
- Preventing infections
- Anxiety management
- Mouth care
- Respiratory management
- Cardiovascular management
- Nutrition/hydration management
- Genitourinary management
- Helping patient and family understand the purpose and dosage of medications
- Coordinating dosage and refills with the physician/nurse practitioner

Psychosocial and spiritual care

The nurse case manager collaborates with other team members to assess and manage psychosocial and spiritual care for patients and family members.

Patient and home safety

The nurse case manager assesses the safety of the home, and help families make improvements and take preventative measures to provide a safe environment, to:

- Reduce the risk of accidents
- Prevent falls
- Protect patients with memory loss
- Prevent fires
- Ensure that oxygen is handled safely
- Ensure that old medications are disposed of safely

Support for caregivers

The nurse case manager helps family members and caregivers learn about and practice:

- Safe transfers
- Hydration
- Oral care
- Toileting
- Bathing and grooming
- Self-care

Physical and behavioral changes as death approaches

The physical changes a hospice patient goes through can be unfamiliar, and might include weight loss, lack of appetite, nausea, or breathing difficulties. Generally, these are not emergencies; the nurse case manager, along with the rest of the team, will help keep the patient as comfortable as possible, and educate the patient, family, and caregivers about how to handle physical difficulties as they arise.

While each death is unique, patients reaching the end of life may also exhibit certain physical and behavioral changes that signal that death is near.

Withdrawal

A person facing the end of life may begin to withdraw from family and friends. The person may be less communicative and may seem unresponsive. Remember that the patient can still hear conversations; speak in a calm, normal tone of voice.

Confusion and disorientation

People near the end of life may:

- See or speak to those who are already dead
- Describe a place of light, peace, or beauty
- Use symbolic language such as journeys, luggage, or going home
- Ask for people with whom the patient needs closure
- Seem confused

Changes in appetite

As a person's metabolism slows, the body cannot handle food at the same rate or volume as before. Cravings may change, and the patient may be uninterested in food or drink. While we often use food as a way to nurture and share time together, volunteers should remember that these changes are natural. Let the patient indicate whether food or fluids are needed or wanted. Always respect the patient's wishes, and don't force food or drink.

Changes in elimination

As circulation slows, muscles relax, and fluid intake decreases, it is natural for a person to experience changes in elimination. The loss of bladder and bowel control can be embarrassing and uncomfortable. The nurse will help caregivers learn how to keep the patient clean and dry in a way that offers the patient comfort and dignity.

Changes in breathing

As the body becomes weaker, breathing often changes. A patient's breathing may slow down; they may take several shallow, quick breaths followed by no breathing at all. If the patient is so weak they have trouble swallowing, saliva may gather in the back of their throat, and create a rattling sound. Gently turning the patient to one side may help drain the saliva. If the patient is breathing with his or her mouth open, frequent mouth care is important.

Changes in body temperature

The brain's ability to control body temperature diminishes as death approaches. The patient may develop a fever or may feel cool as circulation decreases. As a volunteer, being alert to these changes can help you regulate the patient's temperature with a cool washcloth and/or blankets as needed.

The person may turn pal, and develop a blue coloration around the lips and under the fingernails. This is not uncomfortable, but a natural part of the dying process.

Restlessness and agitation

You may notice that the patient is restless or performs repetitive movements. This kind of agitation may be due to slowing circulation or may represent physical or emotional pain.

The nurse will bring in other members of the team (social worker, spiritual counselor) as needed to help the patient. Reading aloud, playing calming music, holding hands, and sharing memories can help you comfort someone who is restless.

Signs of approaching death

You may observe some of these things in the days or hours before death:

- Many, many hours of sleep
- A surge of energy
- Changes in breathing, including long pauses between breaths and rattling sounds
- Decrease in blood pressure, and weak pulse
- Increased agitation
- Difficulty swallowing
- Further discoloration of the skin
- Decreased urination
- Lack of responsiveness

As death approaches, the nurse case manager will educate and support the family. The nurse will coordinate the care team, with attention to the personal, cultural, and religious preferences of the patient and family.

At the time of death

Surprisingly, it can sometimes be difficult to tell whether a patient has died.

Signs that a person has died include:

- Absent heartbeat and no breathing. It can be difficult to tell if the heart has stopped beating or the patient has stopped breathing. Patients can have weak heartbeats and may take little breaths very slowly with long pauses between breaths.
- Skin may look very blue, pale, and waxy.
- Eyes are often half open and will not close.
- Jaw may relax causing the mouth to be partially open; it may not close.

At the time of death, the family should call Mission Hospice at 650.554.1000.

They should NOT call 911.

One of our hospice nurses will come to provide support and assistance, including confirming the death, removing any tubes that are present, providing guidance on disposal of leftover medications, calling the funeral home, notifying the physician and hospice team, and arranging for removal of medical equipment.

Practical matters

Safe disposal of medicines

Don't flush old medications! Sewage systems can't remove them, and the drugs wind up polluting streams – affecting fish, other wildlife, and even drinking water.

You can find local drop off sites for medicines or dispose of them safely at home. Keep medicines (especially liquids) in their original containers to prevent leakage and remove or black out the labels for privacy.

BEST CHOICE:

Hazardous waste drop-off

Contact your local Household Hazardous Waste agency to find a place to drop off medicines.

Find locations at
baywise.org/disposal-locations
or by calling 1-888-229-9473.

Pharmacy take-back

Ask if your pharmacy offers a medicine take-back program.

Police station drop-off

Many police stations have confidential drop-off containers for medication. Call your local non-emergency police information number to find a site near you, or visit www.smchealth.org/RxDisposal

SECOND CHOICE:

Safe home disposal

For solid medications such as pills or capsules, add water to the container, and then add something nontoxic and unpalatable such as sawdust, kitty litter, cayenne pepper, or charcoal.

Close the container and seal the lid tightly with packing or duct tape.

Place the container inside a durable package (such as a cardboard box) that hides what's inside; place it in your trash bin.

This information is from the CA State Board of Pharmacy and the UCSF Center for Consumer Self Care.

The following sections include information given to patients. They are provided here so that you, as a volunteer, are familiar with Patients' **Rights and Responsibilities** and our agency's **Privacy Practices**.

Patients' rights and responsibilities

It is the policy of Mission Hospice to provide care that supports and protects your rights.

You have the right to be notified in writing of your rights and obligations before your care begins. Consistent with state and federal laws, your family or guardian may exercise the patient's rights when the patient is unable to do so. You have the right to exercise these rights and not be discriminated against or punished for exercising these rights. If you are not able to understand these rights and the effects of treatments, your representative can exercise these rights for you.

You have the right to be fully informed in a spoken language and in writing about your rights before you are admitted or at the time of admission (before care begins). We have an obligation to protect the following rights of the patient.

Decision-making

Mission Hospice is committed to assisting individuals in voicing their needs and in making their own decisions. You have the right to make an advance directive, to get information in writing about advance directives, and to complete one that will meet California state laws (including a description of the California laws that apply).

Privacy

Mission Hospice is committed to protecting the information in the medical records and health information of those in our care. You have the right to have your medical records kept private. You have the right to allow – or refuse – their release to anyone outside Mission Hospice, except if you transfer to another health care facility, or as required by law or third-party contract (see *Notice of Privacy Practices*.)

Dignity and respect

Patients and their caregivers have a right to mutual respect and dignity. You have the right:

- To be treated with full consideration, respect, dignity, and individuality, including privacy during treatment and personal care.
- To have relationships with the hospice team that are based on honesty and ethical standards of conduct.
- To be free from discrimination because of race, color, national origin, religion, sex, age, sexual orientation, disability, diagnosis, or because you do not have an advance directive.
- To express grievances about treatment or care that is or is not given, or about lack of respect for your property by anyone providing services for Mission Hospice. We will investigate complaints made by you or your family/guardian. You have the right to do this without fear that you will be discriminated against or punished in any way and to know the disposition of your complaint.
    - To make a confidential complaint to Mission Hospice:
      call (650) 554-1000 and ask to speak to the Compliance Officer.
    - To make a confidential complaint to the State Department of Public Health Services, Licensing and Certification: call (800) 554-0353, 8 AM to 5 PM, Monday – Friday. The hotline can accommodate English, Spanish, Cantonese or Mandarin, and TTY (hearing impaired).
    - To make a confidential complaint to the Joint Commission: call (800) 994-6610, 8:30am – 5pm CST or email complaint@jointcommission.org.
- To have your property treated with respect and not be subject to theft.
- To not experience mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, or physical punishment. Mission Hospice employees will immediately report alleged violations, conduct an investigation and take corrective action as needed, which may include filing a report with the Department of Public Health.

Financial

You have a right to information about the financial aspects of your care. You have the right to receive information about the services covered by the Medicare Hospice Benefit before your care begins and about what services Mission Hospice can provide and specific limitations of those services. You have the right to be informed before care begins, in spoken language and in writing, what your insurance will cover and if you will have any out-of-pocket costs. You have the right to be told if there are changes as soon as possible, but no longer than 30 days from the date Mission Hospice becomes aware of the change.

Quality of care

You have a right to information about your care and to receive quality care, to be informed of what services Mission Hospice will provide, who will provide them, and how often. You have the right to take part in planning your medical treatment, including pain and symptom management, and to be given an opportunity to participate in designing and updating your plan of care. You have the right to receive care from people who are qualified through education and experience, and to receive pain management and symptom control for conditions related to your illness. You have the right to have your family/caregivers taught about your illness, so that you can help yourself and they can understand and help you, unless to do so is against your wishes.

You have the right to choose your own doctor, to be fully informed by a doctor of your medical condition, to refuse to be part of experimental research, to refuse care or treatment, and to be told how this may affect your health. You have the right to be told in advance if there will be changes in your care, and to be told in a reasonable amount of time if Mission Hospice intends to discharge you from service. You have a right to leave Mission Hospice, or to change hospice agencies, even after service has started (within the limits of insurance, medical assist, or other health programs). You also have the right to a coordinated transfer to another agency.

Your responsibilities

While you are with Mission Hospice, you have the responsibility to stay under the care of a physician, cooperate with your doctor, Mission Hospice staff and other staff, and tell Mission Hospice if you have any problems or dissatisfaction with your care.

Tell Mission Hospice about any changes to your telephone number or address; call Mission Hospice if you are unable to keep an appointment with our staff; and treat Mission Hospice’s employees, volunteers, and property with respect and consideration. Make sure the environment where our staff provides services to you is safe. If the safety or the welfare of our staff is threatened, services may be stopped. You must also tell us if you believe there are any risks involved in your care.

Your responsibilities include having your medical supplies and equipment ordered by your doctor if Mission Hospice does not supply them; signing the necessary forms agreeing to allow Mission Hospice to provide services to you and to release information so that we may bill insurance; and providing insurance and financial records as requested. Services may be terminated if you refuse treatment or do not follow your plan of care.

Mission Hospice & Home Care Notice of Privacy Practices

This notice describes how medical information about patients may be used and disclosed and how you can get access to this information. **Please review it carefully.**

Your rights

When it comes to your health information, you have certain rights. This section explains your rights and some of our responsibilities to help you.

Get an electronic or paper copy of your medical record	You can ask to see or get an electronic or paper copy of your medical record and other health information we have about you. Ask us how to do this. We will provide a copy or a summary of your health information, usually within 30 days of your request. We may charge a reasonable, cost-based fee.
Ask us to correct your medical record	You can ask us to correct health information about you that you think is incorrect or incomplete. Ask us how to do this. We may say “no” to your request, but we’ll tell you why in writing within 60 days.
Request confidential communications	You can ask us to contact you in a specific way (for example, home or office phone) or to send mail to a different address. We will say “yes” to all reasonable requests.
Ask us to limit what we use or share	You can ask us not to use or share certain health information for treatment, payment, or our operations. We are not required to agree to your request, and we may say “no” if it would affect your care. If you pay for a service or health care item out-of-pocket in full, you can ask us not to share that information for the purpose of payment or our operations with your health insurer. We will say “yes” unless a law requires us to share that information.
Get a list of those with whom we’ve shared information	You can ask for a list (accounting) of the times we’ve shared your health information for six years prior to the date you ask, who we shared it with, and why. We will include all the disclosures except for those about treatment, payment, and health care operations, and certain other disclosures (such as any you asked us to make). We’ll provide one accounting a year for free but may charge a reasonable, cost-based fee if you ask for another one within 12 months.

Your rights

Get a copy of this privacy notice	You can ask for a paper copy of this notice at any time, even if you have agreed to receive the notice electronically. We will provide you with a paper copy promptly.
Choose someone to act for you	If you have given someone medical power of attorney or if someone is your legal guardian, that person can exercise your rights and make choices about your health information. We will make sure the person has this authority and can act for you before we take any action.
File a complaint if you feel your rights are violated	If you believe we have violated your rights, please contact: Chief Compliance Officer or CEO Mission Hospice & Home Care 66 Bovet Road, Suite 100, San Mateo, CA 94402 650.554.1000 You can also file a written complaint with: U.S. Department of Health and Human Services Office for Civil Rights 200 Independence Avenue S.W. Washington, D.C. 20201, 877-696-6775 www.hhs.gov/ocr/privacy/hipaa/complaints/ We will not retaliate against you for filing a complaint.

Your choices

For certain health information, you can tell us your choices about what we share. If you have a clear preference for how we share your information in the situations described below, talk to us. Tell us what you want us to do, and we will follow your instructions.

In these cases, you have both the right and choice to tell us to:	• Share information with your family, close friends, or others involved in your care • Share information in a disaster relief situation • Include your information in a hospital directory • Contact you for fundraising efforts If you are not able to tell us your preference – for example, if you are unconscious – we may go ahead and share your information if we believe it is in your best interest. We may also share your information when needed to lessen a serious and imminent threat to health or safety.
In these cases we never share your information unless you give us written permission:	• Marketing purposes • Sale of your information • Most sharing of psychotherapy notes
In the case of fundraising:	We may contact you for fundraising efforts, but you can tell us not to contact you again.

Our uses and disclosures

We typically use or share your health information in the following ways.

Treat you	We can use your health information and share it with other professionals who are treating you.	*Example*: A doctor treating you for an injury asks another doctor about your overall health.
Run our organization	We can use and share your health information to run our practice, improve your care, and contact you when necessary.	*Example*: We use health information about you to manage your treatment and services.
Bill for your services	We can use and share your health information to bill and get payment from health plans or other entities.	*Example*: We give information about you to your insurance plan so it will pay for your services.

How else can we use or share your health information?

We are allowed or required to share your information in other ways – usually in ways that contribute to the public good, such as public health and research. We have to meet many conditions in the law before we can share your information for these purposes.

For more information, see:
www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html.

Help with public health and safety issues	We can share health information about you for certain situations such as: • Preventing disease • Helping with product recalls • Reporting adverse reactions to medications • Reporting suspected abuse, neglect, or domestic violence • Preventing or reducing a serious threat to anyone's health or safety
Do research	We can use or share your information for health research.
Comply with the law	We will share information about you if state or federal laws require it, including with the Department of Health and Human Services if it wants to see that we're complying with federal privacy law.
Respond to organ and tissue donation requests	We can share health information about you with organ procurement organizations.
Work with a medical examiner or funeral director	We can share health information with a coroner, medical examiner, or funeral director when an individual dies.
Address workers' compensation, law enforcement, and other government requests	We can use or share health information about you: • For workers' compensation claims • For law enforcement purposes or with a law enforcement official • With health oversight agencies for activities authorized by law • For special government functions such as military, national security, and presidential protective services
Respond to lawsuits and legal actions	We can share health information about you in response to a court or administrative order, or in response to a subpoena.

Our responsibilities

- We are required by law to maintain the privacy and security of your protected health information.
- We will let you know promptly if a breach occurs that may have compromised the privacy or security of your information.
- We must follow the duties and privacy practices described in this notice and give you a copy of it.
- We will not use or share your information other than as described here unless you tell us in writing that we can. If you tell us we can, you may change your mind at any time. Let us know in writing if you change your mind.

For more information, see:
www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/noticepp.html

Changes to the terms of this notice

We can change the terms of this notice, and the changes will apply to all information we have about you. The new notice will be available upon request, in our office, and on our website.

BLOODBORNE PATHOGENS

A sharper image

Introduction

Our image of bloodborne diseases has sharpened in recent years due to research and technological advances. More is known about the transmission, prevention and treatment of diseases such as hepatitis B, hepatitis C and HIV (Human Immunodeficiency Virus) infection.

Research shows that safety precautions such as handling all blood and body fluids as though infectious, disposing of sharps properly, and using sharps safety devices have decreased the numbers of exposures to bloodborne pathogens. However, healthcare workers fail to use safety precautions consistently. You can change that by following safety measures. Let's take a closer look at the bloodborne pathogens putting you at greatest risk on the job: hepatitis B virus, hepatitis C virus and HIV.

Hepatitis B Virus

Hepatitis B virus (HBV) causes serious liver disease. About half of the people infected with hepatitis B have no symptoms. Those with symptoms may experience jaundice, fatigue, abdominal pain, loss of appetite, occasional nausea or vomiting. Most people infected with HBV recover and clear the infection. But about 10 percent become chronically infected. Each year, more than 5,000 people die from chronic liver disease and liver cancer linked to hepatitis B. As many as 200 of those who die are healthcare workers.

The hepatitis B virus poses a greater risk to healthcare workers than either the hepatitis C virus or HIV, since it is more easily transmitted. Fortunately, the hepatitis B vaccine can prevent the disease.

Hepatitis C Virus

Hepatitis C virus (HCV) causes a serious liver disease known as hepatitis C. This liver disease may cause symptoms similar to hepatitis B. However, there are important differences between hepatitis B and hepatitis C.

While 85 percent of people infected with HCV have chronic infections, only about 10 percent of those infected with HBV are chronically infected. The Centers for Disease Control and Prevention (CDC) reports about three million people in the United States are chronically infected with the hepatitis C virus while about 1.25 million are chronically infected with the hepatitis B virus. Further, many people infected with these two viruses have no symptoms at all: that includes about 50 percent of those infected with HBV and up to 75 percent of the people infected by HCV.

People chronically infected with hepatitis C may have no symptoms for up to 30 years, yet during that time the infection may be slowly damaging the liver. Hepatitis C is the leading indicator for liver transplants. Every year, up to 10,000 people die from hepatitis C related chronic liver disease. There is no vaccine to prevent hepatitis C. However, newly approved antiviral drugs have been effective in some people who have contracted the infection.

HIV

HIV attacks the immune system and causes it to break down. The clinical picture of HIV infection differs widely from person to person. A number of those infected remain apparently healthy for many years. The infected person becomes seriously ill when the immune system loses its ability to fight infections. Some infected people go on to develop AIDS.

As many as 900,000 people in the United States are infected with HIV, according to the CDC. The number of HIV-infected people who develop serious illness and who die from AIDS has decreased, thanks to the success of recent treatments. People with HIV now live longer and healthier lives. There is no preventive vaccine against HIV.

Transmission

The Big Picture

Hepatitis B, hepatitis C and HIV spread most easily through contact with blood. They also spread through contact with other potentially infectious materials, or OPIM, including semen and vaginal secretions, as well as any other body fluid or tissue containing visible blood.

OPIM also includes cerebrospinal fluid, synovial fluid, pleural fluid, peritoneal fluid, pericardial fluid, amniotic fluid and saliva in dental procedures. Non-intact skin or organs from living or dead humans and, cell tissue or organ cultures and other biological matter from laboratory experiments are also considered to be OPIM.

In our society, bloodborne viruses are most commonly transmitted through sharing needles to inject drugs, by having unprotected sexual intercourse with an infected person, or passed from mother to unborn child before or during birth.

Focus on Exposures at Work

At work, you can be exposed to bloodborne pathogens if:

- A contaminated sharp punctures your skin
- Blood or OPIM splash your broken skin or mucous membranes of your eyes, nose or mouth.

According to the research, needlestick injuries cause 80 percent of exposures to healthcare workers. The Occupational Safety and Health Administration (OSHA) reports most needlestick injuries occur when disposing of needles, including cleaning up after a procedure, giving medications, drawing blood, recapping needles or handling trash and dirty linens.

Safety Guidelines

A Safe Picture
Your facility's Exposure Control Plan (ECP) details bloodborne pathogen safety measures, including a method of identifying and evaluating safety devices such as protective sharps. Your Exposure Control Plan is based on OSHA's Bloodborne Pathogen Standard and CDC guidelines for healthcare personnel. Here's a snapshot of the safety precautions you should take.

Hepatitis B Vaccine
According to OSHA, immunization against the hepatitis B virus has proven very effective. In 1985, 12,000 healthcare workers were infected with HBV on the job. By 1995, after immunizations were promoted, only 800 healthcare workers were infected at work, and that's currently true.

Today's vaccines are safe and very effective at protecting you from getting hepatitis B infection if the series is completed.

Standard Precautions

Standard Precautions means treating blood, all body fluids, excretions and secretions (except sweat), plus non-intact skin and mucous membranes as though infected with bloodborne or other pathogens. Standard Precautions incorporates features of both Universal Precautions and Body Substance Isolation practices to protect you against the risk of bloodborne pathogens as well as pathogens from moist body substances. Remember: all body fluids pose a potential risk of infection.

Personal Protective Equipment

To follow Standard Precautions you must use barrier protection, or personal protective equipment (PPE), when you anticipate touching blood, body fluids, secretions, excretions and contaminated surfaces. PPE may include gloves, gowns, lab coats, face shields or masks and eye protection, resuscitation bags, pocket masks or other ventilation devices. Some tasks require more PPE, some less and some none at all. The point is, you need to wear only as much equipment as necessary. Read your Exposure Control Plan for details.

Gloves
Gloves are the most common type of PPE. Single-use, disposable gloves that are low protein and powder-free are used for medical procedures, and heavy-duty utility gloves are used for some housekeeping duties. Gloves can be torn or punctured, so cover any hand cuts you may have before being gloved. They should fit snugly over your fingers and be pulled as far over your wrists as possible.

Single-use, disposable gloves should be worn only once, then thrown away. Always change gloves between each patient. If a glove tears, punctures, leaks or becomes contaminated, remove it as soon as you can and discard. Never reuse gloves. Utility gloves may be cleaned or decontaminated and reused if not damaged. If they are damaged, throw them out.

Avoid touching the outside of contaminated gloves when removing them. Then, wash your hands.

Other PPE

- Wear a mask and eye protection or a face shield to protect your eyes, nose and mouth during activities that may generate splatters of blood or OPIM.
- Wear a gown if you need to protect your clothing or skin from exposure. Use a fluid-resistant gown if you anticipate contact with large amounts of blood or body fluids, such as during childbirth.
- Wear a surgical cap or hood and shoe covers or boots when large amounts of blood may be encountered, for instance, during surgery or trauma care.
- Wear PPE when resuscitating a patient. Emergency respiratory devices and pocket masks isolate you from contact with a patient's body fluids. Make sure emergency ventilation devices are available where they're most needed, such as on crash carts and in certain patient and procedure rooms.

Your facility will provide you with necessary PPE and train you to use it. Make sure PPE fits properly. Check it routinely for physical flaws or damage. Remove as soon as possible if blood or OPIM penetrates PPE. Always remove PPE before leaving the work area. Immediately dispose of used PPE or have it laundered or decontaminated according to your facility's policy. Always wash your hands after removing PPE.

Safe Work Practices

Handwashing
Handwashing is your number one protection against infection, and it keeps you from infecting other people or objects. Wash hands with soap and running water for at least 15 seconds. Also wash your hands between all patient contacts to avoid transferring pathogens to other patients. Here's how. Wash hands with soap and running water for at least 10 to 15 seconds. Rub vigorously over all surfaces including above your wrists. Rinse thoroughly. Then dry with a clean paper towel and discard. Now using a clean paper towel, turn off the faucet. Use antimicrobial soaps only when indicated since they remove your skin's natural protective defenses and may cause dryness. The Centers for Disease Control and Prevention (CDC) recommends use of approved waterless alcohol antiseptic hand rubs if hands are not visibly soiled. Apply the product to the palm of one hand, rub hands together covering all hand surfaces and fingers until hands are dry. If hands are visibly soiled, you still must wash your hands with soap and water as soon as you can.

More of the Picture on Safe Work Practices

- You should not eat, drink or smoke where you are likely to be exposed to blood or body fluids. Also do not handle contact lenses or apply cosmetics or lip balms where exposure is possible. Never keep food or drinks in places where blood or OPIM are present.
- Never mouth-pipette or mouth-suction blood or OPIM.
- Always minimize splashing, spraying and spattering when performing procedures involving blood or OPIM.
- Transport specimens of blood or OPIM in closed, leak-proof containers. Wear gloves and handle carefully.
- Handle contaminated patient equipment with care. Do not let it touch your skin, mucous membranes, clothing, other patients, visitors or items in the environment. Clean reusable equipment properly before using it on another patient. Discard single-use items appropriately.
- Clean all blood and fluid spills promptly, according to your facility's policy. Keep work surfaces and protective coverings clean.
- Handle contaminated laundry carefully to prevent exposure of your clothing and skin. Wear gloves. Place in an appropriate container in the area where used. Deposit wet laundry in a leak-resistant container.
- Never use your hands or feet to push down trash since it may contain sharps or OPIM. Instead, gently shake down waste containers. Carry waste bags by the top, away from your body.
- Dispose of blood and other regulated medical waste in appropriately labeled, closable, leak-proof containers. Follow your state's regulations, as specified in your Exposure Control Plan.
- Be aware of fluorescent orange-red labels, red bags and containers, and warning signs. They warn you that the contents contain blood or OPIM.

Sharps Safety

You are at greatest risk of exposure to bloodborne pathogens when handling contaminated sharps. More than half a million sharps-related injuries occur each year, according to OSHA. Studies show that sharps safety devices may significantly reduce your risk of injury during procedures such as joining IV lines, drawing blood, injecting medications and suturing during surgery. The FDA and OSHA now recommend use of breakage-resistant blood capillary tubes to decrease exposure. Safety devices include needleless systems and engineered protective devices for needles and other sharps. You will be trained in the proper use of safety devices beforehand and will help evaluate their effectiveness.

Your Exposure Control Plan details sharps safety rules you should follow. Here are some general guidelines.

- Use a safe-needle device or needleless system for withdrawal of body fluids, accessing a vein or artery, or administering medications or fluids.
- Use either a needleless system or a needle with engineered sharps protection for any other procedure requiring needle devices, when available.
- Use non-needle sharps with engineered sharps protection when available.
- When using sharps, always follow effective, safe handling techniques to prevent injury.
- Never shear, break, bend, or recap contaminated needles or sharps, except in cases when recapping is required by the procedure. Then, use a resheathing device or a one-handed "scoop" method.
- Never reuse disposable sharps.
- Do not pick up contaminated broken glass (also a sharp) with your hands. Instead, use a broom and dustpan, forceps or tongs.
- Discard contaminated sharps immediately after use in an appropriate, puncture-resistant, color-coded container. Nearly one-third of all sharps injuries happen during disposal. The National Institute for Occupational Safety and Health (NIOSH) suggests this risk can be decreased by placing sharps containers within easy reach and slightly below eye level. Do not allow containers to overfill. Never reach into a container of contaminated sharps.
- Report all sharps injuries as directed in your Exposure Control Plan. Document sharps exposure incidents including date, time and type of sharp used; effectiveness of any safety device used; and how the injury could have been prevented, if possible. This information, entered into the Sharps Injury Log, is used to judge the effectiveness of current sharps safety devices.

What to Do if Exposed

Immediately, wash the exposed skin area, needlesticks and cuts with soap and water. Flush eyes and exposed mucous membranes with large amounts of clean water. Do not use caustic agents, such as bleach. Next, report the exposure to the designated person right away, so that post-exposure evaluation, counseling and any necessary treatment can begin. Act quickly, because for some infections, treatment should start right away. If you are exposed, don't panic. Remember: Most exposures do not lead to infection. To become infected, a large enough dose of the live virus must enter your bloodstream and overcome your body's defense system. To put it in perspective, here are the risks of contracting a bloodborne infection after a sharps injury. Studies report the risk of acquiring hepatitis B if unvaccinated is between 6-30 percent; for hepatitis C it's 1.8 percent; and for HIV the risk is approximately 0.3 percent or 1 in 300.

Summary

The risks of infection are real and should be taken seriously. You can protect yourself by using safe work practices. Research, better surveillance, preventive treatment and advances in technology will continue to give us a sharper image of bloodborne pathogens. The more we know about preventing the risks, the better we can protect ourselves.

Mission Hospice & Home Care

Blood-Borne Pathogens Quiz KEY

02.2023

1. Healthcare workers most often become exposed to Hepatitis B, Hepatitis C and HIV through accidental needlesticks. [✓ True] False
2. HIV poses a greater risk to healthcare workers than Hepatitis B or Hepatitis C because it is transmitted more easily. True [✓ False]
3. Most people infected with the Hepatitis B virus do recover and clear the infection. [✓ True] False
4. Most people infected with Hepatitis C become chronically infected. [✓ True] False
5. People infected with HIV usually experience symptoms in two weeks. True [✓ False]
6. Fortunately, there are vaccines to prevent both Hepatitis B and Hepatitis C. True [✓ False]
7. Hepatitis B virus, Hepatitis C virus and HIV spread most easily through contact with blood. [✓ True] False
8. You can be exposed to bloodborne pathogens at work if blood or other infectious material splashes on your broken skin or mucous membranes. [✓ True] False
9. Most needlestick injuries occur when disposing of needles, giving medications, drawing blood or handling trash or dirty linens. [✓ True] False
10. The Hepatitis B vaccine is very effective only if the series is completed. [✓ True] False
11. Standard Precautions means wearing gloves when having direct contact with any patient. True [✓ False]
12. Standard Precautions incorporates features of both Universal Precautions and Body Substances Isolation practices to protect you against the risk of bloodborne pathogens as well as pathogens from moist body substances. [✓ True] False
13. After removing gloves, you need to wash your hands only if you touch the outside of the gloves. True [✓ False]
14. It is always good practice to know whether your patient has a bloodborne pathogen that could be an infection risk, so you can take proper infection precautions. [✓ True] False
15. You do not need to wear gloves when handling dirty linens unless the linens are contaminated with blood. True [✓ False]

Blood-Borne Pathogens Quiz, continued

02.2023

16. If you happen to find a needle, it is ok to just throw it in the garbage as long as you put the protective cap back on the needle. True [✓ False]

17. Nearly one-third of all sharps injuries occur during the disposal process. [✓ True] False

18. According to research, safety precautions such as handling all blood and body fluids as though infectious, using PPE when needed, and handling sharps carefully will decrease your risk of exposure to bloodborne pathogens. [✓ True] False

19. If your skin is punctured by a contaminated sharp, wash the area with soap and water or a diluted mixture of bleach and water, if available True [✓ False]

20. Most needle sticks that puncture the skin result in a blood infection. True [✓ False]

21. It is good precautionary practice to never touch a patient if you know that they are infected with AIDS or hepatitis. True [✓ False]

22. If you are accidently stuck by a sharp, or get contaminated with blood or body fluids on broken skin or splashed on mucus membranes, it is best to immediately contact the Mission Hospice triage nurse. [✓ True] False

Tuberculosis exposure control

Mission Hospice has policies and procedures to reduce the risk of staff and volunteer exposure to tuberculosis. The following section includes excerpts from our official procedures.

Patient assessment

- Patients will be assessed on admission for high-risk categories, conditions, signs, and symptoms of TB.
- Any patient who is considered high risk and has exhibited a cough lasting longer than two weeks and at least one other symptom will be identified as a potential TB patient.
- The attending physician will be contacted for an order to perform a Tuberculin Skin Test (TST) (with patient permission).
- For patients with signs/symptoms suggestive of TB (persistent cough longer than two weeks' duration, bloody sputum, night sweats, weight loss, anorexia, fever), respiratory precautions will be applied as part of the initial assessment and care planning process.
- If a patient is already diagnosed with TB, the patient will be accepted into hospice after a confirmed follow-up appointment with a licensed physician has been arranged, sufficient medication has been given to the patient until the outpatient appointment, and an RN case manager has been assigned to coordinate care.
- Patients should not be sent home if there are persons in the household who are at high risk of active TB transmission.

Clinical personnel assessment

- All MHHC clinical personnel will be tested or screened for TB annually, following CDCs recommendation for health care staff classified as Medium Risk.
- The testing procedure, reading, documentation and record keeping of TSTs will be kept in compliance with applicable laws and regulations. The person(s) conducting the testing procedures and reading the results of the tuberculin skin testing will be competency tested in the appropriate procedures.
- All MHHC Clinical Personnel will receive baseline TB screening upon hire, using TST, or a single Blood Assay Mantoux Test (BAMT) to test for infection with TB. After baseline testing for TB, personnel will receive TB testing annually.

    1. TST Skin Testing for TB for MHHC personnel with baseline negative test results using MHHC, 9-002Form1
    2. Symptom screen for all MHHC personnel with prior positive test results using MHHC, 9-002Form2.
    3. These records will be maintained by HR.

- MHHC Clinical Personnel with a baseline positive or newly positive test result for TB or documentation of previous treatment for (Latent Tuberculosis Infection) LTBI or TB disease should receive one chest x-ray result to exclude TB disease.

  1. Instead of participating in annual TST testing, HCWs who test positive will receive a symptom screen annually using 9-002Form2, Part 1. This screen will be used to educate personnel about symptoms of TB disease and instructing how to report any such symptoms.
  2. Following completion of Part 1, employee submits form to HR for RN Nurse Manager review of results.
  3. RN Nurse Manager documents their assessment and follow-up actions within Part 2.
  4. Follow-up with a physician will be mandatory for any employee identified through the use of the questionnaire,9-002Form2, Part 2, to have signs or symptoms of active TB.
  5. This record will be maintained by HR.

For further information regarding tuberculosis:

Centers for Disease Control (CDC)
Morbidity and Mortality Weekly Report (MMWR)
"Guidelines for Preventing the Transmission of Mycobacterium Tuberculosis in Health-Care Settings, 2005"
December 30, 2005 /Vol. 54/No. RR-17

US Department of Labor
Occupational Safety and Health Administration (OSHA)
Directive CPL 02-02-078, Eff 6/30/2015

For a list of resources, visit www.cdc.gov/tb/topic/basics/default.htm

CDC TB Surveillance Department
Atlanta, GA
(404) 639-1819
www.cdc.gov

Mission Hospice & Home Care

Tuberculosis Control Competency Quiz KEY

01.2020

1. Tuberculosis (TB) is passed through the air when a person with active TB coughs, speaks, or sneezes. [✓ True] False
2. The concentration of droplets in a room is higher, and therefore more likely to cause infection, if the room is poorly ventilated. [✓ True] False
3. Touching the surfaces in a room where a TB patient has coughed can cause transmission of TB. (It depends on the length of time between the coughing and the touching of the surface) [✓ True] [✓ False]
4. A person with a weakened immune system (e.g., someone with AIDS/HIV, or someone on chemotherapy) is at greater risk for getting active TB. [✓ True] False
5. It is okay for a healthcare worker to provide care to a client if they have NOT had a Mantoux/PPD test (or, for those who historically have a positive skin test, a chest x-ray.) True [✓ False]
6. If you have a latent TB infection, you are infectious to others. True [✓ False]
7. Symptoms of active TB include a productive, persistent cough that lasts more than three (3) weeks; bloody sputum; weakness; fatigue; weight loss; fever; loss of appetite; night sweats. [✓ True] False
8. If a person with active TB does not complete the full course of treatment with medication, there is a risk of producing a drug-resistant strain of TB. [✓ True] False
9. Multi-drug resistant (MDR) TB has a 100% cure rate. True [✓ False]
10. If you visit a patient who is suspected or known to have active TB, you can wear any mask you have available. True [✓ False]

Mission Hospice & Home Care

Handwashing Competency Certification

01.2018

HANDWASHING COMPETENCY

Name ____

Position ____

Evaluator Name (printed) _______________________________________

Evaluator signature _______________________________________ Date ______________

Can you identify times when hand washing is required? ___ Yes ___ No

Additional comments:

PERFORMANCE EVALUATION: ALCOHOL-BASED HANDRUB

	Satisfactory	Unsatisfactory
Apply palm full of the product in a cupped hand covering all surfaces		
Rub palm to palm		
Right palm over left dorsum with interlaced fingers and vice versa		
Palm to palm with fingers interlaced		
Backs of fingers to opposing palms with fingers interlocked		
Rotational rubbing, backward & forward with clasped fingers of right hand in left palm and vice versa		

Mission Hospice & Home Care

Handwashing Competency Certification

01.2018

PERFORMANCE EVALUATION: SOAP AND WATER

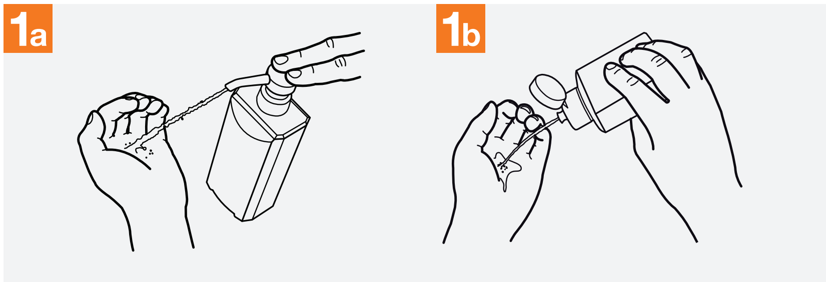
	Satisfactory	Unsatisfactory
Using warm running water, wet hands and wrists (back and front)		
Apply enough soap to cover all hand surfaces		
Rub hands palm to palm		
Right palm over left dorsum with interlaced fingers and vice versa		
Palm to palm with fingers interlaced		
Backs of fingers to opposing palms with fingers interlocked		
Rotational rubbing of left thumb in right palm and vice versa		
Rotational rubbing, backward and forward with clasped finger of right hand in left palm and vice versa		
Rinse hands with water		
Dry hands thoroughly with single use towel		
Use towel to turn off faucet		
Dispose without touching garbage receptacle		

How to Handrub?

RUB HANDS FOR HAND HYGIENE! WASH HANDS WHEN VISIBLY SOILED

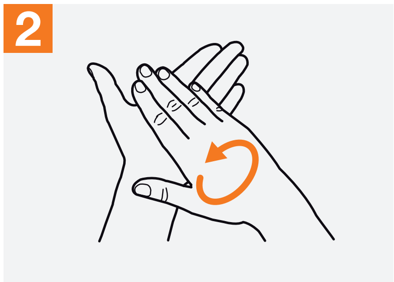
Duration of the entire procedure: 20-30 seconds

1a 1b



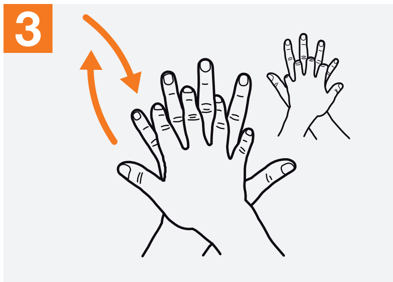
Apply a palmful of the product in a cupped hand, covering all surfaces;

2



Rub hands palm to palm;

3



Right palm over left dorsum with interlaced fingers and vice versa;

4

Palm to palm with fingers interlaced;

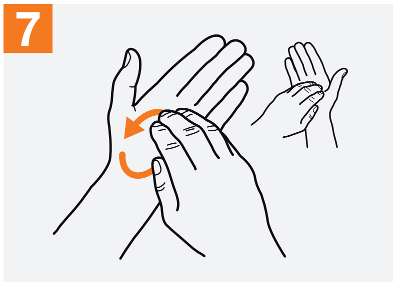
5

Backs of fingers to opposing palms with fingers interlocked;

6

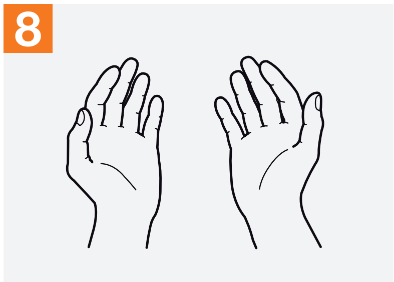
Rotational rubbing of left thumb clasped in right palm and vice versa;

7



Rotational rubbing, backwards and forwards with clasped fingers of right hand in left palm and vice versa;

8



Once dry, your hands are safe.

World Health Organization

Patient Safety

A World Alliance for Safer Health Care

SAVE LIVES

Clean **Your** Hands

WHO acknowledges the Hôpitaux Universitaires de Genève (HUG), in particular the members of the Infection Control Programme, for their active participation in developing this material.

May 2009

7 • Bereavement

Bereavement services

Mission Hospice offers bereavement services to help those who are grieving or facing the death of a loved one. Services include anticipatory grief support, check-in calls with the newly bereaved, support groups, and individual grief counseling. These programs are led by grief counselors, social workers, spiritual counselors, interns, and volunteers with special training in bereavement, and are open to anyone in the community.

Grief support allows people to:

- Express feelings of grief
- Talk about one's loved one
- Sort through the stresses and anxieties that may come with new roles and responsibilities of caregiving and loss
- Reflect upon one's natural strengths and use them to get through a difficult time
- Learn about the grief process

What is bereavement?

Although the word **bereavement** refers to the state of loss which results from the death of a loved one, our bereavement support actually begins as soon as a patient is admitted to our service. Loss and grief occur a long time before a patient dies. Both loss and grief are present (in one form or another) from the moment a terminal diagnosis is given and both, in most cases, continue to accumulate over the course of an illness. As a hospice agency, we are committed to supporting both our patients *and* their families as they experience these losses.

Supporting patient families

When nurse case managers and social workers do initial intakes, and as they and other members of the team follow the patients and their families over time, they identify the caregivers and family members closest to the patient and assess their bereavement risk. The bereavement risk (low, moderate, or high) is determined based on how difficult a time they are having now, and how difficult a time they are anticipated to have after the patient dies. Risk factors for bereavement include numerous elements including multiple losses in the family, family members in frail health, complex family dynamics, short course in hospice or with terminal condition, substance abuse and/or mental health issues, or children present in the home.

Those who seem to be at greater risk than average are offered additional emotional support while the patient is still alive, including:

- Extra visits from a social worker
- Visits from a spiritual counselor, as appropriate
- Supportive anticipatory grief counseling with bereavement counselor, either in the home or in our office
- Increased volunteer support

After a patient dies, social workers refer specific family members /loved ones (usually no more than two per family, and *family* however defined) to bereavement counselors, who follow identified family members with a specific care plan, including:

- An initial letter two weeks after the death that explains our bereavement services and provides an insert with information about our services and what to expect in grief
- Supportive telephone calls at two months and five months after the death (or more frequently, if needed, based on risk level)
- Notes sent to acknowledge important dates for the family (the deceased person's birthday and the one-year mark of the death)
- An invitation to our annual remembrance ceremony

Of course, all bereavement services are optional. Some families prefer to grieve privately or have adequate support systems. Family members have the choice to decline calls, mailings, and counseling.

Individual grief counseling

Mission Hospice offers individual and family counseling sessions to support patients and family members. Family members of our hospice clients receive eight free sessions; additional sessions for our hospice bereaved, and counseling for members of the general public located in our service area, are $100/session or sliding scale.

Our state license permits us to provide counseling only for family members living in California; we can provide referrals and resources for people who live outside of California.

Bereavement support groups

Mission Hospice offers a range of grief support groups, all free of charge and open to everyone in the community (within Mission Hospice's geographical service area, the San Francisco Peninsula and South Bay).

Current programs are always listed on our website:

www.missionhospice.org/events

and in our monthly *Community Connections* guide:

www.missionhospice.org/connections

Programs include drop-in support groups as well as specialized 8-week support groups, including special topics such as “Writing through Loss” and “Coping with the Holidays.”

Bereavement volunteers

Volunteers are key to our bereavement support. Experienced and trained volunteers call the low-risk family members, as well as co-facilitate some of the grief support groups. Volunteers also assist in writing cards for birthdays and “anniversaries,” and help at events such as our annual remembrance ceremony. Volunteers may also assist with specific office tasks such as organizing a library, help with mailings, etc.

Volunteers may be exposed to anticipatory grief prior to the death of a patient. Some volunteers may have limited contact with the family following the death of a patient. It is important for volunteers to have some background in the grief process to help guide them in interacting with bereaved family members with sensitivity, compassion, and authenticity.

About loss and grief

Anticipatory grief

Anticipatory grief is grief that occurs prior to an actual loss. It is most often used to refer to the grief that someone is experiencing as they anticipate the death of a loved one. But, of course, patients themselves experience anticipatory grief as they face their own death and all the many losses associated with it. It is important to note that there are many losses for patients and families that occur during the course of an illness – from the moment they receive a diagnosis to quitting work, losing a sense of self (appearance, function, identity), becoming dependent, etc. – losses that they are grieving before death.

Anticipatory grief counseling with the patient is usually done by the social worker, but may also be done by spiritual counselors or bereavement counselors. This counseling allows the patient or family member to talk about impending death (their own anticipated death or that of their loved one), what “unfinished business” the patient and family members have, and how to prepare emotionally, spiritually, and practically for the death.

In working with dying patients and their families, the theory of *Maslow’s hierarchy of needs* can be a helpful framework to prioritize interventions.

Maslow’s Hierarchy of Needs – for hospice patients

1. **Physical needs**: biological needs, pain, and symptom control, meeting basic life needs, such as breathing, eating, toileting
2. **Safety issues**: security, both physical and emotional, to be free of fears about too much pain, dying, choking (e.g. lung cancer), drowning (e.g. pulmonary edema), anxiety, stable place to live, generally feeling safe

3. **Love and belonging**: love for patient is reaffirmed by family/caregivers despite illness, relationship issues, social network, family issues, giving and receiving affection
4. **Self-esteem**: dignity, not being a burden, respect for past and present value of the person, prestige of societal recognition, narratives of life work
5. **Self-actualization**: existential issues, what gives meaning and value to life, personal journey and growth in illness, maximizing unique potential in life – deep connection to others, nature, God, spiritual and religious issues, peace, transcendence, closure, perception of beauty, truth, goodness and sacred in the world – such experiences become highly motivating, helping people feel alive and enlightened

Key terms

Bereavement: The personal and social status of one who has had a loved one die. It is one's position as an individual in relation to the person who died, and to others around that individual.

Grief: A natural reaction to the loss of a loved one. It may be a combination of physical sensations, thoughts, feelings, extra sensory perceptions, social changes, spiritual questioning or affirmation, and behaviors. It also can be a time for personal growth and development. Each person's journey through grief is unique.

Grieving: The emotional processes needed for healing to occur before, during, and after a loss; nature's way of healing a broken heart.

Loss: An occurrence or event that shatters dreams that were core to one's existence (Ken Moses, Ph.D.).

Mourning: The process of adapting to a death. It is a process with cycles, such as denial, anger, fear, depression, etc. It is also referred to as *the ritual response* to death and is culturally conditioned.

What is grief?

Grief is expressed physically, emotionally, socially, and spiritually.

- **Physical** expressions of grief often include crying and sighing, headaches, loss of appetite, difficulty sleeping, weakness, fatigue, feelings of heaviness, aches, pains, and other stress-related ailments.
- **Emotional** expressions of grief include feelings of sadness and yearning. But feelings of worry, anxiety, frustration, relief, anger, or guilt are also normal.
- **Social** expressions of grief may include feeling detached from others, isolating oneself from social contact, and behaving in ways that are not typical for the mourner.
- **Spiritual** expressions of grief may include questioning the reason for the loss, the purpose of pain and suffering, the purpose of life, and the meaning of death.

Factors that impact the grieving process

1. The nature of the relationship with the deceased

- The strength and security level of the attachment
- The type of relationship: mother/father, child, sibling, grandparent/grandchild, friend, etc.
- Any ambivalence or conflicts in the relationship
- Dependencies (emotional, financial, etc.)

2. The type of death and circumstances surrounding the death

- Natural, accidental, suicidal, or homicidal
- Suddenness or expectedness of the death
- Violent or traumatic death
- Multiple simultaneous deaths (or within a short time period)
- Was the death preventable, or believed to be so?
- Ambiguous death: (not sure if s/he is dead or alive, i.e. MIA, kidnapped, etc.)
- Stigmatized death, i.e. AIDS, suicide, drug overdose, etc.

3. Personality variables of the bereaved

- Age and gender
- Uniqueness of temperament and coping style
- Life experience, birth order, only child, etc.
- Ego strength: self-esteem level, general mental health
- Physical health
- Assumptive world view: beliefs and values (cultural, religious, spiritual); the ability to make meaning from a tragedy
- Past grief experiences

4. Social variables

- Support network availability (family, friends, religious/spiritual affiliation, community, etc.)
- Cultural or ethnic influences and expectations
- Disenfranchised grief caused by a socially stigmatized relationship

5. Other stressors on the bereaved

- Multiple losses over a lifetime and/or relatively short time period
- Secondary losses (of job, home, etc.)

Grief is universal and personal: Respect differences

Everyone grieves differently – there is no right or wrong way to grieve. Each one of us grieves in our own way, with our own intensity and at our own pace.

What may be a profound loss to one person may be a less significant loss to another. For instance, one person may be devastated when they lose their ability to drive a car while another person may relinquish driving without difficulty. That same person may have a very difficult time accepting the need to use a walker. What defines a significant loss varies from person to person.

Everyone copes with loss differently. For instance, one person may have a need to turn inward and pull away from people, while another may have a strong need to share their grief with others. Some may grieve with a great deal of intense emotion, while others may process their grief in a more cognitive way or engage in activity that addresses their grief. For others, grief comes out in the body (somatic), with symptoms such as tension headaches, digestive problems, or insomnia.

The most common symptoms of grief are sadness (tearfulness, preoccupation with deceased, yearning, pining, overwhelming flood of energy-consuming sorrow) and anxiety (fear of being abandoned, fear of one's own death and suffering, fear of living alone, fear of the future and of the unknown).

It is important to remember these differences, so we don't make unfair judgments about how one is grieving and coping with their losses.

Grief as opportunity

Loss and grief and end-of-life issues provide much opportunity for personal growth – people can find their strengths and use their loss in a transformative and meaningful way. Much of this growth may occur over time; premature mention of grief's potential may feel empty to an acutely grieving person. Gradually, with *adaptive integration* of the loss, and moving forward successfully in life – with other relationships, work/purpose, and life enhancement (finding joy) – a grieving person (*griever*) can gain confidence in their ability to cope with challenge. Personal growth often occurs when a grieving person has found a sense of meaning to their loss – either spiritually or emotionally – giving rise to lessened pain and greater peace. When it happens, it can be quite amazing to witness.

> ***"He who has a why to live***
> ***Can bear almost any how."***
>
> *– Friedrich Nietzsche*

Myths and facts about grief

Myth: The pain will go away faster if you ignore it.

Fact: Trying to ignore your pain or keep it from surfacing will only make it worse in the long run. For real healing it is necessary to face your grief and actively deal with it.

Myth: It's important to be "be strong" in the face of loss.

Fact: Feeling sad, frightened, or lonely is a normal reaction to loss. Crying doesn't mean you are weak. Showing your true feelings can help them and you.

Myth: If you don't cry, it means you aren't sorry about the loss.

Fact: Crying is a normal response to sadness, but it's not the only one. Those who don't cry may feel the pain just as deeply as others. They may simply have other ways of showing it.

Myth: Grief should last about a year.

Fact: There is no right or wrong timeframe for grieving. How long it takes can differ from person to person.

Children and grief

Some of Mission Hospice's bereavement counselors specialize in supporting grieving children. It is also helpful for volunteers to understand some basic developmental grief responses of children.

Age and emotional development influence the way a person grieves a death. Most grieving children have three main concerns (the 3 C's):

> **Care**: Kids need to know who is going to care for them.
>
> **Contagion**: Kids need to know they won't catch the disease that made their loved one die.
>
> **Cause**: Kids need to know they didn't do anything to cause the death.

Children younger than age 7 usually perceive death as separation. They may feel abandoned and scared, and they may fear being alone or leaving people they love. Grieving young children may not want to sleep alone at night, or they may refuse to go to day care or school. Children under age 7 usually are not able to verbally express their feelings; instead, they tend to act out their feelings through behaviors such as refusing to obey adults, having temper tantrums, or role-playing their lives in pretend play.

Children between the ages of 2 and 5 may develop eating, sleeping, or toileting and bed-wetting problems.

Children younger than age 2 may refuse to talk and be generally irritable.

Children between the ages of 7 and 12 often perceive death as a threat to their personal safety. They tend to fear that they will die also and may try to protect themselves from death. While some grieving children want to stay close to someone they think can protect them, others withdraw. Some children try to be very brave or behave extremely well; others behave terribly. A grieving child may have problems concentrating on schoolwork, following directions, and/or doing daily tasks. Children in this age group need to be reassured that they are not responsible for the death they are grieving.

Teens perceive death much like adults do, but they may express their feelings in dramatic or unexpected ways. For example, they may join a religious group that defines death in a way that calms their feelings. They may try to defy death by participating in dangerous activities such as reckless driving, smoking cigarettes, drinking alcohol, taking illegal drugs, or having unprotected sex. Like adults, preteens and teens can have suicidal thoughts when grieving. Warning signs of suicide in children and teens may include preoccupation with death or suicide or giving away belongings.

Guidelines for supporting grieving children:

- Answer their questions, even the hard ones. It’s okay to say, “I don’t know.”
- Give the child choices, whenever possible.
- Talk about and remember the person who died.
- Give the child permission to share his or her feelings about the deceased.
- Respect differences in grieving styles.
- Give a child options to express him/herself: art, music, sports, play.
- Listen without judgment.
- Hold a memorial service and allow for saying goodbye.
- Allow breaks from grief – to play, focus on friends, school, and fun.

When does grief counseling end?

Although Mission Hospice offers eight free counseling sessions to bereaved family members, we all know grief does not go away after eight weeks, or eight sessions. A person begins to feel “healed” when they realize they have their own resources to cope with their loss. Those resources may be external (friends, family, sense of purpose) or internal (self-soothing, perspective, faith, confidence, self-efficacy, resilience). The acute symptoms of grief, such as insomnia, fatigue, physical sensations of panic or anxiety, and chaotic and uncontrollable emotions will have reduced, with more frequent periods of routine, stable emotional health. The intensity of the pain of grief will have lessened, and the person will focus less on the pain of loss and more on the love that they once had with their loved one. The bereaved recognize there may be occasional times of intense grief, such as during anniversaries, but they will feel confident enough to handle them on their own, perhaps with connection to their own personal support system.

Coping with feelings

When clients/family members show difficult emotions (fear, anger, sorrow, shame), we can:

- Normalize
- Generalize
- Personalize

Our job is to *allow and accept* the expression of emotions. Some feelings are not acceptable if they intimidate, threaten harm for self or others. Look at emotions with curiosity and friendliness.

Self-care for caregivers

Being a caregiver can be stressful, emotional, and exhausting. Finding ways to take care of oneself while caring for another can be challenging. Our social workers help caregivers develop coping abilities, manage family relationships, and recognize sources of stress – as well as find ways to relax. We also help caregivers learn to grieve, both before and after their loss.

Volunteers also need to care for themselves; you will find more tips for self-care at the end of this manual.

We encourage caregivers, including volunteers, to:

- Tend to their own health
- Get plenty of sleep and eat well
- Exercise regularly
- Find ways to relieve the stress that accompanies caregiving
- Seek and accept help
- Know their limits
- Accept and talk about their grief

It's important for caregivers to identify what they need or want help with. Some people find it difficult to ask for – and accept – help.

When caregivers get overwhelmed:

- Naming emotions is the first way to control them: "If we don't know what we feel, we can't feel what we don't know."
- Be mindful (not judging but accepting) of emotions.
- Emotions are teachers, not burdensome problems.
- Emotions are energy.
- When difficult emotions are stopped, denied, energy can become toxic.
- "Emotional energy unimpeded flows in the direction of healing." – Miriam Greenspan
- Emotions live in the body; be mindful of physical signs of stress.

- Our goal as human beings is to let ourselves experience strong emotions and also realize there may be times when we need to put on hold experiencing them in order to continue functioning. This is called compartmentalizing.
- We are in a continual struggle to balance stepping forward and taking action to deal with our difficult emotions and meet the demands of daily living, and also stepping back to rest and re-energize ourselves.
- As a volunteer, it is okay to show your empathy, including tears, as long as your emotions do not take away the focus from the client/family.
- Your reactions to suffering, illness, dying, grief, and death deserve to be heard and are also your strengths.

Practical ideas for managing difficult emotions in the moment:

- Deep breathing
- Mindfulness
- Hand over heart gesture / soothing gestures
- Re-framing/perspective
- Prayer
- Guided imagery – imagining positive experiences
- Social support
- Safe touch, hugging (human or animal!)
- Writing
- Music
- Art
- Exercise

Things to watch out for:

- Numbing. “It’s too much.”
- Shutting down. “I don’t care.”
- Burnout. “When is this over?”
- Irritability. “He bugs me.”
- Depression. “I’m too weary.”

Bereavement is a process, a journey, with many paths to walk, each unique to the griever. At Mission Hospice, our bereavement program is designed to meet, as best we can, the specific needs of our bereavement clients, through phone contact, letters and cards marking significant occasions, counseling sessions, and/or support groups.

We are honored to be a part of the healing that comes from active, compassionate engagement with our grievers, knowing that we, too, have been and will be in their shoes. It is humbling, and it is a privilege.

Mission Hospice Criteria for Bereavement Risk Levels, Pre- and Post-Death of Patient

This is a clinical tool for Mission Hospice Bereavement Counselors to assess the bereavement risk levels of a patient's loved ones. **As a volunteer, you will not be assessing bereavement risk,** but you may find this helpful.

At least three (3) criteria determine a risk level. Where there are criteria in more than one risk category, the clinician will err on the side of the higher risk level.

Low risk

- ☐ No substance / alcohol abuse
- ☐ No suicidal ideation and/or homicidal ideation
- ☐ Understands and/or accepts diagnosis / prognosis
- ☐ Affect and behavior appropriate to situation
- ☐ Denial not dysfunctional
- ☐ Healthy relationship with patient and/or other family members
- ☐ Minimal complications to physical and/or mental health
- ☐ Good support system in place regarding family, friends, social groups, faith community
- ☐ Spiritual pain absent or negligible

Moderate risk

- ☐ Evidence of some substance / alcohol abuse, client still functional
- ☐ No suicidal ideation and/or homicidal ideation
- ☐ Trouble understanding and/or accepting diagnosis / prognosis
- ☐ Affect and/or behavior causing moderate level of dysfunction
- ☐ Denial affecting some ability to cope with patient's condition
- ☐ Some level of dysfunctional relationship with patient and/or other family members
- ☐ Some complications regarding physical and/or mental health
- ☐ Inadequate support system

☐ Multiple losses

☐ Spiritual pain present with mild to moderate degree of client dysfunction

☐ Short-term diagnosis and/or patient’s short stay on service

☐ Children in the home

☐ Alienated from cultural supports

☐ Difficult end-of-life experience

High risk

☐ Multiple high risk factors including substance/alcohol abuse, causing dysfunction for client

☐ Active suicidal ideation (SI) and/or homicidal ideation (HI)

☐ Unable to understand and/or accept diagnosis / prognosis

☐ Affect and/or behavior causing significant level of dysfunction

☐ Denial significantly impacting client’s ability to cope with patient’s condition

☐ Significant dysfunctional relationship with patient and/or other family members

☐ Significant complications to physical and/or mental health

☐ Multiple losses, some may be traumatic

☐ Poor or non-existent support system

☐ Spiritual pain significantly impacting client’s ability to function

☐ Children in home/parent death

☐ Significantly alienated from cultural supports

☐ Traumatic end-of-life experience

As always, clinical judgment should guide use of above risk level categories and criteria.

8 • Social work

The role of the medical social worker

Our medical social workers provide emotional and practical support to patients and families, anticipatory grief counseling, and information about local resources such as attendant care and Lifeline services.

The medical social worker can help families understand hospice philosophy and Medicare insurance benefits, and will regularly assess practical and psychosocial-spiritual needs to help patients and families cope. Medical social workers specialize in working with family systems and conflict resolution. (See the article at the end of this section, *Family Conflict at the End of Life*.) Medical social workers can also help with Advance Care Directives, funeral and/or memorial planning, and general problem-solving.

Advance Care Planning

Advance care planning is a process that helps people decide and document what kind of care they would want – and what kind they would not want – if they have a health crisis and are not able to communicate or make decisions. The process allows them to identify someone to make medical decisions for them if they are unable to make their own.

Mission Hospice helps people with Advance Care Planning in advance of critical need, through our Take Charge program (MissionHospice.org/TakeCharge).

When a patient is admitted to our care, if they have not already done Advance Care Planning, our Medical Social Workers will help them complete two important legal documents: California Advance Health Care Directive and POLST (Physician Orders for Life-Sustaining Treatment). Both documents are in this handbook.

MISSION HOSPICE
& HOME CARE
it's about life

California Advance Health Care Directive

Part 1 of this form lets you name another individual as agent to make health care decisions for you if you become incapable of making your own decisions, or if you want someone else to make those decisions for you now even though you are still capable. You may also name an alternate agent to act for you if your first choice is not willing, able, or reasonably available to make decisions for you.

Your agent may not be an operator or employee of a community care facility or a residential care facility where you are receiving care, or your supervising health care provider or an employee of the health care institution where you are receiving care, unless your agent is related to you or is a coworker.

Unless you state otherwise in this form, your agent will have the right to:

1. Consent or refuse consent to any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect a physical or mental condition.
2. Select or discharge health care providers and institutions.
3. Approve or disapprove diagnostic tests, surgical procedures, and programs of medication.
4. Direct the provision, withholding, or withdrawal of artificial nutrition and hydration and all other forms of health care, including cardiopulmonary resuscitation.
5. Donate organs or tissues, authorize an autopsy, and direct disposition of remains.

However, your agent will not be able to commit you to a mental health facility, or consent to convulsive treatment, psychosurgery, sterilization or abortion for you.

Part 2 of this form lets you give specific instructions about any aspect of your health care, whether or not you appoint an agent. Choices are provided for you to express your wishes regarding the provision, withholding, or withdrawal of treatment to keep you alive, as well as the provision of pain relief. You also can add to the choices you have made or write down any additional wishes. If you are satisfied to allow your agent to determine what is best for you in making end-of-life decisions, you need not fill out Part 2 of this form.

Give a copy of the signed and completed form to your physician, to any other health care providers you may have, to any health care institution at which you are receiving care, and to any health care agents you have named. You should talk to the person you have named as agent to make sure that he or she understands your wishes and is willing to take the responsibility.

You have the right to revoke this advance health care directive or replace this form at any time.

About your Advance Health Care Directive

Mission Hospice & Home Care is dedicated to providing you the best care possible in a way that respects your individual needs and choices. In order to do this, we need to be aware of your choices, and to inform you if any of your choices might not be possible for us to meet, given our organization's policies and California state law.

If you have a written Advance Health Care Directive, we request a copy to review and keep for our records. If, after we review your document, any of your wishes conflict with our policies or with CA state law, we will let you know immediately. **If you have not completed a written Advance Health Care Directive and have the legal capacity to do so, we encourage you to complete one now.** We will inform you of any limitations Mission Hospice & Home Care may have in following that Advance Directive.

California law (Health and Safety Code Section 442.5) gives an individual with capacity the right to execute a power of attorney for health care and provides a form for that purpose (see CA Probate Code Section 4670 – 4701.) We have attached a copy of that form, should you choose to use it. California law does not require that you use this form, but the law does specify what is required in order for your written document to be legal. This form meets the legal requirements.

California law also states that you have the right to information and counseling about the Advance Health Care Directive, should you so desire. Please let us know if we can provide you with that counseling, information or with assistance in completing this form. You may also want to consult an attorney for legal advice regarding an Advance Health Care Directive. You are also encouraged to discuss any questions or concerns about completing an Advance Health Care Directive with your physician, family/friends, and particularly with the person you name as your health care agent.

In addition, Mission Hospice & Home Care has adopted the following policy:

> *Mission Hospice & Home Care recognizes that all adults have a fundamental right to make decisions relating to their own medical treatment, including the right to accept or refuse medical care. It is the policy of Mission Hospice & Home Care to encourage patients and their family/caregivers to participate in decisions regarding care and treatment. Valid Advance Directives, such as living wills, Durable Powers of Attorney for Health Care, and DNR (Do Not Resuscitate) orders will be followed to the extent permitted and required by law.*
>
> *In the absence of Advance Directives, Mission Hospice & Home Care will provide appropriate care according to the plan of care authorized by the attending physician and the hospice interdisciplinary group and hospice Medical Director. Mission Hospice & Home Care will conform to state laws regarding implementation of an Advance Directive. Mission Hospice & Home Care will not determine the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an Advance Directive.*

Revised 8/18/14

CALIFORNIA ADVANCE HEALTH CARE DIRECTIVE

Name ______________________ **Date of birth** ______________________

PART 1 – POWER OF ATTORNEY FOR HEALTH CARE

DESIGNATION OF AGENT: I designate the following individual as my agent to make health care decisions for me:

Name of individual you choose as agent: ______________________

Address: ______________________

Home phone: ______________ Work phone: ______________ Cell phone: ______________

OPTIONAL: If I revoke my agent's authority or if my agent is not willing, able, or reasonably available to make a health care decision for me, I designate as my first alternate agent:

Name of individual you choose as first alternative agent: ______________________

Address: ______________________

Home phone: ______________ Work phone: ______________ Cell phone: ______________

OPTIONAL: If I revoke the authority of my agent and first alternate agent or if neither is willing, able, or reasonably available to make a health care decision for me, I designate as my second alternate agent:

Name of individual you choose as second alternative agent: ______________________

Address: ______________________

Home phone: ______________ Work phone: ______________ Cell phone: ______________

AGENT'S AUTHORITY: My agent is authorized to make all health care decisions for me, including decisions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care to keep me alive, except as I state here:

____

______________________ (Add additional sheets if needed.)

WHEN AGENT'S AUTHORITY BECOMES EFFECTIVE:

(Initial) __________ My agent's authority becomes effective when my primary physician determines that I am unable to make my own health care decisions.

OR

(Initial) __________ My agent's authority to make health care decisions for me takes effect immediately.

AGENT'S OBLIGATION:

My agent shall make health care decisions for me in accordance with this power of attorney for health care, any instructions I give in Part 2 of this form, and my other wishes to the extent known to my agent. To the extent my wishes are unknown, my agent shall make health care decisions for me in accordance with what my agent determines to be in my best interest. In determining my best interest, my agent shall consider my personal values to the extent known to my agent.

AGENT'S POSTDEATH AUTHORITY: My agent is authorized to make anatomical gifts, authorize an autopsy, and direct disposition of my remains, except as I state here or in Part 3 of this form:

____

____ (Add additional sheets if needed.)

NOMINATION OF CONSERVATOR: If a conservator of my person needs to be appointed for me by a court, I nominate the agent designated in this form. If that agent is not willing, able or reasonably available to act as conservator, I nominate the alternate agents whom I have named, in the order designated.

PART 2 – INSTRUCTIONS FOR HEALTH CARE

If you fill out this part of the form, you may strike any wording you do not want.

END-OF-LIFE DECISIONS: I direct that my health care providers and others involved in my care provide, withhold, or withdraw treatment in accordance with the choice I have marked below:

Choice Not To Prolong Life

(Initial) __________ I do not want my life to be prolonged if (1) I have an incurable and irreversible condition that will result in my death within a relatively short time, (2) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (3) the likely risks and burdens of treatment would outweigh the expected benefits,

OR

Choice To Prolong Life

(Initial) __________ I want my life to be prolonged as long as possible within the limits of generally accepted health care standards.

RELIEF FROM PAIN: Except as I state in the following space, I direct that treatment for alleviation of pain or discomfort be provided at all times, even if it hastens my death:

____

____ (Add additional sheets if needed.)

OTHER WISHES: (If you do not agree with any of the optional choices above and wish to write your own, or if you wish to add to the instructions you have given above, you may do so here.) I direct that:

____

____ (Add additional sheets if needed.)

3 – DONATION OF ORGANS AT DEATH (OPTIONAL)

PART I. Upon my death:

(Initial) __________ I give any needed organs, tissues, or parts.

OR

(Initial) __________ I do not authorize the donation of any organs, tissues or parts.

OR

(Initial) __________ I give the following organs, tissues, or parts only: ______________________

____

If you wish to donate organs, tissues, or parts, you must complete parts II and III.

PART II. My gift is for the following purposes (initial all that you accept):

________ Transplant ________ Research ________Therapy ________ Education

PART III. I understand that tissue banks work with both nonprofit and for-profit tissue processors and distributors. It is possible that donated skin may be used for cosmetic or reconstructive surgery purposes. It is possible that donated tissue may be used for transplants outside of the United States.

1. My donated skin may be used for cosmetic surgery purposes (initial your choice): _____ Yes _____ No
2. My donated tissue may be used for applications outside of the United States. _____ Yes _____ No
3. My donated tissue may be used by for-profit tissue processors and distributors. _____ Yes _____ No

(Health and Safety Code Section 7158.3)

PART 4 – PRIMARY PHYSICIAN (OPTIONAL)

I designate the following physician as my primary physician:

Name of Physician: ______________________ Phone: ______________________

Address: ______________________

OPTIONAL: If the physician I have designated above is not willing, able, or reasonably available to act as my primary physician, I designate the following physician as my primary physician:

Name of Physician: ______________________ Phone: ______________________

Address: ______________________

PART 5 – SIGNATURE

The form must be signed by you and by two qualified witnesses, or acknowledged before a notary public.

PATIENT

Printed name: ______________________ Signature: ______________________

Address: ______________________

Date: ______________________ Time: ______________________

STATEMENT OF WITNESSES: I declare under penalty of perjury under the laws of California (1) that the individual who signed or acknowledged this advance health care directive is personally known to me, or that the individual's identity was proven to me by convincing evidence, (2) that the individual signed or acknowledged this advance directive in my presence, (3) that the individual appears to be of sound mind and under no duress, fraud, or undue influence, (4) that I am not a person appointed as agent by this advance directive, and (5) that I am not the individual's health care provider, an employee of the individual's health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.

FIRST WITNESS

Printed name: ______________________ Signature: ______________________

Address: ______________________

Phone: ______________________ Date: ______________________ Time: ______________________

SECOND WITNESS

Printed name: __________ Signature: __________

Address: __________

Phone: __________ Date: __________ Time: __________

ADDITIONAL STATEMENT OF WITNESSES: At least one of the above witnesses must also sign the following declaration.
I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance health care directive by blood, marriage, or adoption, and to the best of my knowledge, I am not entitled to any part of the individual's estate upon his or her death under a will now existing or by operation of law.

Printed name: __________ Signature: __________

Address: __________

Date: __________ Time: __________

A notary public or other officer completing this certificate verifies only the identity of the individual who signed the document to which this certificate is attached, and not the truthfulness, accuracy, or validity of the document.

YOU MAY USE THIS CERTIFICATE OF ACKNOWLEDGMENT BEFORE A NOTARY PUBLIC INSTEAD OF THE STATEMENT OF WITNESSES.
State of California, County of __________

On (date)__________ before me, (name and title of the officer) __________ __________ personally appeared (name(s) of signer(s)) __________ __________ , who proved to me on the basis of satisfactory evidence to be the person(s) whose name(s) is/are subscribed to the within instrument and acknowledged to me that he/she/they executed the same in his/her/their authorized capacity(ies), and that by his/her/their signature(s) on the instrument the person(s), or the entity upon behalf of which the person(s) acted, executed the instrument.

I certify under PENALTY OF PERJURY under the laws of the State of California that the foregoing paragraph is true and correct. WITNESS my hand and official seal.

Signature: __________ [Seal]

PART 6—SPECIAL WITNESS REQUIREMENT

If you are a patient in a skilled nursing facility, the patient advocate or ombudsman must sign the following statement.

STATEMENT OF PATIENT ADVOCATE OR OMBUDSMAN
I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman as designated by the State Department of Aging and that I am serving as a witness as required by Section 4675 of the Probate Code.

Printed name: __________ Signature: __________

Address: __________

Date: __________ Time: __________

9 • Standards of conduct & core competencies

Standards of conduct for volunteers

Direct Care Volunteers are expected to adhere to the following standards of conduct, policies, and procedures.

Professionalism, dress, and grooming

Mission Hospice's reputation is dependent on providing service to clients in a professional and capable manner. Be punctual. If you cannot keep an appointment, or will be late, phone ahead.

Volunteers are expected to maintain good personal hygiene with a neat and clean appearance, and to dress in attire that is appropriate for their environment and responsibilities. Fragrance should not be used in the workplace or in external homes and facilities.

Volunteers must use good judgment in determining their dress, and should not wear clothing with offensive words or pictures, shorts, beach wear, clothing with rips or holes, or other items that are inappropriate for interacting with patients. In addition, volunteers should not wear short/low cut revealing items, or items that may become revealing with general movement.

Substance use

Never smoke, or wear clothes that smell of smoke, in the presence of a patient. Smoking is prohibited in the office and at all Mission Hospice functions and events.

Mission Hospice prohibits the following:

- Possessing, using, or being under the influence of alcohol or an illegal drug, intoxicant, or controlled substance during working (volunteering) hours or while on company business.
- Operating a vehicle on Mission Hospice business while under the influence of alcohol or an illegal drug, intoxicant, and controlled substance.

Health

- All volunteers are required to have been vaccinated for Covid and received at least one booster shot. Volunteers must provide proof of their Covid vaccinations.
- We highly recommend you receive an annual flu shot.
- If you have a communicable illness or disease, believe you may have been exposed to a person so diagnosed, or have recently visited a location where there was an outbreak of such an illness and you are exhibiting any symptoms of the illness, report this to the Volunteer Coordinator immediately.

Harassment

Mission Hospice will not tolerate harassment of employees, volunteers, or contractors, including verbal, visual, or physical conduct that is intimidating, offensive, or hostile.

Harassment on the basis of sex, sexual orientation, gender identification, age, race, medical condition, pregnancy, race, national origin, religion, marital or veteran status, citizenship, physical or mental disability, or other characteristics protected by local, state, or federal law is strictly prohibited.

Sexual harassment is also strictly prohibited. If you feel that you have been harassed or unfairly discriminated against, you should immediately contact the Director of Volunteer Services, the Human Resources Director, or the CEO.

Conflicts of interest

Volunteers have a duty of loyalty to Mission Hospice and should always act in the best interest of Mission Hospice. Moreover, volunteers are expected to use good judgment, to adhere to high ethical standards, and to avoid situations that create an actual or potential conflict between their personal interests and the legitimate business interests of Mission Hospice.

A conflict of interest exists when the volunteer's loyalties or actions are divided between Mission Hospice's interests and those of another, such as a competitor, supplier, contractor or patient. Both the fact and the appearance of a conflict of interest should be avoided. Volunteers who are unsure as to whether a certain transaction, activity, or relationship constitutes a conflict of interest should discuss it with the director of volunteer services for clarification.

Other

- Violence in the home: If you experience or observe violence in a patient's home, leave immediately and call the Director of Volunteer Services **and** 911.
- Workplace violence: Acts or threats of physical violence, including intimidation, harassment, and /or coercion will not be tolerated.
- Speaking to the media: Volunteers should refer any media inquiries to the Communications Director. Speaking to the media about a patient or family member is a direct HIPAA violation.

VOLUNTEER SERVICES

Policy No. 2HOS-009.1

PURPOSE

To ensure that qualified volunteers provide appropriate services in accordance with the interdisciplinary plan of care and hospice program needs.

POLICY

Mission Hospice & Home Care will provide volunteer services under the direction of a volunteer coordinator and with the assistance of trained hospice volunteers. The duties and responsibilities of the volunteer coordinator and volunteers will be identified in appropriate job descriptions.

Volunteers may work in a variety of capacities, including but not limited to:

1. Patient care volunteers – provide emotional support and practical assistance that enhances the comfort and quality of life for patients and family/caregivers. These services include being available for companionship, listening, simply “being there,” and preparing meals.

2. Bereavement volunteers –support bereavement department with facilitating drop in groups for family/caregivers and administrative support.

3. Errands and transportation volunteers – offer a type of practical support often needed by hospice patients and family/caregivers. These duties may include picking up prescriptions or supplies, or grocery shopping.

4. Community Volunteers – provide practical assistance to patients such as gardening and haircuts.

5. Office volunteers – lend their services working in Mission Hospice & Home Care’s administrative offices. These activities may include assembling information packets, filing, photocopying, tuck-in calls and assisting with mailings.

6. Pet Visitor Volunteers

PROCEDURE

1. The volunteer coordinator will develop, implement, and regularly evaluate the volunteer services program.

2. The volunteer coordinator will arrange for volunteers to provide volunteer support to patient and family/caregiver, in accordance with the plan of care.

3. Volunteers will document their activities on volunteer activity/clinical notes and submit this documentation for the patient's clinical records.

4. Volunteer Coordinator will develop and implement a volunteer orientation and training program that is sufficient to meet the needs of the patients and families and will include, but will not be limited to:

   A. History, mission, philosophy and structure of the hospice concept

   B. Volunteers' roles and responsibilities

   C. Volunteer program policies

5. The volunteer coordinator will track the use of volunteers and that hours of volunteer services exceed 5% of the total patient care hours of paid and contracted hospice personnel.

6. The volunteer coordinator will document ongoing efforts to recruit, train, and retain volunteers of all ages..

Things to do and NOT do as a volunteer

Do

- Talk with patient and family
- Assist the family with patient care
- Provide companionship by just being there
- Be a listener
- Perform light housework, shopping, errands, transporting
- Observe and report changes in the patient or in relationships
- Facilitate relationship of the doctor/patient, patient/family, and patient/family/community
- Strengthen patient's sense of being in control
- Read to and/or play games with patient
- Record as requested for data collection and continuity of care
- Stay neutral in family disagreements, but offer an open ear so grievances can be aired
- Attend funeral, memorial, or other services after death of patient
- Be supportive of family members during the mourning period

Do NOT

- Provide 8-hour or 24-hour care
- Proselytize, correct, judge, fix, or give unsolicited advice
- Give legal, medical, or financial advice
- Dispense dosages from bottles or review medications with patients/families/caregivers
- Refer patient/family to a specific medical professional
- Suggest specific alternative therapies regarding patient care
- Suggest or start the conversation about ELOA
- Enter into family differences of opinion
- Contribute to family/patient dependency on you/us

Timeline of a volunteer assignment and visit

You are assigned

1. Patient is accepted into Mission Hospice care.
2. IDT (Inter Disciplinary Team) creates a “Plan of Care.”
3. IDT member (social worker) submits a “Volunteer Request to Volunteer Coordinator.”
4. Volunteer coordinator calls the family to discuss volunteer options, if necessary.
5. Volunteer coordinator contacts the volunteer team with the request.
6. Volunteer team members email back if available.
7. Volunteer coordinator assigns Direct Care Volunteer (DCV) to case.
8. Volunteer coordinator may send the nursing, psychosocial, or spiritual counselor assessments or progress notes to the DCV.

After you are assigned

1. DCV reads over the material and contacts volunteer coordinator with any questions.
2. DCV calls patient to introduce himself/herself and set up a visit time.

On the day of your visit

1. DCV calls patient to make sure visit is still desired.
2. DCV reconfirms the time, location, and how to get into the house/facility.
3. DCV arrives **promptly** at the designated time.

At the visit

1. Upon your arrival and before going in, take a few minute to ground yourself, calm yourself, let go of distractions, and focus on the visit.
2. Introduce yourself to the patient and/or family.
3. Ask if you could wash your hands.
4. Wash hands with soap and hot water – wash long enough to sing “Happy Birthday” all the way through. Dry with paper towels, or use disinfectant solution. If washing your hands is not an option, use hand sanitizer.
5. When you see the patient, ask if they are in any pain.
6. Ask them to rate the pain 0-10 (if patient is non-verbal, use the non-verbal pain scale on the visit report form).
7. Continue visit.
8. Wash hands again upon leaving.
9. Sit in your car and download your visit for a few minutes.

After visit

1. Fill out a Volunteer Visit Report. You should have this as an email template.
2. Be sure to put a number from 1-10 in the Pain column (do not leave this blank).
3. Email the report to volunteerstaff@misionhospice.org within 24 hours of your visit.

Elder abuse

Patients in our care are often frail and vulnerable. The law requires Mission Hospice staff members to report any elder abuse, or abuse of any dependent adults age 18-or older.

Elder abuse includes

- Physical abuse (beatings, assault, unreasonable physical restraint, or prolonged deprivation of food or water)
- Fiduciary abuse (misuse or theft of money or property)
- Neglect/denial of needs (failure to provide adequate water, food, clothing, and care; health or safety hazards)
- Abandonment (desertion of a dependent adult or elder)

If you observe any elder abuse, please notify the director of volunteer services immediately.

Special volunteer opportunities

Vigiling

A vigil consists of people sitting at the bedside of a dying patient, usually during the last 48 hours of their life. Sometimes vigils occur when a patient may otherwise be alone, such as during hours when their family cannot be at the bedside. At other times, families appreciate having vigilers at the bedside of their loved ones, even when family members are present, to help normalize the dying process and to support family members during those last hours.

What vigilers do

Vigilers accompany the patient (and family) during the hours they are with them, being fully present and offering what is needed in the circumstances. Sometimes families need and want comfort and compassion; sometimes they want to be reassured about the dying process, and even knowing that someone in the room, the vigiler, knows when to call a nurse or notice if the patient appears uncomfortable.

Some vigilers read, play music, talk, or sing quietly. Some are skilled in coma work and helping family members, as well as the patient, to complete unfinished business. The greatest gift vigilers provide is being fully present and available, to patient and family, during the last hours of life.

To become a vigiling volunteer

After completing the Direct Care Volunteer training, volunteers may sign up for additional training to prepare them for becoming a vigiling volunteer. Please let us know if you are interested in our Vigil Program.

Mission House – Our hospice house

As in private homes, volunteers in our six-bed hospice house in Redwood City may provide direct care for patients, offering companionship, life review, vigiling, and more. To volunteer at the house, you must have at least six months of hospice volunteer experience and a "toolbox" of skills such as vigil training, Gentle Touch massage, Healing Touch, or Reiki.

In addition, there are opportunities for volunteers to help with flower arranging, pickup and/or delivery, cooking, gardening, shopping, and administrative tasks.

Complementary therapies

Volunteers can add to the physical, social, and spiritual care provided by the Mission Hospice team through any of several complementary therapies. These non-invasive, holistic practices promote comfort for patients and families, and include:

- Pet therapy
- Music therapy
- Healing Touch
- Gentle Touch massage

These and other complementary therapies require additional training and/or certification. To learn more, contact the director of volunteer services.

We Honor Veterans

Mission Hospice participates in We Honor Veterans, a nationally-recognized program of the National Hospice and Palliative Care Organization (NHPCO) in collaboration with the Department of Veterans Affairs (VA).

The program focuses on respectful inquiry, compassionate listening, and grateful acknowledgment of our Veterans. We Honor Veterans helps us understand and address their special needs at the end of life:

- Military training and the culture of stoicism can often prevent Veterans from sharing difficult experiences.
- When one Veteran talks to another, stoicism and secrecy dissolve.
- Veterans share a common language and code of conduct.
- Sharing supports life review and healing.

You will find more information about caring for Veterans on the Mission Hospice volunteer portal.

End of Life Option Act

Mission Hospice is dedicated to providing compassionate, team-oriented, holistic palliative care and comfort for all patients, while respecting their individual rights, needs, and choices, including those offered by the End of Life Option Act (ELOA). Passed in June 2016, the California End of Life Option Act (ELOA) allows a terminally ill patient to request a drug from his or her physician that will end the patient's life.

We will support our patients' end-of-life care decisions. We acknowledge that some of our hospice patients may, after considering all other options, wish to exercise their legal rights under the End of Life Option Act. While we never suggest or recommend this option, if a patient is interested in pursuing this option, we will not abandon them.

As a Mission Hospice team member, you are not allowed to suggest or recommend this option to your patient. If your patient indicates that they are interested in ELOA, you must immediately report this interest to the Volunteer Coordinator.

COALITION FOR
COMPASSIONATE CARE
OF CALIFORNIA

California End of Life Option Act

The Coalition for Compassionate Care of California does not take a position on the End of Life Option Act. We are a source of neutral information on the provisions of the law.

The California End of Life Option Act (EoLOA) is a state law that permits terminally ill adult patients with capacity to make medical decisions to be prescribed an aid-in-dying medication if certain conditions are met. Signed into law by Governor Brown in October 2015, the law went into effect on June 9, 2016. California is the fifth state to enact an aid-in-dying law.

In October 2021, Governor Newsom signed SB 380, which makes significant changes to California's End of Life Option Act, including reducing the required waiting period between a patient's oral requests from 15 days to 48 hours. The changes went into effect on January 1, 2022.

To be eligible to request a prescription for the aid-in-dying drugs, an individual must:

- Be an adult (18 years old or older).
- Be a California resident.
- Have a diagnosis from his/her primary physician of an incurable and irreversible disease which will, within reasonable medical judgement, result in death within six months.
- Be able to make medical decisions for themselves as determined by health professionals.
- Voluntarily request a prescription for an aid-in-dying drug without influence from others.
- Be able to self-administer (eat, drink, and swallow) the aid-in-dying drug.

The request must be made solely and directly by the patient to the attending physician, and cannot be made on behalf of the patient through a power of attorney, an advance health care directive, a conservator, health care agent, surrogate, or any other legally recognized health care decisionmaker.

Participation is voluntary for patients and health providers

Participation in the End of Life Option Act is voluntary for individual patients, health providers (physicians, nurses, pharmacists, etc.) as well as health systems, HMOs, hospitals, medical offices, nursing homes, pharmacies and hospices. Insurance providers are not required to cover aid-in-dying drugs or related physician fees. Check with your health insurance company about their rules regarding costs associated with aid-in-dying drugs or related physician fees.

If the patient's provider or the organization where the patient receives care is not participating in the End of Life Option Act, the patient may request basic information or ask for a referral. Healthcare entities are required to post their current policy regarding medical aid in dying on their internet website.

Some providers may not be comfortable giving patients information about the Act or even providing a referral. In this case, patients may wish to consult with advocacy organizations or others who provide information about the End of Life Option Act and to find participating providers.

New in 2022, physicians who cannot or will not support patient requests are required to tell the patient they will not support them, document the patient's request and provider's notice of rejection in the patient's medical record, and transfer the relevant medical record upon request. A healthcare provider or healthcare entity is prohibited from engaging in false, misleading, or deceptive practices relating to their willingness to qualify an individual or provide a prescription for an aid-in-dying medication to a qualified individual.

Prior To Discussing The Aid-In-Dying Drug, A Patient And Their Physician Should Discuss:

- The patient's understanding of his/her diagnosis and prognosis
- The patient's hopes and fears
- The benefits of palliative care and hospice care
- Options for pain control and symptom management

The process for requesting aid-in-dying drugs

If a terminally-ill patient meets the requirements to receive the aid-in-dying drug, the patient and his or her attending physician must follow several steps which are carefully defined in the law, including:

The patient must make two oral requests, at least 48 hours apart, directly to his or her physician (the attending physician)

- The patient must also make one request in writing, using the Patient's Request for Aid-in-Dying Drug form, which must be signed by the patient and two witnesses, and provided directly to his or her attending physician. The law does not say specifically when the written request must be made.
- The patient must discuss the aid-in-dying drug request with his/her attending physician without anyone else present (except an interpreter, if needed), to make sure the request is voluntary.
- The patient must then see a second physician (a consulting physician) who can confirm the patient's diagnosis, prognosis, and ability to make medical decisions.

If either physician thinks the patient's ability to make medical decisions could be impaired, the patient must also see a mental health specialist (psychiatrist or licensed psychologist) to make sure his or her judgment is not impaired.

The law requires that the patient and attending physician discuss all of the following:

- How the aid-in-dying drug will affect the patient, and the fact that death might not come immediately.
- Realistic alternatives to taking the drug, including comfort care, hospice care, palliative care, and pain control.
- Whether the patient wants to withdraw the request.
- Whether the patient will notify next of kin, have someone else present when taking the drug, or participate in a hospice program. (The patient is not required to do any of these things.)
- That the patient will not take the drug in a public location.

The physician must ensure the patient knows they do not have to take the drug, even once they have obtained the aid-in-dying drug.

If the patient still wishes to proceed and the attending physician agrees, the attending physician may provide the aid-in-dying drug by either dispensing it directly to the patient or by delivering the prescription to a participating pharmacist. By law, the physician cannot hand a written prescription directly to the patient or their representative.

The law is not specific about which aid-in-dying drug(s) can be prescribed.

A Final Attestation for Aid-in-Dying Drug form is no longer required.

More information: https://coalitionccc.org/CCCC/Resources/End-of-Life-Option-Act

May 2022

Mission Hospice & Home Care

Core Competency Quiz KEY

Feb 2023

COMPETENCY #1:

To have knowledge of the agency's mission, policies, and procedures.

1. As a Medicare-certified agency, we accept patients for hospice care when their prognosis is 12 months or less. True [✓ False]
2. For patients on the hospice benefit, we pay for their medical equipment. [✓ True] False
3. For patients on the hospice benefit, we pay for medications related to the terminal illness. [✓ True] False
4. For patients on the hospice benefit, we never pay for radiation or chemotherapy. True [✓ False]
5. Medicare and MediCal pay us a fixed amount for each home visit. True [✓ False]
6. Hospice patients are required to sign advance directives such as a living will, Durable Power of Attorney for Health Care, or Do Not Resuscitate form. True [✓ False]
7. Where would you find our agency's personnel policies?

   Ask the Chief Compliance Officer.

8. What is the Mission Statement of Mission Hospice & Home Care?

   Mission Hospice & Home Care honors and supports people's wishes for the last phase of life by providing our community with exceptional end-of-life care and education.

Mission Hospice & Home Care

Core Competency Quiz KEY

Feb 2023

COMPETENCY #2

To be familiar with and knowledgeable about the issues involved in death and dying, and to be effective in communicating with patients, families, and the public about these issues.

1. Match the definitions below with the terms. Hint: there are 10 terms & 9 definitions.
    - A. Advanced Directive
    - B. Durable Power of Attorney for Health Care
    - C. Euthanasia
    - D. Hospice
    - E. The Medicare medical requirement for eligibility for hospice admission
    - F. Palliative Care
    - G. End of Life Option Act (ELOA)
    - H. Prognosis
    - I. Terminal illness
    - J. Palliative sedation

_I__ An illness that will, if it follows its normal course, eventually cause death.

_A__ Written instructions concerning the provisions of health care, to be followed in the event the individual is incapacitated at the time a health care decision must be made.

_C__ Death caused by the deliberate action of someone other than the patient, with the intention of ending the patient's life.

_E__ A person who is terminally ill with a prognosis of 6 months or less to live if the disease follows its normal course.

_G__ California's End of Life Option Act (ELOA) allows a terminally ill patient to request a drug from his or her physician that will end the patient's life. Patients who choose to end their lives in this way, and who follow the steps in the law, will not be considered to have committed suicide.

_H__ A foretelling of the outcome of a disease; a forecast of the outcome of a disease.

_J__ The use of high doses of sedatives to relieve extremes of physical distress, for the purpose of addressing unmanageable suffering during the final days of the patient's illness.

_B__ A document that includes designation of one or more individuals to make health care decisions on behalf of an incapacitated patient.

_F__ Provides an extra level of physical, emotional, and spiritual support to improve quality of life for people with serious, life-limiting illness who are not ready for hospice.

2. Name two of the common signs or symptoms of approaching death.

   Shortness of breath, erratic breathing, gurgling breathing sounds, extremities coloring changes to bluish, cold skin

3. Does California have a law that allows physician-assisted suicide?

   No. The End of Life Option Act (2016) is not classified as physician-assisted suicide.

COMPETENCY #3

To recognize one's own attitudes, feelings, values, and expectations about death and the individual, cultural, and spiritual diversity existing in these beliefs and customs.

Write one or two sentences about your own attitudes about death and dying. If possible, touch on how your attitudes have altered since being associated with Mission Hospice & Home Care.

COMPETENCY #4

To have a general understanding of palliative care and pain and symptom management.

1. Pain is always an accompaniment to a cancer diagnosis. True [✓ False]
2. Pain medication doses should only be given when the patient has pain they cannot tolerate. True [✓ False]
3. Palliative care may include radiation therapy and blood transfusions. [✓ True] False
4. If a patient takes pain medication such as morphine early in the illness, they may develop a tolerance that would mean pain medication would not work later when the pain is worse. True [✓ False]
5. Symptoms that hospice care frequently addresses are pain, nausea, anxiety, constipation, and shortness of breath. [✓ True] False
6. There are very few cases in which the hospice team cannot manage a patient's pain. [✓ True] False

Mission Hospice & Home Care

Core Competency Quiz KEY

Feb 2023

COMPETENCY #5

To have a general understanding of grief and bereavement.

1. Anticipatory grief is just as valid and important as grief occurring after the patient dies. [✓ True] False
2. Grief and depression are exactly the same. True [✓ False]
3. Medicare guidelines require that we offer our support to the bereaved for only six months. True [✓ False]
4. Our regular bereavement services are free of charge. [✓ True] False
5. Bereavement care is mostly listening. [✓ True] False
6. Becoming the bereaved's friend is one of the most caring and professional things we can do. True [✓ False]
7. Children grieve like adults but for a shorter period of time. True [✓ False]
8. Signs or symptoms of high-risk grief are normal and should not unduly concern us. True [✓ False]
9. We can give bereaved families the names of at least three outside professionals and three community agencies, if needed. [✓ True] False

COMPETENCY #6

To understand how to manage stress of hospice work.

1. Which of the following are positive responses to stress?

[✓ _____ A walk on the beach]

_____ Having several drinks at the end of a hard day

[✓ _____ Talking it out with someone]

[✓ _____ Writing in a journal]

[✓ _____ Having a massage]

[✓ _____ Seeing a counselor]

_____ Keeping a bright face and not talking about your stresses

_____ All of the above

2. Name two things Mission Hospice & Home Care provides to help employees with the stresses of hospice work.

Open door policy, compassionate work environment, generous PTO policy, availability of Spiritual Counselors and Bereavement Counselors as needed

Mission Hospice & Home Care

Core Competency Quiz KEY

Feb 2023

COMPETENCY #7

To have the ability to work effectively as a team member, to understand the roles of other team members and office staff, and to utilize each others' expertise.

1. Name the team member whose job it is to:

Take referrals: Clinical outreach team

Visit patients and families with existential concerns: Spiritual Counselors

Clean patients, provide bed baths, change diapers, change linens: Home Health Aides

Order gloves, diapers, and other patient care supplies: Case Manager

Assign Direct Care Volunteers to patients and families: Volunteer Coordinator

Help patients and families complete advance health care directives, make funeral arrangements, and find caregivers: Medical Social Workers

Take calls in the office from patients and families who have medical concerns: Triage

Coordinate grant proposals and solicitations for donations to Mission Hospice & Home Car
Development

Bill Medicare: Accounting

See that bereavement follow-up is done for family members: Bereavement Coordinator

Send physician surveys and discharge summaries after a patient's death: Quality control

Mission Hospice & Home Care

Core Competency Quiz KEY

Feb 2023

2. Mark the four “core disciplines” that are required to participate in care planning.

___ Medical Social Workers

___ Direct Care Volunteers

___ Physicians

___ Patient care coordinators

___ Dieticians

___ Home Health Aides

___ Nurses

___ Spiritual Counselors and other counselors

___ Physical Therapists

___ Pharmacists

3. List two things that a Medical Social Worker might do with/for a patient or family:

Help with Durable Power of Attorney paperwork, help family complete a POLST, help arrange funeral plans, family counseling, assist pt/family with placement, assist family in arranging caregiving, assist pt in completing Advance Directives

4. List two things that a Spiritual Counselor might do with/for a patient or family:

Connect with their faith community, provide life review opportunities, help pt/family find meaning in illness, provide funeral services to family, provide spiritual and/or religious support, listen

5. List two things that a Direct Care Volunteer might do with/for a patient or family:

Respite for family, errands, transportation, massage. pet therapy, listen, shop, take patient on an outing, hold hands with a patient who can’t speak, companioning, vigiling,

Mission Hospice & Home Care

Core Competency Quiz KEY

Feb 2023

COMPETENCY #8

To have good listening skills and to understand concepts of active listening.

1. List one way you show that you are listening actively to another person:

   When appropriate, maintain eye contact; show calm body language

2. In a situation in which you wish to offer empathetic, reflective listening, which of the following responses would be useful?

   a. "Let's talk about pleasant things."
   b. "You sound very tired."
   c. "That happened to me too."
   d. "That must be very frustrating."
   e. "So, what I would do is…"
   f. "It sounds as though you don't feel much hope."
   g. "It's all for the best."
   h. "That must be very disappointing."
   i. "You'll feel better soon."

3. The way in which you ask a question can make a difference in how it is answered. An ope ended question will invite the client to give you more information. Which of the question below are open-ended?

   a. Tell me about your relationship with your brother.
   b. Tell me about your mother.
   c. How has your illness affected you?
   d. What has been the most difficult for you recently?
   e. What are your favorite holidays?
   f. Are you afraid of dying?
   g. How many times have you been in the hospital?
   h. How has the experience in the hospital been for you?

4. What is the difference between an open-ended and a closed-ended question?

   Open-ended questions allow for discussion and expansion. Closed-ended questions can be answered with a ‘yes’ or ‘no,’ or a short response.

5. Describe empathetic listening.

   Listening ‘with’ the person you are speaking with, rather than listening for them or with a goal of providing answers; allowing the experience to be shared, rather than back and forth talking; non-judgmental

Mission Hospice & Home Care

Core Competency Quiz KEY

Feb 2023

PAIN ASSESSMENT COMPETENCY EXAM

1. Pain exists whenever the patient says it does. [✓ True] False
2. All pain has an identifiable cause. True [✓ False]
3. Pain tolerance varies from patient to patient. [✓ True] False
4. Pain tolerance varies from one time to another in a particular patient. [✓ True] False
5. If a patient has a positive placebo response (pain relief), the pain was probably imaginary. True [✓ False]
6. The nurse, not the patient, is the expert on a patient's pain. True [✓ False]
7. Pain behaviors or facial expressions of pain are very reliable indicators of the presence of pain in any patient. True [✓ False]
8. The best source of assessment information is usually the patient's family. True [✓ False]
9. I will assess pain at each visit primarily by observing the patient's attitude. True [✓ False]
10. When using a numeric pain scale, if the rating given is "4 to 5," that is what I will write on the visit note. True False

11. If the patient reports a pain level of 4, I will:

    Call 650.554.1000 immediately and let the case manager know, by speaking to him/her or to a nursing supervisor.

12. If the patient reports a new pain, I will :

    Call 650.554.1000 immediately and let the case manager know, by speaking to him/her or to a nursing supervisor.

Mission Hospice & Home Care

Core Competency Quiz KEY

Feb 2023

BASIC SAFETY COMPETENCY

1. The percentage of people who have back pain at some time in their life is:
   a. 10-20%
   b. 35-45%
   [✓ c. 60-80%]

2. Which of these could cause spinal pain?
   a. Slouching at your desk
   b. Holding the phone between your ear and shoulder
   c. Turning to the side and lifting at the same time
   [✓ d. All of the above.]

3. A basic principle of back safety is to lift with your:
   a. Hands
   b. Head
   [✓ c. Leg muscles]

4. Another basic principle of back safety is to lift with:
   a. Gusto
   [✓ b. No rotation]
   c. Exhalation

5. Stretching exercises and staying in shape can help to prevent back injury. [✓ True] False

6. The natural curves of the spine allow even distribution on the vertebrae and muscles of the back. [✓ True] False

7. You can safely lift heavier weights down from a height than up from the floor. True [✓ False]

8. Sitting is a stressful position for the back. [✓ True] False

9. For safe lifting, bend at the waist. True [✓ False]

10. When carrying, it is safest to hold objects close to your body. [✓ True] False

Mission Hospice & Home Care

Core Competency Quiz KEY

Feb 2023

TRAINING EXERCISE – PERSONAL INVENTORY – PROFESSIONALISM/BOUNDARY ISSUES

This exercise is to encourage your active thinking about boundary issues. Please indicate when you think each behavior on the part of a health care professional would be OK.

	Always OK	Sometimes OK	Never OK
1. Accepting cash, or equivalent, as a gift for personal use.			X
2. Buying gifts for individual patients or families.		X	
3. Sharing information a client reveals in a support group with his/her physician.			X
4. Inviting patients or families to join you in activities or parties outside of work.			X
5. Meeting with a client who comes to you in crisis after you have transferred the case to a peer.		X	
6. Sharing personal information about yourself with patients or families.		X	
7. Sharing personal problems with patients or families.			X
8. Giving an update to a neighbor on the medical condition of a football star's son.			X
9. Sharing information about one patient/family with another patient/family.			X
10. Giving out your cell phone number to patients or families.		X	
11. Calling in on days off to check on how your patient is doing.		X	
12. Loaning money or personal belongings to patients or families.			X

Mission Hospice & Home Care

End of Life Option Act Quiz Key

01.2020

1. Who can use this option? Mark all that apply.

   ___ Patient must be 18 years or older and be a resident of California
   ___ Have a terminal illness. A physician must determine that the disease cannot be cured or reversed and is expected to result in death within six months.
   ___ Have the capacity to make medical decisions.
   ___ Not have impaired judgement due to mental disorder.
   ___ Have the ability to take the drug at the time they want to take it.
   [✓ ___ Must meet all the above requirements.]

2. The patient must take the drug if he or she requests a prescription. True [✓ False]

3. If a patient is too weak to speak for him or herself, but told a family member they want to take advantage of the ELOA, the family member can request a prescription on the patient's behalf. True [✓ False]

4. A volunteer cannot pick up the ELOA prescription for the patient. [✓ True] False

5. Volunteers are required to support patients who elect to exercise their rights under the End of Life Option Act. True [✓ False]

6. If the patient is too weak, family or staff can give medication to a patient who wants a cup placed to his or her mouth. True [✓ False]

7. Which of these topics can a volunteer discuss with a patient?

   Mark all that apply.

   ___ The medications available for ELOA, and how they work.
   ___ The mental stability of the patient and assessment tests to evaluate in order to be a candidate for ELOA.
   ___ The involvement of family and how they can be in on the conversation with the doctors.
   [✓ ___ The patient's emotions and thoughts on ELOA, and how this affects the patient and loved ones.]

Mission Hospice & Home Care

We Honor Veterans Quiz Key

01.2020

1. Veterans account for 25% of all deaths in the United States. [✓ True] False

2. Most Veteran deaths are in VA facilities because it's easy for Veterans to access the benefits they've earned and are entitled to receive. True [✓ False]

3. Mission Hospice is partnering with *We Honor Veterans* Hospice program to:

   ___ Ensure that patients who are Veterans receive appropriate, high quality services provided by skilled staff.

   ___ Ensure that care teams communicate with our Veterans honestly and effectively.

   ___ Help coordinate transitions across the VA and other community settings of care.

   [✓ ___ All the above]

4. All Veterans have similar needs, so it is not important to know in which war, or in what branch someone has served. True [✓ False]

5. If you are visiting a patient and notice a Certificate of Honor, or photo of the patient or their family member in a military uniform, it's best not to say anything because Veterans are trained not to talk about how they feel, and it may upset them. True [✓ False]

10 • References

Assessing pain in patients

Always ask about pain. Non-verbal patients can answer questions by nodding or with eye movements.

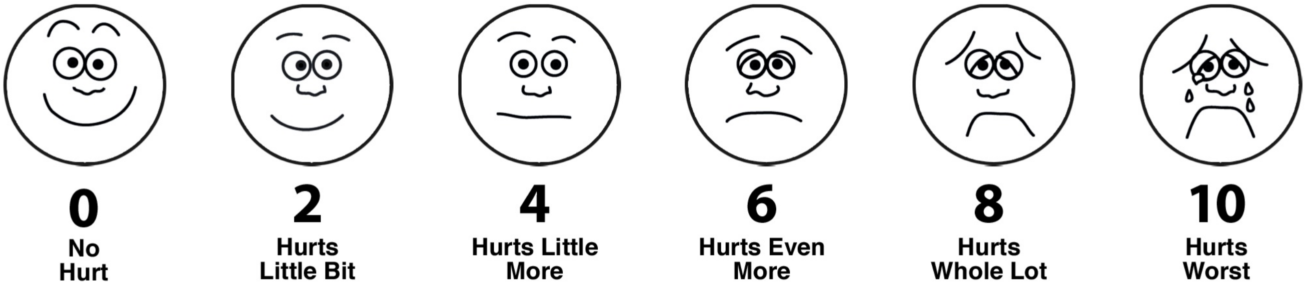
Every person copes with pain differently. Patients may express pain through:

- Facial expressions such as grimacing, frowning, and wrinkling the brow
- Restlessness, fidgeting, moving slowly, rocking
- Moaning, groaning, or crying out
- Rubbing or protecting a place that hurts

Patients in pain may have difficulty concentrating or may change their eating habits, behaviors, or activity levels. They may withdraw from family or friends, sleep more, or have difficulty sleeping.

You will record the pain rating from this scale on the Volunteer Visit Report.

Wong-Baker FACES$^{\text{TM}}$ Pain Rating Scale



Symptom Relief Kit

Mission Hospice Symptom Relief Kits include a number of medications for treating pain.
As a volunteer, you should never touch or administer medications, but you may find it helpful to know their purpose.

Medication	Dose	Purpose
Morphine Sulfate concentration (Roxanol)	.25ml / 5mg	For pain
Haloperidol (Haldol)	.5mg / 1 tab	For agitation, confusion, or nausea
Lorazepam (Ativan)	.5mg / 1tab	For anxiety
Atropine opthalmic solution	1 drop in mouth	For an actively dying patient, to dry secretions in the mouth and stop gurgling
Prochlorperazine suppository	25mg	For nausea, vomiting
Acetaminophen suppository	650mg	For temperatures >101°F, if patient cannot take oral medications
Bisacodyl suppository	10mg	If no bowel movement in 3 days

Non-emergency phone numbers

Here's who to call when you need assistance – for example, if the patient has fallen out of bed and you need help. **For patient emergencies, always call Mission Hospice first.**

Community	**Police / Sheriff** For general safety concerns	**Fire Department** If someone has fallen and needs help; for lift assists
Atherton	(650) 323-6131	(650) 368-1421
Belmont	(650) 595-7400	(650) 368-1421
Brisbane	(415) 467-1212	(650) 368-1421
Burlingame	(650) 692-0310	(650) 692-0313
Campbell	(408) 866-2121	(408) 299-3144
Colma	(650) 997-8320	(650) 755-1500
Cupertino	(408) 299-3233	(408) 299-3144
Daly City	(650) 992-1225	(650) 992-2313
East Palo Alto	(650) 321-1112	(650) 368-1421
El Granada	(650) 363-4911	(650) 368-1421
Emerald Hills	(650) 363-4911	(650) 368-1421
Foster City	(650) 286-3300	(650) 368-1421
Half Moon Bay	(650) 726-8286	(650) 368-1421
Hillsborough	(650) 579-3818	(650) 574-1155
Kings Mountain	(650) 363-4911	(650) 345-1611
La Honda	(650) 363-4911	(650) 345-1611
Ladera	(650) 363-4911	(650) 368-1421
Loma Mar	(650) 363-4911	(650) 345-1611
Los Alto Hills	(408) 299-3233	(650) 948-1071
Los Altos	(650) 947-2779	(650) 948-1071
Los Gatos	(408) 354-8600	(408) 354-8600
Los Trancos Woods	(650) 363-4911	(650) 368-1421
Menlo Park	(650) 325-4424	(650) 368-1421
Millbrae	(650) 697-1212	(650) 368-1421
Milpitas	(408) 263-1212	(408) 998-7212
Montara	(650) 363-4911	(650) 728-5500
Monte Sereno	(408) 354-8600	(408) 354-8600
Morgan Hill	(408) 779-2101	(408) 354-8600
Moss Beach	(650) 363-4911	(650) 728-5500
Mountain View	(650) 903-6395	(650) 968-4411

Community	**Police / Sheriff** For general safety concerns	**Fire Department** If someone has fallen and needs help; for lift assists
Pacifica	(650) 355-4151	(650) 368-1421
Palo Alto	(650) 321-4433	(650) 321-4433
Pescadero	(650) 363-4911	(650) 345-1611
Portola Vallev	(650) 363-4911	(650) 368-1421
Redwood City	(650) 369-3331	(650) 368-1421
Redwood Shores	(650) 369-3331	(650) 368-1421
San Bruno	(650) 877-8989	(650) 368-1421
San Carlos	(650) 802-4277	(650) 368-1421
San Francisco	3-1-1	3-1-1
San Gregorio	(650) 363-4911	(650) 345-1611
San Jose	(408) 277-8911	(408) 277-8911
San Mateo	(650) 522-7700	(650) 368-1421
Saratoga	(408) 299-3233	(408) 867-3896
South San Francisco	(650) 873-3333	(650) 873-3333
Stanford	(650) 321-4433	(650) 321-4433
Sunnyvale	(408) 736-6244	(408) 730-7180
Unincorporated San Mateo County	(650) 363-4911	(650) 368-1421
Unincorporated Santa Clara County	(408) 299-3233	(408) 299-3233
Woodside	(650) 363-4911	(650) 368-1421

Self-care

What do you imagine when we talk about self-care?

Pitfalls of care

- Heroism – too many hours, I'm the only one. The antidote is to engage others.
- Burnout. Learn to pace yourself; find a place of rest in the middle of things.
- A sense of knowing what is best. Remember to not know, so the truth can emerge.
- Being controlling. Controlling with patients who have lost control. Not helping them regain control.
- Too attached to caregiving role; feeling special.
- Hiding behind the caregiving role – being the role instead of human to human. Covering up our fears.
- Interfering with the dying experience; trying to divert the dying. Talking too much, giving unwanted advice, entertaining the dying.
- Not recognizing boundaries. Sometimes boundaries become unclear, particularly emotional ones. Sometimes boundaries change. When they need to pull in, we need to let go.
- Transference and counter-transference – perceive patient needs in unrealistic ways, idealized – our own unresolved stuff coming into the relationship.
- Wanting gratitude – wanting to be thanked or reassured. Wanting to be thanked for bringing the water and then "they better drink it."
- Spiritually inflated – feeling that we know what the patient needs and what a good death looks like. Leave expectations behind.
- Concealed grief of the caregiver. Acknowledge your grief, but take care of it outside the patient relationship or it leads to idiot compassion.
- Idiot compassion is when we want to help when help is not really needed.

Take care of your body

- Distribute the energy that has built up.
- Do not self-medicate with chocolate, etc.
- Residue needs to be dealt with.

Learn how to care for yourself

- "Love yourself as if you were your only child." – Stephen Levine
- Contemplative practice, particularly metta practice, is helpful. Use a sacred space.
- Where can you set boundaries, limits in your life?
- Set a realistic, sane, practical schedule.
- Identify practices that refresh you.
- Bring refreshing practices into your work day, not just at the end of day.
- Involve, include, and support other caregivers – community of support.

Eliminate roadblocks

- What gets in the way of your own care?
- What support do you need to implement self-care?
- Life gets in the way of fulfilling the self-care plan; continue with the plan or life will overwhelm.

Write self-care plans for your:

Body

Mind

Spirit

Social life

Self-care concepts

A study on the self-care strategies of over 550 hospice workers in the U.S. and their self-care strategies found that physical activity and social support were the most commonly cited strategies in managing stress.

Protective practices will:

- Help compartmentalize work from the rest of life – identify ways to leave the job behind.
- Clarify and support staff in establishing professional boundaries.
- Promote emotional and physical health.
- Include regular self-care techniques for managing stress.

Resources for self-care

A self-care plan for hospice workers, by S.H. Jones.
American Journal of Hospice and Palliative Care. 2005 Mar-Apr;22(2): 125-8.
www.ncbi.nlm.nih.gov/pubmed/15853090.

End-of-Life Care & Supporting Staff; a literature review, by the Irish Hospice Foundation, 2013.
hospicefoundation.ie/wp-content/uploads/2013/04/End-of-Life-Care-Supporting-Staff-a-literature-review.pdf

A practical approach to promote reflective practice within nursing, by D. Somerville and J. Keeling.
J. Nursing Times. 2004 Mar 23-29;100(12):42-5.
www.ncbi.nlm.nih.gov/pubmed/15067912

Stress, burnout, compassion fatigue, and mental health in hospice workers in Minnesota, by RR Whitebird, *et al*.
Journal of Palliative Medicine 2013 Dec;16(12):1534-9.
www.ncbi.nlm.nih.gov/pubmed/24199789.

Enhancing emotional well-being through self-care: the experiences of community health nurses in Australia, by J. Rose and N. Glass.
Holistic Nursing Practice 2008 Nov-Dec;22(6):336-47.
www.ncbi.nlm.nih.gov/pubmed/18981814

Volunteer Visit Report

It is your responsibility to complete a Volunteer Visit Report (VVR) after each patient visit with in 24 hours. These are submitted by email; instructions and the template follow.

Instructions for completing the VVR

Copy the information in the template below into a new email. After sending your first report for a patient, **send your next report by replying to the last report you sent.** This helps you (and our department) make sure reports have been turned in each week. It is a Medicare requirement for us to file weekly reports, including missed visits. If you need to miss a visit, send a report using same format, note phone time informing patient /family, and Volunteer Department; include the reason why visit was missed. We typically enter 10 mins for missed visit which includes time spent communicating and sending report.

Send completed reports to volunteerstaff@missionhospice.org. This allows each of us to read all volunteer reports and add them to the patient's medical chart.

Email template for VVR

Subject line of email: VVR for [patient initials] on [date of visit]

Volunteer Name:

Patient initials:

Date of visit:

Phone Time:

Arrival Time:

Departure Time:

Travel Time Roundtrip:

Travel Miles Roundtrip:

Observations:
Pain Level: (use scale of 0 – 10; if pain is greater than 4, speak with patient's caregiver or call 650-554-1000 and note in your visit report that the pain was reported to a supervisor)

VVR Example 1

Subject: VVR for RD on 10/17

Volunteer Name: Sam Smith

Patient Initials: RD

Date of Visit: Mon Oct 17

Phone Time: 0 mins

Arrival Time: 12:00

Departure Time: 4:00

Travel Time Roundtrip: 20 mins

Travel Miles Roundtrip: 10 miles

Observations:
When I arrived at the residence RD was awake in his recliner. As usual, KD, the primary caregiver, attended his class via Zoom from the basement. RD spent 90% of the time sleeping while we watched TV. He woke up from sleep saying that he had dropped his sandwich. I offered to make him one. He said that would be nice. He ate the entire sandwich. His level of alertness and wakefulness is about the same as the previous week and he continues to be polite when he is awake.

Pain Level: 0

VVR Example 2

Subject: VVR for RD on 10/10

Volunteer Name: Sam Smith

Patient Initials: RD

Date of Visit: Mon Oct 10

Phone Time: 0 mins

Arrival Time: 12:00

Departure Time: 4:00

Travel Time Roundtrip: 20 mins

Travel Miles Roundtrip: 10 miles

Observations:
When I arrived at the residence RD was awake in his recliner. KD, the primary caregiver, as usual, attended his class via Zoom from the basement. RD spent 80% of the time sleeping while I was there while we watched TV. RD recognized Tom Cruise in a movie. He woke up from a sleep remarking that he needs to work on the concrete sidewalk outside of the house. His level of alertness and wakefulness is off from the peak three weeks ago.

Pain Level: 0

Common abbreviations

A/O	Alert and oriented
ADL	Activities of daily living
A Fib	Atrial fibrillation
ALS	Amyotrophic lateral sclerosis
APS	Adult protective services
BM	Bowel movement
BP	Blood pressure
CAD	Coronary artery disease
CHF	Congestive heart failure
COPD	Chronic obstructive pulmonary disease
CPS	Child protective services
CVA	Cerebrovascular disease
CVD	Cardiovascular disease
CVP	Cardiovascular pulmonary
DCV	Direct Care Volunteer
DM	Diabetes mellitus
DOA	Dead on arrival
DOB	Date of birth
DTR	Daughter
DX	Diagnosis
ER	Emergency room
ETOH	Alcohol
FR	Father
F/U	Follow-up
FB	Gallbladder
HHA	Home Health Aide
HOB	Head of bed
HOH	Hard of hearing
HTN	Hypertension
Incont	Incontinence
IV	Intravenous
Lax	Laxative
MS	Multiple sclerosis
MSW	Medical Social Worker
N/A	Not applicable
Na+	Sodium
Neg	Negative
NWB	Non-weight bearing
O2	Oxygen
OPD	Obstructive pulmonary disease
OT	Occupational therapy
OTR	Occupational therapy registered
PCN	Penicillin
Pharm	Pharmacy
PHN	Public health nurse
PRN	As needed
pt	Patient
PT	Physical therapist
Pulm	Pulmonary
RA	Rheumatoid arthritis
Resp	Respiration, respiratory
RN	Registered nurse
ROM	Range of motion
Rx	Prescription
SL	Sublingual
SOB	Short of breath
SQ	Subcutaneous
TB	Tuberculosis
UTI	Urinary tract infection
Vag	Vaginal
VNA	Visiting Nurse Association
W/C	Wheelchair
Wt	Weight