



Hospice Care Guide

INFORMATION ABOUT CARE, COMFORT AND SUPPORT FOR
OUR PATIENTS, THEIR FAMILIES AND CAREGIVERS

**PLEASE KEEP THIS BINDER WHERE IT CAN BE ACCESSED EASILY.
YOUR HOSPICE CARE TEAM WILL USE IT DURING EACH VISIT.**

March 2021





To our valued patients and families,

Your comfort and safety are always our highest priorities. In response to the Coronavirus situation, we are following national and local guidelines to protect you and your loved ones, and to prevent spreading the virus.

These measures include supporting you through telehealth, which includes phone calls and video visits, and reducing the number of in-person visits unless necessary. Minimizing face-to-face contact is absolutely the best way to keep everyone safe. We want to assure you, however, that if symptoms come up that cannot be managed effectively via Telehealth, we will visit you in order to address your needs.

Your expert care team, made up of a Nurse, Social Worker, and Spiritual Support Counselor, in collaboration with your physician, is here to provide excellent care and support by telehealth, and in person when needed. Hospice Aides will make personal care visits if required for the physical well-being of the patient. Your care team will check in with you regularly. Please don't hesitate to reach out when you need them.

In order to keep you safe when we make in-person visits, our staff is required to wear face coverings, maintain social distancing, and minimize physical contact unless it is necessary for the care of the patient.

To help keep our staff safe, we require family members and caregivers to wear a face covering when we are visiting, unless it is medically contraindicated.

While these safety measures may feel awkward, they will not get in the way of our compassionate care. To expedite communications with your team using telehealth, consider downloading Zoom (instructions can be found in the next page) — we would love to be able to see you. Telehealth is a great way for us to stay connected to you and provide support during this time.

We want to assure you we will continue to provide the very best care during this challenging time, and to take every measure to keep our patients, families, and communities safe.

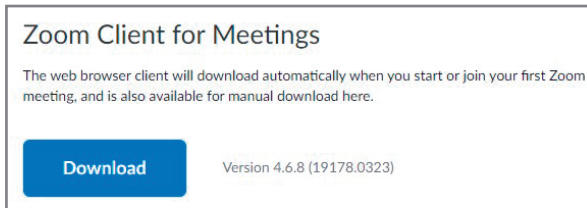
Warmly,

Kai Romero, MD
Chief Medical Officer
By the Bay Health

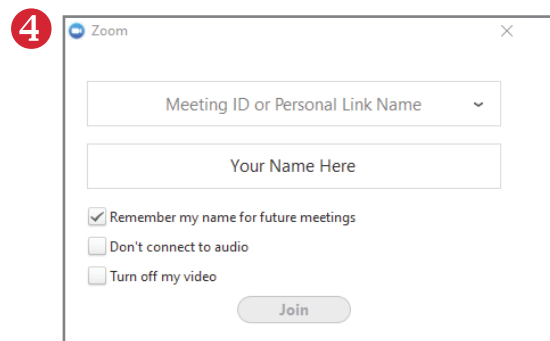
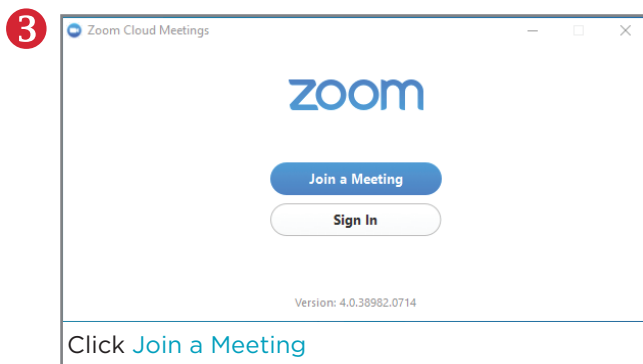
HOW TO DOWNLOAD ZOOM TO YOUR COMPUTER

Note: The computer you are using must have a working camera, audio and microphone.

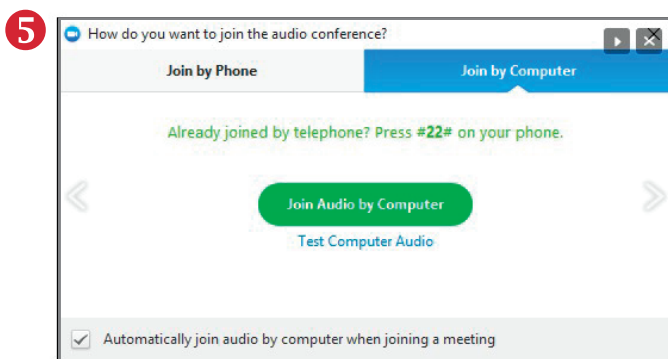
- 1 Go to <https://zoom.us/download> in your web browser and click Download



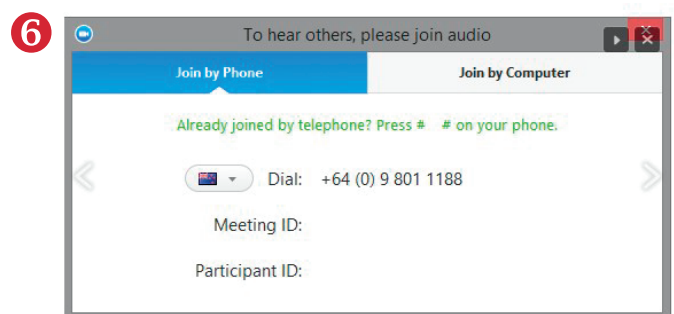
- 2 Find the application installer in the “Downloads” folder on your computer.
On a [Windows PC](#) the file is called [Zoominstaller.exe](#)
On a [Mac](#) the file is called [Zoom.pkg](#)
Double click on it and the program will automatically install.



Copy the [Meeting ID Number](#) from your emailed meeting invitation and enter your name.



When you join by computer you can test that your audio is working as well.



If you join the meeting by phone others can hear you but cannot see you. You may see them if they have joined by computer.

To Install Zoom on the iPhone / Android or iPad



Click on the [App Store](#) / [Google Play](#) icon on your device and search for [Zoom](#) and then click “GET” to download the app: [Zoom Cloud Meetings](#). Once installed, follow the prompts to join a meeting (entering your meeting ID number), to Sign Up or Sign In.



Google Play





Dear Patients, Families and Friends,

Thank you for choosing By the Bay Health. It is our honor to support you and your loved ones.

By the Bay Health's priorities are your comfort and quality of life. We commit to be by your side — providing care, support and training with compassion and expertise.

This Hospice Care Guide is an important part of that support and training. It contains expert guidance and information, and explains what to expect — and what to do — when we're not present.

We recommend you **read the Approaching the End of Life booklet** in the front pocket, and encourage you to review the pages after this letter through the "Hospice Basics" section. There is a lot of information, so simply explore this resource as needed.

If there is anything you need, or need to be done differently, please ask us. We always strive to do our best and need to know how we can serve you better.

We're here for you, so talk with your team about your wishes and concerns. Please do not hesitate to let us know at any time if you have questions or worries.

Sincerely,

Kitty Whitaker, RN, MS
Chief Executive Officer
By the Bay Health

Kai Romero, MD
Chief Medical Officer
By the Bay Health

Your Care Team

Call us 24 Hours a Day, Seven Days a Week:

(415) 927.2273

Marin County

(415) 626.5900

San Francisco and
San Mateo Counties

(707) 935.7504

Sonoma County
and the cities of American
Canyon, Napa and Vallejo

Patient: _____ Medical Record No.: _____

Primary Contact/Caregiver: _____

Attending Physician: _____

Nurse: _____

Social Worker: _____

Hospice Aide(s): _____

Hospice Aide Scheduler: _____

Spiritual Support Counselor: _____

Volunteer(s): _____

Volunteer Coordinator: _____

Team Leader: _____

In an Emergency — CALL HOSPICE FIRST.

- In many instances, we can help you determine whether a visit to the emergency room is necessary. By calling By the Bay Health about a rapidly changing condition, you can help prevent unnecessary hospitalization and emergency room stress.
- You always have the option to call 9-1-1, but it is best to consult with a BTBH clinician first, before calling 9-1-1.
- When you call, please be prepared to tell us your name, the patient's name, the reason you're calling, and any medications being used.
- We're here for you, to provide support, advice or make an emergency visit.
- Call us anytime and speak to a Hospice Nurse regarding changes in symptoms, medication questions, worsening health or problems with medical equipment.

Other Resources You May Find Helpful:

Resource	Purpose	Contact Information

Care Team Visit Log

Patient Name: _____

Each time a member of your Hospice Care Team visits, they will sign in below. This will help you and your caregivers keep track of who has visited, and when.

Name/Title	Date	Comments (as needed)

Name/Title	Date	Comments (as needed)

Sometimes, right after someone from your Hospice Team leaves, you realize you forgot to ask an important question. If you prefer to wait until your next Care Team visit, use the spaces below to jot down your thoughts for future reference.

Remember, you can speak to a Hospice Nurse anytime, day or night, at the number indicated on the **blue "Your Care Team" sheet**, located at the front of this binder.

We love to hear from you and always want you to get the best care possible.

Date	Question

Patient/Caregiver Instructions

Patient: _____ MR #: _____

Date	Instructions	Initials

If you have questions about these instructions or other concerns, please call us:

Marin County **(415) 927.2273**

San Francisco and San Mateo Counties **(415) 626.5900**

Sonoma County and the cities of American Canyon, Napa and Vallejo **(707) 935.7504**

Date	Instructions	Initials

Patient Name: _____ MR#: _____

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FORMS LIBRARY

What is Hospice?

Hospice is specialized end-of-life care that aims to enhance quality of life. The goal is compassionate care and comfort.


Hospice care is provided by a team of health professionals skilled in pain and symptom management for the patient, and in supporting the family and caregivers.

To be eligible for hospice, a physician must estimate a prognosis of six months or less of life if the patient's illness runs its natural course. However, hospice care may be extended if medical eligibility criteria continue to be met and the patient wishes to continue hospice care.

In some instances a person may “graduate” from hospice care because of an improved prognosis. In such cases, the patient has the option to stay in touch with a hospice nurse through our Monitor at the Client's Home (MATCH) Program. If their condition changes, the nurse may recommend a return to hospice care.

➔ See page 42 for details about our Monitor at the Client's Home (MATCH) Program.

Our care team will visit you wherever you live, whether that is in your home, a care facility or hospital. We can also help you find around-the-clock caregiver support and other outside resources.

 In addition to scheduled visits, a hospice nurse is available by phone 24 hours a day, seven days a week, to answer questions or schedule a visit.

During visits, your care team will provide you with:

- Pain and symptom management
- Medical care, including medical supplies and equipment, and hospice medicines
- Counseling about practical issues, including your health care wishes, planning for your financial needs, and accessing benefits or additional support from other agencies
- Help to ensure physical safety in your living environment
- Personal care, including bathing and dressing when needed

Team members also offer:

- Education about the end of life
- Caregiver education and training
- Emotional counseling and grief support

-
- Interfaith spiritual comfort
 - Volunteers

Your Care Team

All the people involved in your care — from the hospice staff to the patient, family and caregivers — form a very special care team with a common goal: helping the patient enjoy the best quality of life for as long as possible.

By the Bay Health uses a *transdisciplinary approach* to symptom relief. This means our entire team works together to provide comfort to our patients and their families.

Attending Physician

Your attending physician is the doctor who oversees your care, approves medicines and works closely with your care team to fulfill your plan of care. The attending physician can be your own doctor or a By the Bay Health physician.

Any other physician you see is considered a **consulting physician**. You may continue to see other physicians while on hospice care. However, please inform your care team before seeing any physician, as some procedures and medicines may require authorization. Without authorization, you may be responsible for associated charges.

Hospice Physician

Our hospice physicians are board-certified in the medical specialty of hospice and palliative care. They participate in ongoing discussions with your hospice nurse and care team about the best medical care to meet your individual needs. Hospice physicians also provide back-up medical support when your attending physician is unavailable.

Nurse Practitioner

Our care team includes nurse practitioners (NP) who may see and care for you. They have received specialized training and work very closely with our expert physicians.

Hospice Nurse

A registered nurse (RN) will visit regularly to assess your general condition, manage the use of medicines and help maintain your comfort. Our nurses are specifically trained in pain and symptom management and in coping with health issues faced by those with life-threatening illnesses. Your hospice nurse stays in close contact with your attending physician and other team members about your medicines and need for additional services. You may also be visited by our licensed vocational nurses (LVN), who provide additional nursing support.



At all times – evenings, nights, weekends and holidays – hospice nurses are available by phone or for a visit, if needed. Call with your concerns or questions. If a visit is needed, you may be seen by a nurse other than your regular hospice nurse. They will be up-to-date on your care needs and have your most current medical information. Your hospice nurse will be informed of the visit.

Hospice Social Worker

A social worker provides the patient, family and caregivers with practical and emotional support and helps with preparation for the days ahead.

Information can include:

- Benefits of By the Bay Health services, including grief support and other programs
- Counseling to help patient, family and caregivers cope with changes
- How to find home care resources you may need between care team visits
- What additional help is available through local community resources
- Legal and financial choices and resources, including advance health care planning or issues with insurance, finances and legal arrangements
- Creating a plan of support for the patient and family while under our care
- Help in planning funeral and memorial services

Hospice Aide

A hospice aide supports patients with their personal care needs. They can provide assistance with:

- Bathing and showering
- Skin and mouth care
- Toileting
- Walking, moving (transferring) and dressing
- Changing Linens
- Cleaning up the bedside or bathroom after care



Please note: Once a patient is only able to receive personal care in bed, then the patient **MUST** use a hospital-style bed, for safety reasons. We can order one for you; talk to your hospice nurse for more information

Some things hospice aides cannot do include:

- Cashing checks or doing banking
- Picking up or administering medicines
- Vacuuming
- Cooking meals

-
- Driving the patient or family in a car
 - Clipping nails
 - Providing care to anyone other than the patient
 - Scrubbing walls or floors, doing heavy lifting, or climbing up on chairs or ladders

Spiritual Support Counselor

Patients and families often find it helpful to talk with one of our spiritual support counselors. They can:

- Provide comfort through secular counseling or spiritual support, inspirational reading and prayer
- Assist in coordinating support from a preferred local spiritual group, congregation, clergy or spiritual leader
- Help plan for a funeral or memorial service, and, if you wish, officiate at the gathering

Patient and Family Support Volunteers

Our carefully screened, well-trained volunteers offer support between visits by other care team members. Although volunteers cannot provide physical care for patients, they offer:

- Companionship for the patient and respite care for the caregiver, typically for 1–3 hours
- Help with errands, such as grocery shopping, or light chores, like meal preparation
- Patient transportation for appointments or short outings (talk to your social worker about availability)
- A supportive presence during the patient's final hours

We can also suggest local non-medical care options that may promote well-being, reduce stress and provide other benefits for hospice patients and their families. Contact your care team to learn more.

Caregivers and 24-hour Care



While you can always talk to a hospice nurse by phone 24 hours a day, 7 days a week, By the Bay Health does not provide round-the-clock care. If you feel that you need a hired caregiver to provide you with assistance at all times, your hospice social worker can help you make arrangements.

Please note that 24-hour care is not covered by the Medicare Hospice Benefit and must be covered by your private insurance or other funds.

Email Communication with Your Care Team

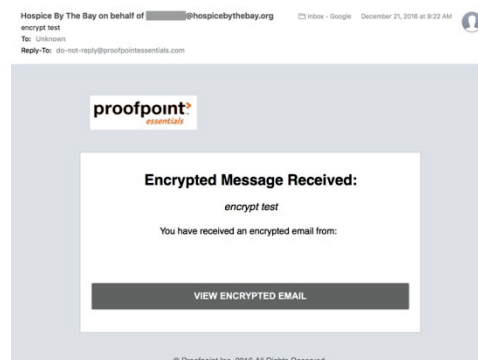
Your privacy is important to us. If you would like to communicate by email with your hospice care team, you must first sign a paper or electronic authorization form. You can discuss this with any team member during their next visit, or simply call us for more information.

Once you have done so, you can use the instructions below to ensure your emails remain secure.

By the Bay Health will accommodate requests by patients/representatives to communicate with assigned team members via email. An authorization form must be completed and signed by all interested parties before email communication can begin. Email exchanges with team members may become part of the medical record.

By the Bay Health uses an encrypting service to help protect the privacy and security of email communication. All emails you receive from By the Bay Health staff will be encrypted. When you receive an encrypted email from By the Bay Health, follow these instructions to access the message.

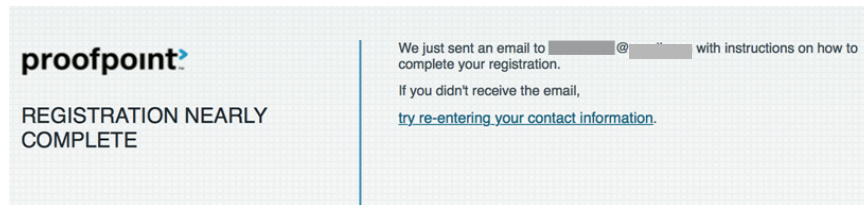
The first time you receive an encrypted email from By the Bay Health, you will see a message like the one below. Click on the link — **VIEW ENCRYPTED EMAIL** — for registration and set-up.



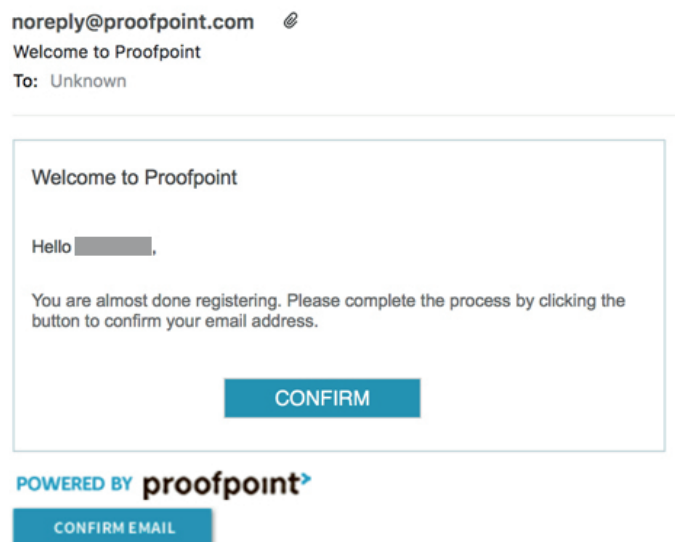
You must complete the following information in the Registration page to setup your encrypted email account:

A screenshot of the Proofpoint registration page. On the left, the Proofpoint logo is at the top, followed by the word "REGISTER" and a note: "Passwords must contain at least eight characters, and must contain three out of the four following characteristics: uppercase letters, lowercase letters, numbers, or special characters." On the right, there are input fields for "Email address:", "First Name:", "Last Name:", "Password:", and "Re-enter Password:". Below these fields is a checkbox labeled "I agree to the Terms of Service" with a link to "Terms of Service". At the bottom right is a blue button labeled "REGISTER".

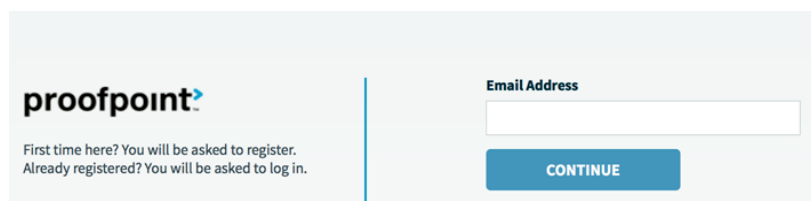
Once you click REGISTER, you will see the notice below.



Next, check your email inbox for a confirmation message and click CONFIRM.



Now that you are registered, each time you receive an encrypted email, all you will have to do is log in with your email and password to view your messages:



How long can I stay on hospice?

There is no time limit for care while your attending physician certifies that you meet the Medicare Hospice Benefit criteria: a terminal illness with a life expectancy of six months or less. Those who continue to meet the criteria after six months may be recertified and continue to receive our services.

Can I receive By the Bay Health's care in a nursing facility or other long-term care facility?

Yes. Hospice care can be provided wherever you are — in a hospital, nursing facility or long-term care facility. Visits by care team nurses, social workers, home health aides, spiritual support counselors and volunteers complement the services provided by the facility.

Do I have to see everyone on the care team or can I limit visitors to just the nurse?

Most patients benefit from visits by all of our caret members: nurse, social worker, hospice aide, spiritual support counselor and trained volunteers. However, the hospice nurse is the only one you must see on a regular basis.

Are nurses available on weekends and evenings?

Yes. You can speak to a hospice nurse anytime, day or night, for advice and support, or to schedule an emergency visit. Please note that it may take 1–2 hours for the nurse to arrive for a previously unscheduled visit.

➔ Refer to the blue Your Care Team contact sheet at the front of this binder.

Can I still make regular visits to my other doctors?

Yes. You are free to see your attending physician and continue treatments for other medical conditions not related to your hospice diagnosis, while using your regular Medicare benefits. If needed, additional visits with other physicians can be scheduled, free-of-charge, as part of your hospice plan of care.

Can a By the Bay Health physician also serve as my attending physician?

Yes. Talk to your hospice nurse or social worker to arrange this.

What happens if I call 9-1-1? What if I need or want to go to the hospital?

Please call By the Bay Health first, at any hour of the day or night. We will coordinate your care and obtain pre-authorization to go to the hospital for symptoms related to your hospice diagnosis. If you don't contact By the Bay

Health first, please call us immediately after or you may be responsible for associated charges. If you go to the hospital for symptoms unrelated to your hospice diagnosis, there is no need for pre-authorization, however, you still need to notify hospice. For more on pre-authorization, talk to your hospice nurse or social worker.

Does By the Bay Health use morphine for pain and symptom management?

By the Bay Health clinical staff work with your attending physician and/or our hospice physician to recommend the right medicine for your pain or symptom management. One of those medicines may be morphine. No medicine is given without your consent, discussion and alignment of its benefits with your symptoms and goals for care.

➔ Refer to page 31 for details about morphine as a pain and symptom management medicine.

Do I need to have a Do Not Resuscitate (DNR) order to be on hospice service?

No. You do not need to have a signed DNR at the time of your admission to hospice. To get all the facts, ask your hospice social worker for information about advance care planning and DNRs. Your care team will work with you and your family to determine the best time to sign a DNR after you are on our service.

➔ See page 37 for more about DNRs.

Does By the Bay Health support the End of Life Option Act (EOLOA)?

By the Bay Health takes a neutral stance toward the 2015 California End of Life Option Act (EOLOA) and will respect your decision regarding this legal option. Talk to your attending physician and hospice team if you have any questions.

How do I get my medicines that By the Bay Health doesn't pay for?

Speak to your hospice nurse or social worker to learn about your coverage and other medicines. Medicines for symptom management are provided by By the Bay Health. Other medicines will be paid by your insurance or privately, just as they were before you began hospice care.

Please note that the Medicare Hospice Benefit does not cover treatments and medicines with the goal of curing your illness.

Can I travel out of state?

Yes. If you plan to travel outside of our service area, contact your hospice social worker to discuss how your needs will be met while you're away. Please allow several days to make arrangements.

➔ Refer to page 41 for information about traveling while receiving hospice care.

How does By the Bay Health get reimbursed for my care?

In most instances, hospice care is reimbursed on a fixed per-diem (per day) fee basis. By the Bay Health is paid a standard rate for each day a patient is in our care. This differs from other types of health care providers who are reimbursed for each individual visit or component of care. By the Bay Health is reimbursed in this manner since the total care for the patient is coordinated by the hospice; we are required to be available 24/7; and we are required to cover the cost of many items (related medicines, medical supplies, coordinated doctor's visits, etc.) out of the per-diem fee received.

What if I don't have insurance or can't afford the insurance co-payments?

By the Bay Health is a non-profit health care provider. Our mission is to provide hospice services to all qualified patients who need our care, regardless of their insurance coverage or ability to pay.

Talk with your hospice social worker about support. All uninsured or under-insured patients can receive our care for a greatly reduced or waived fee. All patients are evaluated using a standardized sliding scale. You will not be required to provide proof of income.

How much will I need to pay out-of-pocket for my hospice care?

It depends on the specifics of your health insurance plan, but many patients have little to no out-of-pocket expense. Standard out-of-pocket expenses may include:

- A five percent co-pay for authorized five-night respite stays in a skilled nursing facility (approximately \$12/day)
- Private insurance deductible and/or co-pay, which vary by insurer
- Medicine costs, not covered by your insurance, that are unrelated to your hospice diagnosis

Will there be additional charges billed to me if I go to the hospital?

Call By the Bay Health first if you feel you need to go to the hospital for symptoms related to your life-limiting diagnosis. We will help coordinate your care and obtain pre-authorization for payment. There should be no additional charges to the patient for trips to the emergency room or stays in the hospital when care is coordinated and authorized through By the Bay Health. If you go to the hospital without contacting By the Bay Health first

(even for conditions related to your hospice diagnosis), you may be held responsible for all associated charges. If you feel you need to go to the hospital for symptoms that are NOT related to your hospice diagnosis, this should be covered by your insurance as if you were not on hospice care. However, please inform your hospice nurse who coordinates your care, just to be sure. In addition, we need to stay up-to-date on all aspects of your medical care.

What if, during a crisis, my caregiver or I call 9-1-1 before calling By the Bay Health?

Contact us as soon as possible after calling 9-1-1 so we can help coordinate your care. If the reason for the 9-1-1 call is related to your hospice diagnosis, we may be able to retroactively authorize the emergency care.

While in By the Bay Health's care, can I see my regular physician(s) and is there a charge for visits?

You may visit your regular physician(s) at any time. For visits unrelated to your hospice diagnosis, these will be paid for as they were prior to when you came under our care. Your regular physician's office should call our billing office for guidance on how to bill for your home or office visit.

Visits related to your hospice diagnosis should be approved by your hospice physician so they can be authorized for reimbursement by By the Bay Health.

I received a Medicare Summary Notice from Medicare. How do I read it?

In January, April, July and October, Medicare mails participants (or their designated Health Care Agent with Durable Power of Attorney) a summary of all claims received and processed on the patient's behalf. The Summary Notice details the charges billed to Medicare by your various providers (including By the Bay Health), what was actually paid to the provider, and what (if any) portion of the bill is the patient's responsibility.



If you have questions, contact By the Bay Health at (415) 927.2273, Monday-Friday, 8:30 a.m.- 5 p.m. Ask to speak to someone in the Finance Department about your bill.

Marin: (415) 927.2273 | Sonoma: (707) 935.7504 | San Francisco: (415) 626.5900 | bythebayhealth.org

Anxiety is a feeling of intense nervousness or unease. It can arise when we think about bad things that could happen, when the mind stays on negative thoughts or things that could go wrong, or without any known reason.

For hospice patients, anxiety is common and normal. Anxiety impacts the mind, the body and sometimes both, and we always address it as quickly as possible.

A WAY TO THINK
ABOUT ANXIETY:

Worry
is in
the mind



We feel
Stress
in our body



Causes

Anxiety may have emotional causes like:

- Fear of pain, disease progression, dying or death
- Feelings of loss, grief or leaving things unfinished
- Spiritual, religious, or personal crisis

Physical changes or symptoms can also cause anxiety including:

- Pain
- Trouble breathing
- Natural changes in brain chemistry due to disease or the dying process
- Cardiac arrhythmias (irregular heartbeat)
- Side effects of steroids, stimulants, antidepressants or other medicines, and drug withdrawal
- Other physical conditions

Signs

Talk to your team immediately if you notice any of these symptoms:

- Irritability
- Sleeplessness (insomnia)
- Inability to focus
- Crying
- Restlessness, fidgeting or squirming
- Increased blood pressure
- Trouble breathing
- Sweating
- Stomach pain, nausea, and/or diarrhea
- Dry mouth



TURN THE PAGE TO LEARN HOW WE REDUCE ANXIETY AND HOW YOU CAN HELP



People commonly take Lorazepam (Ativan), Diazepam (Valium) and/or Clonazepam (Klonopin) for anxiety. It can take minutes or hours for these medicines to work. We may also recommend an anti-depressant for these symptoms, which can take weeks to work. **Talk to your nurse about these medicines and their side effects.**

Caring for Anxiety Without Medicine



- Calm the nervous system by encouraging slow and deep breaths



- Enjoy nature by sitting near a window or outside



- Play the “Name Game” - ask your loved one to say three things they see, three things they hear and three things they feel



- Create a calm space - dim lights, play white noise or peaceful music, talk quietly and move slowly



- Try aromatherapy - lavender, bergamot, ylang-ylang and rose can have calming effects



- Play free audio guided imagery by experts like Dr. Kristin Neff and Leslie Davenport, MFT



- Download a meditation app like Calm, Headspace, Liberate (Black community-centered) or iBreathe



Patients and caregivers can reduce anxiety by talking together about feelings and worries. Social Workers and Spiritual Support Counselors can guide important conversations. Talk with your team to learn more.

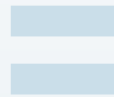
Anxiety is a feeling of worry, nervousness, or unease, often about an event or situation with an uncertain ending. It arises when we think about something bad that could happen, when the mind stays on negative thoughts, or without any known reason.

A WAY TO THINK
 ABOUT ANXIETY:

Worry
 is in
 the mind



We feel **Stress**
 in our body



**Anxiety is natural when caring
 for someone at the end of life.**

It arises when we are:

- Grieving the loss of a loved one, even while they're still alive
- Afraid of a loved one dying and/or their death
- Feeling unprepared or unable to care for a loved one
- Worried about having little or no help, or feel uncomfortable asking for help
- Feeling helpless about a loved one's physical and/or mental decline
- Concerned about money or financial security
- Experiencing other personal stress

**Feelings of anxiety can be mental,
 physical, or both.**

Symptoms include:

- Irritability
- Sleeplessness (insomnia)
- Trouble breathing
- Restlessness or inability to focus
- Sweating
- Crying
- Stomach pain, nausea and/or diarrhea
- Dry mouth
- Tightness in the throat or chest



TURN THE PAGE TO LEARN WAYS TO REDUCE ANXIETY



Feeling anxious is normal for caregivers but constant, intense anxiety can impact your health.

Talk to your Primary Care Physician
about symptoms and to learn about
medicines and other options.

To reduce feelings of anxiety:



- Calm your nervous system with slow and deep breaths



- Take a walk outside with a friend and talk about what's on your mind



- Play the "Name Game" - say or write down three things you see, three things you hear and three things you feel



- Try aromatherapy - lavender, bergamot, ylang-ylang and rose have calming effects



- Pet or talk to a beloved animal



- Listen to free audio guided imagery by experts like Dr. Kristin Neff and Leslie Davenport, MFT



- Learn meditation with an app like Calm, Headspace, Liberate (Black community-centered) or iBreathe



- Give yourself a worry "budget" - 15-20 minutes each day to freely worry - then spend the same time problem-solving



- Calm obsessive thinking by writing down your thoughts



- Create a soothing space with dim lights and peaceful music



- Watch a funny video or movie



- Avoid panic (anxiety that arises suddenly) by **talking** about scary things that *might* happen (ex. acute symptoms, a child seeing a loved one suffer), then **planning** so you're prepared



Sharing feelings and worries can build comfort and trust.

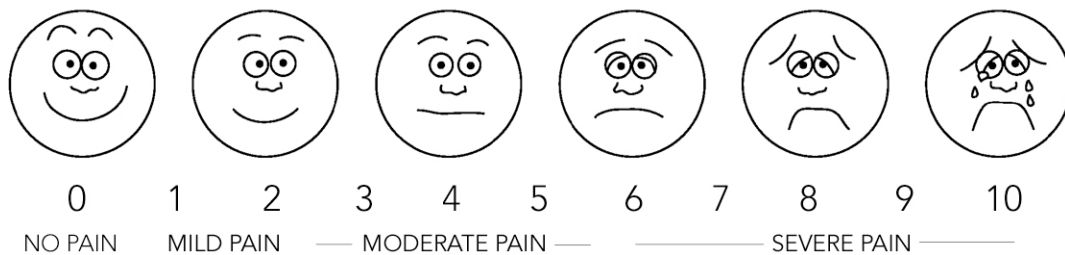
Your Social Worker and Spiritual Support Counselor can guide important conversations with your loved one, family members and other caregivers. Talk with your team to learn more.

Understanding Pain

Pain is a signal your body gives you when it needs help. Pain can have many causes or components. The part that responds to medicines is the physical component, but there are also spiritual, social and emotional aspects that contribute to your experience of pain. All four components are common in hospice and our transdisciplinary team approach can help address every aspect of your pain.

Because each person copes with pain in different ways, pain can only be judged and described by the person experiencing it. That's why it's so important that your care team understand: 1) your level of pain, 2) the type of pain, 3) what you have tried to lessen the pain and 4) what is working?

During every visit, a care team member will ask you to describe the intensity of your pain, using a scale of zero to 10. Zero means you feel no pain, and 10 means the worst pain you can imagine. The illustration below may help you describe the level of your pain.



- Clenched fists
- Grimacing, frowning, wincing, looking sad or wrinkling the brow
- Restlessness, fidgeting or jumpiness
- Facial paleness or flushing
- Patient's body is curled into a fetal position
- Changes in mood, behavior or activity level
- Crying
- Sweating
- Changes in sleeping or eating patterns
- Pacing or rocking back and forth

- 

- Intensity of the pain
- Location of the pain
- Type of pain (such as aching, burning, gnawing or grabbing)
- The degree to which the pain medicine is working
- Any side effects from the pain medicine

Pain Report



A Pain Report form similar to the one at right may be added to the first section of this manual. You will complete this form as requested by your hospice nurse and it will be reviewed during each care team visit.

**Hospice
by the Bay**

Pain Report

Patient Name: _____ MR#: _____

Remember, you can speak to a Hospice Nurse anytime, day or night, at the number indicated on the blue "Your Care Team" sheet, located at the front of this binder.

Nurse Instructions: _____


Rating Symptom Severity:

0	1	2	3	4	5
NO PAIN	MILD PAIN	MODERATE PAIN		SEVERE PAIN	

Date/Time	Location of Pain	Rating (See Above)	What did you do?

Form #129, Updated 1-24-18 *Continued on other side*

Many people downplay their pain, because they want to appear strong for their loved ones. Others are worried about taking medicine to help relieve pain. Some patients may be unable to speak or communicate about pain, and others experience pain without fully realizing it.

 Please talk about your pain with your care team or call us. Our job is to help you understand your options for comfort and to find the best treatments to meet your needs. Communication with your care team is essential.

Non-medical pain relief methods include:

- Relaxation exercises or activities, including watching TV, listening to music or playing a game
- Heat (such as a heating pad or warm compress), or cold (such as a frozen gel pack or bag of ice) on the painful area
- Aromatherapy
- Gentle massage
- Guided imagery or visualization (imagining relaxing scenes)
- Soaking in a tub of warm water
- Frequent changes in position
- Regular rest
- Distraction through music, friends, television or movies

Medicine may be necessary to relieve pain. Be sure to follow the instructions from your hospice nurse or your attending physician. Here are some general guidelines for using pain medicines:

- Take your medicine when you begin to feel pain — don't wait until it becomes intense. It's more difficult to control higher levels of pain.
- Take your medicine 30–45 minutes before an activity that usually causes pain.
- For constant pain, take your medicine around the clock as advised by your nurse or doctor. This keeps a steady level of medicine in your blood and decreases any sedative effects.
- Report any side effects, such as nausea or itching, to your team members. Side effects can often be treated.
- If your attending physician orders more than one pain medicine, let your care team know. We may need to adjust your medicines or use non-chemical pain relief methods.

➔ Refer to page 25 for information about specific pain medicines.

Restlessness & Agitation

For the brain to work properly, it needs the correct balance of oxygen, nutrients and electrolytes. During serious illness, these often get off balance. A person may become confused and behave differently than before their illness. This can be very distressing for family and caregivers, though the confused person is often unaware of the change and often not suffering at all. It can happen quickly and resolve quickly, or it can go on over time. Often in hospice care, the reason for the imbalance is not fixable so the confusion and new behavior must be managed with medicine and other approaches.

Family and caregivers can often help minimize, and even prevent episodes of delirium by reducing stress by reorienting and calming your loved one.

- Keep the environment calm and quiet.
- Speak with a soothing voice.
- Gentle touch, such as holding a hand, can often be soothing.
- Stick to routines and familiar people to avoid further confusion.
- Allowing daylight into the room, or adding a nightlight, can be helpful.
- Be sure eyeglasses and hearing aids are in place.
- Allow loved ones to sit up, drink fluids and move around, if possible or appropriate.
- Describe what you are going to do before doing it.
- Pay attention to things that make the agitation worse and try to avoid those triggers.
- Similarly, if something makes it better, keep doing that.
- Music is soothing for many people.
- Remember that, upsetting as it can be to watch, people do not usually remember being delirious.
- Remember that your loved one can't help their confusion.
- If you are feeling anxious or frightened, ask someone to take shifts with you.
- Please call your care team when you first see signs of confusion or agitation, especially if you feel unsafe or there are sudden changes. We may be able to add or adjust medicines to reduce the patient's distress, or schedule an emergency visit if needed.
- We will support you in any way possible to help you maintain the best possible calm attitude and presence.

UNDERSTANDING COMMON SYMPTOMS



Trouble breathing is the feeling or sound of not getting enough air.

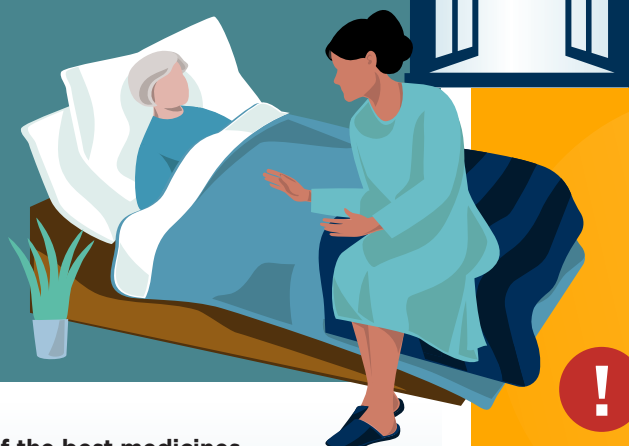
It includes fast, slow, or unusual breathing. People describe feeling like it's hard to "catch" their breath or having tightness or weight in their chest. They can also feel scared or restless.

Trouble breathing can be caused by disease (like heart or lung diseases), muscle weakness, anxiety, or normal changes at the end of life.

During the final days of life...

- **Breathing can be very fast and then slow**, or there can be no breathing at all for up to a minute. It's also normal to see pale or bluish skin or lips, because there's less oxygen moving through the body.
- **It's normal for breathing to be uneven and noisy.** The breathing center of the brain is shutting down, and saliva can collect in the mouth and throat.
- **Oxygen and medicine may help**, but don't always work. Talk with your nurse to learn about these options.

While it may be upsetting for those in the room, people at the end of life are almost always comfortable and unaware of the noises they make.



Morphine is one of the best medicines for trouble breathing, and lorazepam (Ativan) can help with relaxation. Talk with your care team to learn more about how we safely use these medicines and common side effects.

Caring for Trouble Breathing Without Medicine

- Change position so the head is raised.
- Open a window or use a fan to blow cool air on the face.
- Try "pursed lip" breathing, or ask your nurse about this technique.
- If you hear gurgling, turn your loved one on their side.
- Holding hands, gentle massage, and/or a cool cloth on the forehead or back of neck may be soothing. Dim lights, talking softly, quiet music, and petting an animal can also help.



Always call your care team if you're concerned about trouble breathing.

The final days can be difficult for caregivers. **Be gentle with yourself and ask family, friends and/or your hospice team for help.**

Trouble Breathing Report



A Trouble Breathing Report form similar to the one at right may be added to the first section of this manual. You will complete this form as requested by your hospice nurse and it will be reviewed during each care team visit.

[illegible]

Nausea is an unpleasant feeling in the back of the throat or stomach prior to vomiting. Vomiting is the emptying of stomach contents. In order to help with either of these, be sure to tell your care team:

- Amount and frequency of nausea and vomiting
- Description of vomited fluid
- What causes the nausea and vomiting
- What makes it better or worse

Ways to Ease Nausea without Medicine:

- Avoid strong odors, such as perfume and deodorizers.
- Avoid eating immediately after vomiting.
- Try sips of water or ice chips before eating again.
- Sip carbonated drinks that have gone flat.
- Avoid acidic juices, such as cranberry, grape and orange.
- Drink electrolyte drinks. For children, use Pedialyte®.
- Eat foods in small, frequent amounts. Large meals may be overwhelming.
- Try a small amount of salty foods, such as crackers or chicken broth.
- Avoid fried foods, milk products or food with a strong smell.
- Keep the mouth moist. Ask your hospice nurse for information about mouth care.
- Maintain a comfortable room temperature.
- Avoid constipation (➔ refer to page 19 for suggestions on how to avoid this common problem).
- Use medicines as directed.
- Calm, soothing visitors may distract from the nausea. Minimize visits by chatty or anxious visitors.
- Contact a hospice nurse if the nausea or vomiting continues.

There are many medicines to help with nausea and vomiting. The most frequently used nausea medicine in hospice is Prochlorperazine (sometimes called Compazine). It can be taken as needed every six hours. It can cause sleepiness but has few other side effects.

Symptom Management Report



A Symptom Management Report form similar to the one at right may be added to the first section of this manual. You will complete this form as requested by your hospice nurse and it will be reviewed during each care team visit.

[illegible]



By the Bay

Health

BEYOND HOSPICE
An Affiliate of UCSF Health

Marin: (415) 927.2273 | Sonoma: (707) 935.7504 | San Francisco: (415) 626.5900 | bythebayhealth.org

Help for Constipation and Bowel Care

UNDERSTANDING COMMON SYMPTOMS

Bowel movements at the end of life can be difficult.

People become constipated because they eat, drink and move less. Medicines can also affect the bowels, leading to constipation or diarrhea. Your team will ask about bowel movements at every visit. Please be honest, even if talking about it feels embarrassing.

Constipation is when stool is hard and dry, and it's difficult to move the bowels.

Diarrhea is when stool is watery, and movements happen too often.



Caring for the Bowels Without Medicine

✓ Sit upright, with back straight, on the toilet, commode or bedpan.

✓ Drink as many fluids as possible; warm liquids can help.

✓ Eat more fruit or drink fruit juice, especially from prunes.



Caring for the Bowels With Medicine

For comfort, people commonly take Senna, Bisacodyl, Milk of Magnesia and/or other medicines.

- ✓ Always follow instructions about how to take bowel medicines, and talk with your nurse before making any changes.
- ✓ Senna may take 2-3 days to work.
- ✓ These medicines need to be taken daily, even if things are going well.
- ✓ Some people avoid pain medicine, like opiates, because they worry about constipation. We can help with **both** symptoms, so talk with us about any concerns.



Let your care team know if these issues arise:



- ✓ No bowel movement in two days
- ✓ Change in bowel movement frequency or comfort
- ✓ Pain, cramping or tenderness
- ✓ Feeling of fullness or bloating
- ✓ Blood or mucus in the stool

Your care team may recommend Senna and Bisocodyl. Senna is a bowel stimulant, meaning it makes your gut “move,” while Bisocodyl is a stool softener and makes your stool easier to pass. Your care team will recommend doses that will work best for you. We tend to start low and go up, so don't worry if it doesn't work right away. Call your hospice nurse and we will either increase the dose or provide additional laxatives. Following the directions of your care team regarding bowel care can make your experience much more comfortable.

❗ Important Notes about Bowel Medicines:

1. Follow the instructions from your care team.
2. You will need to take the bowel medicine every day even if things are going well; the only reason to stop is if you have diarrhea. Let your care team know if this happens or if you stop your bowel medicine.
3. Notify your team if you have not had a bowel movement in two days, unless you have been instructed differently.
4. If you are prescribed a new medicine for any reason, you may need to increase your bowel medicine. Your care team can tell you if you should, so keep them informed about medicine changes.
5. Some people avoid pain medicines because of fear of constipation. Please discuss this with your care team so we can ensure that your pain and constipation are treated equally.

Bowel Report



A *Bowel Report* form similar to the one at right may be added to the first section of this manual. You will complete this form as requested by your hospice nurse and it will be reviewed during each care team visit.

Hospice
by the Bay

Bowel Report

Patient Name: _____ MR#: _____

Remember, you can speak to a Hospice Nurse anytime, day or night, at the number indicated on the blue "Your Care Team" sheet, located at the front of this binder.

Nurse Instructions: _____

Date/Time	BM Today? (Y/N)	What did you do?

Form #226, Updated 1/24/18 (Continued on other side)

Skin Care & Bedsores

Good skin care reduces discomfort, prevents bedsores, manages odor and drainage, helps people remain as active as possible, and supports quality of life.

The best treatment is prevention. A bedsore (or pressure ulcer) is caused by ongoing pressure to the skin at bony prominences or pressure points, such as the tailbone, elbows, knees, heels, head and buttocks. Pressure restricts blood flow at these points, and may start with areas of skin redness that don't go away. Inadequate nutrition, an inability to feel parts of the body or rubbing against bed linens can all lead to bedsores.

Here's how to help:

- Check skin frequently, especially pressure points, and report changes to your hospice nurse. Bath time is a good opportunity to check.
- If bedbound, turn or reposition your body every two hours.
- If you cannot move, ask to be repositioned every two hours to promote comfort and reduce weight on pressure points.
- Let the nurse know about pain, burning, numbness or tingling of the skin.
- Keep your skin clean and dry by changing absorbent pads often.
- Use mild soaps and apply moisturizers sparingly.
- Use cool, not hot or cold, water on the skin.
- Don't sit or lie on a pressure ulcer.
- To promote blood circulation, wiggle your toes, and move your arms and legs often.
- Do range of motion joint and muscle exercises daily, if directed by your team.
- Never use a heat lamp, electric blanket or heating pad.
- Do not massage pressure points or reddened areas.
- Notify your hospice nurse if splints, braces or oxygen tubing rub or cause irritation.
- Wear cotton clothing that fits loosely.
- Keep bed linens clean, dry and wrinkle-free. Avoid plastic sheets.
- Remove the bedpan within a few minutes to avoid tailbone pressure.
- Ask your hospice nurse for ways to control odors from skin irritations.
- Don't treat the wound yourself. Ask your care team for help.

Even if you are doing all the above, bedsores may persist. Your hospice nurse will advise you on additional comfort measures.

Decreased Appetite

Towards the end of life, people generally lose their desire to eat. This is normal and forcing food may cause more discomfort. Your care team will guide you, but the general rule of thumb is that if a person is not hungry, it is usually better not to make them eat.

It is natural to want to nurture a loved one with food, but this can cause a conflict at the end of life when appetite may decrease. Families may feel responsible for letting their loved one die when, actually, it is the natural process.



Feeding a person whose body is shutting down may only cause more symptoms and does not prevent or delay the death.

Tube Feeding

Because we often show love for our family and friends through food, it can be hard for caregivers to know whether or not a feeding tube is a good option. It is important to talk with your attending physician or hospice nurse about whether a feeding tube will cause more harm than good in your particular situation.



A handout with more detailed information on Tube Feeding is located in the Forms Library tab of this binder.

Social Withdrawal

Friends, family and caregivers often like to spend as much time as possible with their loved one during their time on hospice care. For some people this is a pleasure; for others, it feels intrusive. People on hospice can have many new feelings just as they face the end of their lives. We all handle these emotions differently. Some welcome lots of visitors and some simply want to be alone.

This emotional process is normal and we encourage you to treat your loved one with respect. If you are a caregiver, friend or family member who feels like your loved one is turning away from you just at the time when you long to be closer, talk to your care team. This can be normal and you may need support balancing your feelings and your loved one's desires.

People often wonder what the final days and hours of life will be like. Some fear that talking about it will make it happen, so they don't ask. Actually, talking about what to expect allows you to be prepared. As scary as it can be to think about, our experience has taught us that people who aren't prepared often suffer more than people who are. Please talk to your care team about what might happen in the end. If you are a caregiver, friend or family member who might be present during the final few days of your loved one's life, it is important to us that you know what to expect.

As the Body Shuts Down

During the last days to hours of life, the body is shutting down. This can take a week or just a few days. When the body shuts down, it does so in fits and starts, and in no predictable order. Dying is unique to each person. There may be things to look for or expect, so discussing it with the care team is most important.

However, there are a few things that happen commonly enough, it is worth saying something about them. They are:

1. Noisy, erratic breathing

One of the final areas of the brain to shut down is the part responsible for breathing and swallowing. In the final days, you may hear rapid breathing and/or long pauses. In addition, saliva may pool at the back of the throat and makes a wet noise with every breath. This is normal. When breathing is like this, the person is not thought to be aware of it. In some cases it helps to reposition the person.

2. Agitation

When the body shuts down, the brain does so in spurts. A person might talk normally one minute and then act confused the next, or suddenly call out, grimace, or even stand up after being bedbound for weeks. This is because the brain needs the correct balance of oxygen and nutrients and, during the dying process, this can naturally get "off-kilter." The "misfires" that sometimes result can be upsetting to people who witness them. This kind of agitation is normal, and because the brain is dying, the person is believed to be unconscious of what's happening.

3. Symptoms that are not completely controlled

Occasionally, as the body is shutting down, it cannot absorb medicines effectively. Your care team will help you with other methods of symptom management to keep your loved one comfortable, although this is not always possible.

Also, as a person dies, there are times when they may appear uncomfortable. However, if they are unconscious, grimacing or moaning may be due to the brain “misfiring.” As difficult as it may be to watch, it is not thought to be upsetting to the patient. Please share any concerns about this with your care team.

What Caregivers Can Do at the End

It is believed that touch and hearing are the last senses to go. You may want to talk soothingly to your loved one and hold their hand. You can provide a warm presence and keep a calm atmosphere in the room to help the person transition to death.

➔ See page 38 for helpful information on what happens immediately following death and in the weeks afterward, including disposition of the body, transportation to the mortuary, at the mortuary, and obtaining death certificates



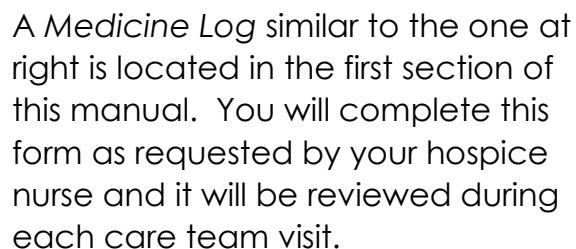
If you and your loved one completed a *Patient Time of Death Planning Checklist* (see Forms Library), take a moment to review it.



Please read the *Approaching the End of Life* booklet located in the front pocket of this binder. It includes a summary of the dying process, what to do at the time of death and immediately after, and information about grief support.

Most hospice patients take one or more medicines. It is important that you understand the medicines we may use and their side effects, as well as how and when to use them. You will receive information and training from your hospice nurse, and we are available 24/7 to answer your questions. The following are some important details:

- ## Medicine Log



Call us first | 33

Medicine Side Effects

As your hospice team, our goal is to help you control your pain, and avoid serious side effects of medicines.

1. If the medicines you are prescribed are not working, or causing a significant increase in sleepiness or trouble thinking clearly, call your hospice nurse immediately. Do not adjust your dose on your own as this may increase the risk of side effects.
2. It is unlikely that your medicines, if used as ordered, will cause serious breathing problems until well after the above symptoms have already prompted you to call your hospice nurse.

However, if breathing is severely slowed and your patient is unresponsive, call 9-1-1 only if emergency resuscitation is consistent with the patient's Goals of Care and POLST (Physician Orders for Life Sustaining Treatment). Then notify hospice immediately by calling the number on the blue *Your care team* form at the front of this binder.

3. The benefits of opioid pain medicines, such as morphine, include better pain control and, often, increased ability to perform tasks, improved sleep and higher energy level. Adverse effects may include constipation, nausea, sleepiness, trouble breathing and even death, so it is important to only use these medications as directed by your physician and hospice team.
4. We advise you not to drive or operate machinery while taking opioid medicines or other medicines that can slow your reflex time or cause sleepiness, unless approved by your physician.
5. Only the patient and a family member or caregiver who has been instructed to help with medicines should have access to your pain medicines. Other people could be harmed if they take medicines prescribed for you, so it is important to keep your prescriptions and medicines secure and under your control.
➔ See page 34 for information regarding how to dispose of unused or outdated medicines.
6. If you are being prescribed opiate medicines, we may be required to consult a California state database that allows us to know all of the physicians who may be prescribing controlled substances for you.

When opioids are used appropriately for pain control, new addiction in hospice is rare. We will work with you to avoid this problem.

Your pain control is very important to us! We are dedicated to helping you improve your quality of life.

Storing and Taking Medicines

While medicines to control pain and symptoms are a key component of hospice care, they can be harmful when administered incorrectly or are taken by people other than the patient. Please observe the following precautions:

Storing

- Keep all medicines out of the reach of children and teens.
- Keep medicines in their original containers with the label intact. Never take medicine from unlabeled containers.
- Never put two kinds of pills in the same bottle.
- Store as instructed.
- Never store medicines in the bathroom. Warmth and moisture may weaken their effectiveness.

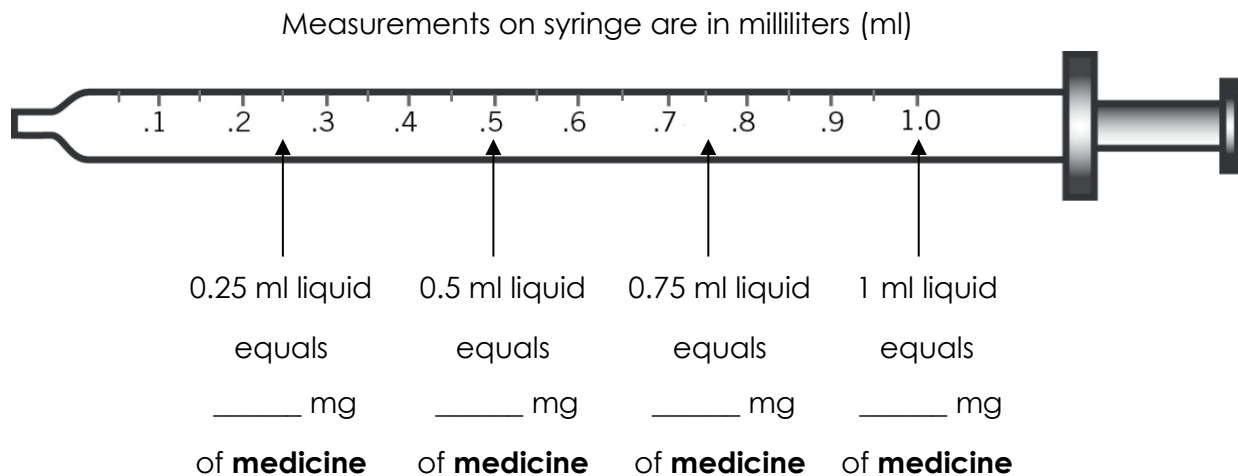
Taking Medicines

- ❗ Be sure your care team is aware of all medicines, vitamins, supplements and herbal remedies you are taking. Let them know of any allergies or alcohol use that might affect prescribed medicines.
- Keep a chart of all your medicines, listing by name when each should be taken.
- If you have multiple medicines, a weekly medicine dispenser may be helpful.
- Before you take a medicine, check the label in good light so you're sure it's the correct one.
- Be sure that the patient's name on the bottle is correct before taking — do not share medicines.
- Follow all medicine dosage instructions exactly. Be sure you understand:
 - what the medicine is,
 - what it is for,
 - how and when it should be taken,
 - how it works,
 - the potential side effects (dizziness, for example).
- Never increase or decrease your dosage of prescribed medicine without instruction from your attending physician or hospice nurse.

-
- Never take a medicine prescribed for someone else, or give your medicine to someone who has similar symptoms.
 - Never take alcohol with any medicine unless your physician assures you that the combination will not cause negative effects.
 - Report any side effects or new symptoms immediately to your care team.
 - Refill medicines within seven days of running out.

How to Measure Liquid Medicines

- Measuring liquid medicine can be confusing. This is because liquid medicines are measured in how many milligrams (mg) of actual medicine are diluted in how many milliliters (ml) of liquid.
- Each medicine also has its own dilution.
- However, syringes are marked only in milliliters (ml) of liquid.
- Most hospice syringes hold a maximum of one milliliter (ml) of liquid. We recommend that you use a one-milliliter syringe for any liquid medicines prescribed for you or your loved one.





A form similar to the one at right will be filled out by your hospice nurse for each medicine that is prescribed, and then placed in the front section of this binder, so that you are confident in giving the correct dosage.

Hospice Day

Liquid Medicine Dosing

How to Measure Your Liquid Medicines

- Giving liquid medicine can be confusing. This is because liquid medicines are measured in how many **milligrams (mg)** of actual medicine are diluted in how many **milliliters (ml)** of liquid.
- Each medicine also has its own dilution.
- However, syringes are marked **only in milliliters (ml)** of liquid.
- Most hospice syringes hold a maximum of **one milliliter (ml)** of liquid. We recommend that you use a one-milliliter syringe for any liquid medicines that are prescribed for you or your loved one.
- To avoid confusion, your nurse will fill out this form for each medicine that is prescribed so that you are confident that you are administering the correct dosage.

Medicine: _____ Dose: _____

Measurements on syringe are in milliliters (ml)

0.25 ml liquid equals _____ mg of medicine

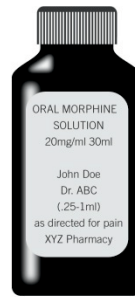
0.5 ml liquid equals _____ mg of medicine

0.75 ml liquid equals _____ mg of medicine

1 ml liquid equals _____ mg of medicine

Taking and Giving Liquid Medicine

1. Check the label to see if you need to shake the bottle.
2. Remove the bottle's lid, and place the oral syringe into the bottle.
3. Pull back on the syringe plunger, so the medicine is drawn from the bottle into the syringe. Pull the plunger until the liquid reaches the mark on the syringe that indicates the prescribed dose. To ensure that you understand the syringe markings, your hospice nurse can show you how much medicine to draw.
4. Carefully remove the syringe from the bottle (or the stopper), holding it by the barrel, not the plunger (see illustration below)



! Note: Markings on the barrel will vary on syringes of different sizes. See previous page on how to measure liquid medicines.

5. Gently slide the tip of the syringe into the patient's mouth, between the teeth and the gum near the inside of the cheek.
6. Slowly and gently, push the plunger down to gradually squirt the medicine into the inside of the cheek, away from the throat. Allow the patient to swallow. DO NOT push quickly or forcefully on the plunger, or squirt the medicine in the back of the mouth or throat.
7. Gently remove the syringe from the mouth.
8. Replace the bottle lid.
9. Rinse the syringe in warm water, and leave to air dry.
10. Repeat the above steps for each dose, as instructed by your Attending Physician or hospice nurse.

Making Liquid Medicines from a Tablet

When swallowing pills becomes difficult, some tablets can be dissolved into a liquid to be swallowed or placed under the tongue. Your hospice nurse can show you how to do this. You will need two spoons, water and syringes. Not all tablets are safe to crush, so do not do this without advice from your hospice nurse or physician.



3. Remove the top spoon.
4. Add a few drops of water to the powder in the bottom spoon.
5. Use the tip of a syringe to stir the powder in the liquid until it is dissolved.
6. Draw the liquid up into the syringe.

Label the syringe with the name of the medicine on a piece of tape.

In order to be ready for unexpected symptoms, By the Bay Health may provide a small pack of five medicines or their equivalents, based on individual needs. Please keep the medicines together in your refrigerator for use later, should you need them. Your attending physician or hospice nurse may prescribe some of these medicines in combination for the best symptom management and you will be provided with instructions on how and when to use them.

A brief description of each medicine follows. If you have allergies to certain medicines or specific medical conditions, your Comfort Pack may differ from this list.

1. **Morphine liquid (Roxanol):** This is one of the best medicines for pain and trouble breathing.

Dosage: Please consult with your hospice nurse.

Side effects: Constipation, dry mouth, nausea, vomiting, headache, itchiness, sleepiness and confusion, but these are rare with the oral morphine we use at By the Bay Health.



Please notify your hospice nurse right away if you or your loved one has unexpected sleepiness or other side effects

Many people are fearful that morphine causes death or addiction, but it is safe as long as you follow the instructions of your nurse and doctor.

➔ See page 31 for more on the use of Morphine in Hospice Care.

2. **Lorazepam tabs (Ativan):** These are mostly used for anxiety. They can also be used for nausea and insomnia. If trouble breathing is worsened by anxiety, this medicine can be helpful.

Dosage: Please consult with your hospice nurse.

Side effects: These are rare and include sleepiness, dizziness, headache and rarely, a reverse reaction of increased agitation.

3. **Prochlorperazine tabs (Compazine):** These are used for nausea or vomiting.

Dosage: Please consult with your hospice nurse.

Side effects: Dry mouth, sleepiness, dizziness and constipation.

4. **Haloperidol liquid (Haldol):** This is used for nausea, vomiting or agitation.

Dosage: Please consult with your hospice nurse.

Side effects: Sleepiness, constipation, dry mouth and restlessness.

5. **Bisacodyl suppository (Dulcolax):** These are used for constipation.

Dosage: Please consult with your hospice nurse.

Side effects: Cramping and diarrhea. Good bowel care may require

daily medicines to stimulate your bowels. This is a “rescue” medicine if you have not had a bowel movement in two or three days.

Morphine in Hospice Care

One of the medicines that may be prescribed for you is morphine, one of the most common opioids. It is used often in hospice care to safely and effectively treat pain, just as it is used to treat pain from such causes as surgery, childbirth, heart attack or cancer.

Morphine is also used to ease trouble breathing. It helps make each breath slower and deeper, which makes it easier to relax and breathe with more comfort. Pain or trouble breathing should be treated as soon as symptoms arise. Quick action allows less medicine to be used and be even more effective in helping ease symptoms. This can also prevent a pain or symptom crisis later.

Ten Common Concerns about Pain and Morphine

1. ADDICTION: “I don’t want to get addicted.”

- At the end of life, addiction is uncommon.
- It is common for patients to require an increase in pain medicine over time. This is not addiction. It is simply increased tolerance, which means that more is needed for the same effect.

2. TOLERANCE: “If I start taking morphine too early, it won’t work when I need it.”

- It is normal for your body to adjust to the pain medicine. Your dose can be increased if necessary so the medicine keeps working.
- Morphine continues to relieve symptoms, even if you take it for a long time.
- Using medicine now will not prevent it from working in the future.

3. SIDE EFFECTS: “I don’t want to feel knocked out/tired/nauseated/constipated.”

- Most people feel more energetic when their pain or breathing symptoms are treated.
- The tiredness and/or nausea that is occasionally associated with pain medicines usually disappears after a few days. If it doesn’t, the dose can be adjusted.
- Anti-nausea medicine can help until you are used to the medicine.
- Constipation can be treated with laxatives and stool softeners.

4. DENYING PAIN: “I don’t want people to think I’m weak or a whiner.”

- Pain can severely affect quality of life, so it is not a sign of weakness to admit to pain.

-
- Honest communication is essential for good pain management. Denying pain makes it more difficult to manage comfort.
 - Pain medicine is appropriate for patients who are in pain.
5. **DRUG-SEEKING: “I don’t want to appear like I’m drug-seeking or a junkie.”**
- Pain medicine is appropriate for patients who are suffering. When someone in hospice says they are in pain, we believe them.
 - Nearly 90 percent of patients receiving hospice care take pain medicine.
6. **BEING A BOTHER: “I don’t want to bother others.”**
- Pain management is important and a key aspect of hospice care. If your pain is not being controlled well we want you to call us day or night.
 - We do not expect you to deal with your pain alone.
7. **OVERDOSING: “I’ll end up giving/taking too much.”**
- Overdosing on pain medicine is extremely rare. Your care team will check often to see how you are responding to the medicines. The dose can be adjusted if needed.
 - If you stop giving/taking pain medicine, the pain will likely return and may be more difficult to get back under control.
 - If you are comfortable, that means the morphine is working. If your pain or trouble breathing is temporary, you may try stopping the morphine to see how you feel. But most of the time, the reason you are taking the morphine has not changed and therefore, it's likely that the symptoms will return.
 - Be sure to talk to your care team before making any changes to medicines.
8. **PAIN CAN’T BE AVOIDED: “I should wait until my pain is severe.”**
- It is always best to treat pain or trouble breathing right away. Severe symptoms are harder to manage and require more medicine to control. Talk with us as soon as symptoms arise so we can help make you comfortable.
 - Pain and trouble breathing harm your quality of life. They make it harder to sleep and move, decrease your appetite, make your heart work harder and cause depression. We can help improve your quality of life by relieving these problems.

9. **TAKING MORPHINE MAKES YOU DIE SOONER:** “I don’t want to speed up or cause my death.”

- Research shows that morphine does not make someone die more quickly, and can help some patients live longer. Because it helps control symptoms and makes each day as comfortable as possible, it allows the body to relax and focus energy on other things.

Excerpted from an article by UNC Cecil G. Sheps Center for Health Services Research

Safe Medicine Disposal

Putting medicines directly in the garbage (with or without their containers), or flushing them down the toilet or sink, is never safe and can be harmful to people, pets and the environment. There are two safe ways to dispose of medicines:

1. Request a Disposa-Script pouch, which can be provided by your care team. Simply follow the instructions that come with it.
2. Take unused medicines to an authorized disposal site. See below for locations and disposal instructions.

Where to Dispose of Medicines

Many pharmacies accept unused medicines and other supplies. Call your local pharmacy about its policy and procedures.

You can also use the medicine drop-off and disposal sites in your county (see the list below). Dispose of unused medicine as described in your county's guidelines.

Preparing Medicines for Drop-off at a Disposal Site:

1. Combine all pills in a sealable, plastic bag or in as few containers as possible. Remove labels or black out with a permanent black marker.
2. Tighten the lids of liquid medicines and place the entire bottle in the sealable bag.
3. DO NOT include personal care products such as toothpaste, thermometers, aerosol cans (except inhaler cartridges, which are accepted), needles or syringes. For assistance in disposal of these other items, speak with your hospice nurse. It's likely that you will need to make a separate trip to dispose of these other items.
4. To find your county's drop-off locations, see the resources below.

Med Project

www.med-project.org

This website has excellent information on a variety of medicine disposal methods. You can search by location for disposal kiosks, take-back events and places to obtain mail-back packaging.

Marin County

www.tinyurl.com/marindisposal

www.med-project.org

For a list of medicine drop-off locations, visit either of the websites above, or call the MED-PROJECT at (844) 633.7765.

San Francisco, San Mateo and Alameda Counties

www.savesfbay.org/pharmaceutical-disposal-sites

www.med-project.org

For a list of medicine drop-off locations, visit either of the websites above, or call SaveTheBay at (510) 463.6850.

Sonoma County

www.safemedicinedisposal.org

For a list of medicine drop-off locations, visit the website above, or call the Safe Medicine Disposal Program (707) 543.3369.

Napa County

www.naparecycling.com/medicine

For a list of medicine drop-off locations, visit the website above, or call the Napa County Household Waste Facility at (800) 984.9661.

Solano County

Visit www.solanocounty.com and search for “drug take back” to find the next Prescription Drug Take Back Event.

Medicines may also be dropped off at:

Napa-Vallejo HHW Collection Facility

889 Devlin Rd. in American Canyon (Fri. & Sat., 9 a.m.- 4 p.m.)).

Vallejo Police Dept.

111 Amador St., in Vallejo (Mon. to Thu. 9:30 a.m.– 5 p.m.)

Advance Health Care Planning

Advance Health Care Planning teaches you about the types of life-sustaining treatments available, and documents the treatments you would or would not want, should you be unable to speak for yourself. During a medical crisis, your family and caregivers will not have to guess or make decisions about what you would want—they will know your wishes.

Typically under California state law, individuals have the right to:

- Accept or refuse medical or surgical treatment,
- Have an Advance Health Care Directive and/or appoint a health care agent.

Your hospice social worker can explain and help you complete documents that can ensure that your health care decisions are known, respected and followed. Your care team can supply any of the following forms you wish to complete and will add them to your medical records.

Advance Health Care Directive

In California, an Advance Health Care Directive includes:

- Durable power of attorney, which names a trusted person to direct your health care if you become unable to do so,
- Living Will, which describes the medical treatment you would or would not like to receive in certain situations.

Physician Orders for Life Sustaining Treatment (POLST)

California's POLST allows you to state specifically what kind of life-sustaining treatment you do or do not want. Printed on bright pink paper and kept with your medical information, your POLST is signed by both you and a doctor. Your POLST has the strength of a doctor's order, which means that your wishes for end-of-life care are more likely to be obeyed. Be sure your caregivers know about your POLST and where to find it, so if there is a call to 9-1-1 and emergency personnel arrive, your wishes will be honored. We also suggest that you call By the Bay Health in any emergency.



You will find copies of an *Advance Health Care Directive* and a *POLST* form located in the Forms Library located at the back of this binder. If you need help in filling them out, please talk to your hospice nurse or social worker.

Do Not Resuscitate Order (DNR)

You may choose to decline specific resuscitation measures that may keep you alive during a medical crisis. The DNR form documents your wishes to decline:

- Being placed on life-assisting equipment if your heart or breathing stops,
- Certain treatment measures, such as CPR, assisted ventilation (breathing), endotracheal intubation, defibrillation and medicines that stimulate the heart.

The DNR doesn't stop your ability to receive other emergency medical care, including treatment for pain, difficulty breathing, major bleeding or other medical conditions.

Final Arrangements

The period immediately following death can be busy and especially stressful. You can make this time more manageable by having a plan in place. Some patients like to do the planning themselves. In other cases, a family member or designated person with legal power of attorney may be put in charge. Your hospice social worker will ask about these details in advance, to ensure you are informed of your options and help with the decision-making process.

Disposition of the Body

There are generally three choices when it comes to disposition of the deceased's body: burial, cremation or body donation. In all cases, your care team will need to know your decision and the funeral home or agency handling the disposition. If the patient lives in a facility, their staff will need to have this information as well.

Financial, Legal and Other Practical Issues

Like advance health care planning, documenting your wishes about other practical concerns keeps you in control, even if you cannot speak for yourself. Your care team members, especially your hospice social worker, can answer questions and help you accomplish your goals.

We recommend you share your decisions with key people, such as family, health care providers, spiritual counselors, and legal and financial advisors. That kind of clarity and communication can relieve the stress on your family and caregivers.



You may also wish to complete the checklist included in the *Just in Case* brochure, located in the back pocket of this binder.

Time of Death Preparation



A *Patient Time of Death Planning Checklist* is located in the Forms Library in the back of this binder. It will help you specify your wishes regarding:

- Whom you would like to be present, along with contact phone numbers
- Any special requests such as massage, hand-holding, music
- Whom to notify following your death
- Contact information for your Durable Power of Attorney for Finances
- Who will take over care of your pets, if needed
- Mortuary and funeral/memorial plans

This is not a complete list. For further information contact:

Funeral Consumers Alliance: www.funerals.org/consumers/

Following Death and the Weeks Afterward

Immediately Following Death

If one of your care team members is not present at time of death, your first call should be to By the Bay Health, using the number on the blue Your Care Team sheet located at the front of this binder. In most cases, once By the Bay Health has been contacted, a nurse will come to the home or facility to confirm death. The nurse will also inform the patient's attending physician so that a death certificate can be completed.



You will want to contact everyone on the *Patient Time of Death Planning Checklist*, located in the Forms Library in the back of this binder, as well as the patient's designated person with Legal Power of Attorney.

If the patient had any pets, you will also want to arrange for their care.

Transportation to the Mortuary

Unless you have chosen a home funeral (preparing the body at home for burial elsewhere), the nurse will call your mortuary of choice on your behalf and provide a release number from the coroner if needed.

For deaths that occur at home, there is no time limit on when transport is required by the mortuary. Some families or caregivers choose to keep their loved one at home so that last goodbyes can be made. The family or person with legal authority should contact the mortuary about arranging the time of pick-up, if the nurse did not coordinate this during the visit.

For deaths that occur at a facility, the facility may require that the mortuary transport the body within a few hours of the death. Please be sure to coordinate with facility staff in advance so this goes smoothly.



Note: For those using a cemetery that is *not* part of a mortuary, check in advance to see if you need to select a mortuary for legal paperwork and transportation.

At the Mortuary

Most mortuaries require the next of kin or person with legal authority to come to the mortuary within 1–2 days of the death to authorize services. They can also assist with obituary notices and will ask for information about the patient's parents, education, and employment history. In some cases, the mortuary may also ask for a birth certificate, marriage license, etc.

Death Certificate

Unless you are planning a home funeral, the mortuary is responsible for arranging for the death certificate and requesting copies from the county. Most individuals need from 3 (minimum) to 15 copies for requests from financial institutions, health and life insurance companies, employers, mortgage companies, credit cards and loans, retirement funds, etc. Your county charges an additional fee for each death certificate.

Returning Durable Medical Equipment

Following death, you should receive a call from the vendor within 48 hours to arrange for pick-up and return of all durable medical equipment (DME) that we provided, such as hospital beds and oxygen systems. If you do not receive a call, contact Patient Care Support Services at (415) 927.2273.

The Weeks Afterward

The next of kin or person with legal authority will need to take care of many items in the coming weeks.

- ☐ Plan service of remembrance/memorial/funeral
- ☐ Plan for home to be occupied during above service
- ☐ Place death notice in the local newspaper (mortuary will assist)
- ☐ Contact your attorney or get legal advice about wills, trusts, and probate
- ☐ File any outstanding claims and pay any outstanding bills
- ☐ Locate necessary paperwork for real estate, investments, bank and retirement accounts, loans, tax returns
- ☐ Forward mail, cancel or archive social media and email accounts
- ☐ File for life insurance benefits through bank, credit cards, employer
- ☐ Notify about the death:
 - ☐ Veterans Administration, religious organizations, membership organizations
 - ☐ Patient's accountant, tax consultant or preparer
 - ☐ Banks, financial institutions, investment companies
 - ☐ Social security and any other government offices providing benefits such as IHSS
 - ☐ Health insurance, Medicare, supplemental health insurer, Medi-Cal
 - ☐ Employer, pension or annuity provider
 - ☐ Department of Motor Vehicles (if vehicle owner, or has driver's license)
 - ☐ Registrar of voters
 - ☐ Credit card companies and credit agencies (Equifax, TransUnion, Experian)



You may wish to complete the checklist included in the *Just in Case* brochure, located in the back pocket of this binder. For further information contact:

AARP: www.aarp.org/home-family/friends-family/info-06-2012/when-loved-one-dies-checklist.html

Changes to Your Hospice Care

Travel While in By the Bay Health's Care

If you visit or travel out of By the Bay Health's service area, you can remain under By the Bay Health's care. To support you at your destination during a long visit, we will contract with a local hospice provider, while still retaining responsibility for managing your care.

To make your trip less stressful and avoid confusion or complications, talk about the details with your care team well before you leave. Patients who develop medical problems while traveling to their destination may need to be temporarily discharged from By the Bay Health's care if they need care by:

- a hospice provider outside the By the Bay Health service area, or
- a provider other than the contracted hospice at your planned destination.

If you have questions or concerns about travel, please contact your care team.

Choosing to Stop Hospice Care

It is your right to stop receiving hospice care at any time, for any reason. To withdraw, you or your representative must file a revocation document that includes a signed statement canceling coverage of hospice care and the date care is to end. Your care team can provide you with the revocation paperwork. Once you end hospice care, you can resume the regular insurance benefits you waived when hospice care was elected.

Changing Hospices

You have the right to change to a different provider of hospice care. With your current hospice provider and the new hospice, you or your representative must file a signed statement that includes:

- Name of the hospice from which you received care,
- Name of the hospice you'd now like to use,
- Date the change is to be effective.

Discharge from Hospice Care for those on Medicare

Your Medicare Hospice Benefit, which covers your care, requires that By the Bay Health evaluate your medical condition and prognosis to ensure that you continue to meet Medicare's hospice eligibility guidelines. Only individuals who are diagnosed as terminally-ill are eligible for the benefit. Medicare regulations require By the Bay Health to evaluate you after 90 days in our care, after 180 days, and every 60 days after that. If your condition improves while in our care, or you go into remission, and you no longer meet Medicare guidelines, you may be discharged from our care.

By the Bay Health is required to discharge a patient if the hospice determines that the patient is not terminally ill. If you are discharged for an improved diagnosis and your condition later changes to again meet Medicare criteria, you are eligible to return to our care.

A patient who moves out of our service area shall be discharged from By the Bay Health's care. However, your care team will work with you and your caregivers to ease the transition to your new plan for care. If, in the future, you move back to our service area, you may return to By the Bay Health's care.

If you disagree with a discharge decision made by our hospice physician, you have the right to appeal to Medicare within two days after you are discharged. This request for an independent review of the discharge decision is called the Medicare Expedited Appeal Process.

For more information, see the booklet provided to you during admission, **Medicare Hospice Benefits**, by the Centers for Medicare and Medicaid Services. Review page 12 of the booklet, "How Long You Can Get Hospice Care" and "Your Medicare Rights" for details and contact information for the Medicare office near you.

By the Bay Health's MATCH Program (Monitor At The Client's Home)

Our MATCH Program meets the need for continued follow-up with patients who have been discharged and/or have chosen to revoke from our hospice services. While patients' primary care providers are responsible for meeting patients' medical needs after they leave our care, our MATCH nurses will continue to monitor and assess for eligibility for readmission to hospice care. This is a voluntary patient follow-up program, so you may opt out at any time.

Only patients who have been previously enrolled in By the Bay Health's care are eligible for the MATCH Program. There is no charge to clients. If you have questions, please contact MATCH at (415) 526.5601, or ask your care team for a brochure.

❗ Transitioning DME After Discharge from Hospice Care

Due to recent changes in Medicare coverage, some of our vendors of durable medical equipment (DME), such as hospital beds, are no longer able to accept Medicare payment from patients who have been discharged from our care. Most offer a two-week grace period, which should give you time to make other arrangements for your DME needs. To search for an alternative supplier, visit: www.medicare.gov/supplierdirectory/search.html. Note that more than one vendor may be required depending on the items needed.

Please contact your care team prior to discharge with any questions. We will be happy to provide you with support and resources to make this transition as smooth as possible.

Knowing how to properly use your medical equipment is an important part of maintaining safety.



If you have life-sustaining equipment that depends on electricity, call your local provider to let them know. This will prevent power shut-off if you do not pay your bill on time.

You may also be eligible for reduced residential service rates under the **PG&E Medical Baseline program**. To learn more, visit www.pge.com.

Here are some helpful hints regarding medical equipment:

- Take time to learn how to use the equipment. Ask your care team for help, if necessary.
- Keep the manufacturer's instructions with or near the equipment.
- Keep phone numbers easily available so you can notify equipment providers and obtain necessary assistance in the case of equipment problems or failures.
- Always lock any wheeled equipment.
- Make sure medical and other equipment (hospital beds, wheelchairs and commodes, for example) are in proper working order.
- Use of extension cords with medical equipment is not recommended.
- Perform routine and preventative maintenance according to the manufacturer's instructions.

Recycling Medical Equipment and Supplies

You can donate other reusable home health equipment (such as walkers, shower chairs, canes), as well as disposable medical supplies in their original packaging (adult incontinence pads, bandages, etc.), to non-profit ReCARES. They have three drop-off sites in the Bay area; visit their website at www.homecares.org, or call for locations and days/hours of operation:

Marin: (415) 388.8198 • San Francisco: (415) 487.5405 • Oakland: (510) 251.2273

To donate unopened nutritional supplements, such as Ensure®, call your local food bank or homeless shelter.

Oxygen Use

Oxygen use presents a fire risk since it can “feed the flames” when there is an open flame (candle) and a flammable item (such as clothing or upholstery). Oxygen is not flammable by itself. However, some materials burn hotter and faster in the presence of oxygen. Smoking is a major reason for burn accidents involving home medical oxygen therapy. As part of your home oxygen safety, a staff member will conduct a safety risk assessment (asking questions and looking around your home). This will happen when you are admitted to By the Bay Health (BTBH) or when you start oxygen and every two weeks to make sure you and the staff are aware of any potential fire hazards due to oxygen therapy.

The BTBH staff will tell you if they find fire risks and discuss with you and your caregivers how to correct these problems. If unsafe oxygen use practices are found, you will be counseled by BTBH to correct them. Sometimes you may need notes or signs posted to help you remember how to be safe when using your oxygen. BTBH will help you and your caregivers write notes as reminders. If you live close to another house or live in an apartment building, a fire in your home could also burn your neighbor's home.

If an oxygen tank is in use:

- Ensure that oxygen tanks are kept in a well-ventilated area and that they are stored according to the vendor's instructions.
- Know how to turn OFF the oxygen in case of emergency/fire.
- Avoid being near an open flame, matches, stoves, grills or space heaters. Use caution around electrical devices or toys that produce sparks.
- Never smoke or use an open flame within 15 feet of the oxygen user or equipment.
- Never use petroleum-based products in and around the nose (such as Vaseline®). Using these with oxygen can cause burns.
- “No Smoking” signs may be posted within the home.
- “Oxygen in Use” signs will be posted in the front window of the home.
- Oxygen collects around the user and the immediate area. Keep flammable materials away from user and tanks.
- Make sure you have working smoke detectors. Consider your neighbors and follow all of the instructions, regarding fire safety, given to you by BTBH.
- Keep oxygen vendor's name and phone number near the telephone and attached to the tank in case of machine problems.

Slips and falls are the most common injury in the home. Your care team, especially hospice aides, will work with you and your caregivers to help you eliminate hazards.

➔ See page 47 for a helpful ***Know Your Falls Risk Assessment***. It will help you pinpoint which risk factors may apply to your situation.

Outdoors

- Both sides of steps should have handrails. Make sure all handrails are securely fastened and easy to grasp.
- Add non-skid treads on each step, or a contrasting color to mark the edge.
- Add a ramp, or replace/repair steps for ease of movement.
- Repair holes, cracks or uneven joints on walkways.
- Arrange to have leaves, water or ice removed from stairs and walkways.
- Make sure outside lighting is working in entryways and other walk areas.

Indoors

- Keep nighttime thermostat settings above 65° F. A low body temperature could lead to dizziness, which can lead to falls.
- If possible, make sure floors are even or make repairs.
- Secure any carpeting that is loose. Remove all throw rugs, as they are a trip hazard.
- Remove or tape down electrical cords.
- Use night lights in hallways, bedrooms, bathrooms and stairways.
- Make sure stairways are well lit. Install light switches at top and bottom of stairs. Replace burned-out bulbs immediately.
- Remove items from the floors of hallways, rooms and traffic areas, including newspapers, boxes, electrical and phone cords, plants and unneeded furniture.
- Store frequently used clothing, bed coverings and other household items where you can reach them comfortably.
- Place other frequently used items in easy-to-reach places. If you must use a step stool, use one with handrails you can hold while reaching.

Walking, Moving and Reaching

- Rise slowly after eating or sleeping, as low blood pressure can cause dizziness.
- If you feel light-headed or dizzy, sit down.
- Keep your glasses nearby and wear them, even when you get up at night.
- Wear firm, supportive shoes.
- Always tie shoe laces securely, even if walking a short distance.
- Wear non-skid socks when walking without shoes, even it's for a short distance.
- Robe hems should be above the ankles and pant hems above the floor.
- Always use a cane or walker if one was recommended. Keep it nearby.
- Add a basket to a walker to carry items, rather than carrying things in hands.
- Pick up feet and avoid shuffling.
- Watch feet on uneven surfaces.
- Take extra care walking when small children or animals are near. Put bells on pet collars so you are aware if they are nearby.
- When going up or down stairs, always use the handrails and take one step at a time.
- To maintain balance, avoid reaching. Keep frequently-used items close by.
- Use a sturdy step-stool with handrails to reach items on high shelves.
- Place frequently used items in easy-to-reach places.

In the Bathroom

- Mount grab bars securely on walls by the toilet, bath and shower.
- Place non-slip strips or mats with suction cups in the shower or tub floor to ensure stable footing.
- Use non-skid bath mats outside of the shower, or secure them with non-slip, double-sided rug tape.
- Consider sitting on a waterproof bench or stool in the shower. Switch to a hand-held shower head.

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- Replace bar soap with easier-to-handle liquid soap in plastic bottles.
 - Make faucets and towel bars easy to reach.
 - Check the water temperature with your hand before entering tub or shower.
 - Install a raised toilet seat and shower seat to make it easier to sit and get up.
 - Consider using a portable toilet beside the bed.

Know Your Falls Risk Assessment

Your safety is a major concern of the entire Bay Health staff. Each of our patients receives a falls risk assessment. Falling is the leading cause of death from injury among older adults. Falls can be prevented.

You or your loved is at risk for falls due to the following risk factors:

Risk Factors for All Ages	Falls Prevention Tips
<ul style="list-style-type: none">❑ You have three or more co-existing diseases, which puts you at high risk for postural hypotension❑ Medicines such as:<ul style="list-style-type: none">○ Sedatives, such as sleeping pills○ Anxiety medicines○ Blood pressure medicine○ Pain medicine○ Medicines for heart disease○ Medicine to decrease blood sugar○ Allergy medicine, especially antihistamines○ Diabetes medicines○ Diuretics (also known as “water pills”)○ Laxatives○ <i>Blood thinners, including aspirin and Coumadin, don’t increase your risk for falling, but they increase your risk of getting seriously injured if you do fall.</i>	<ul style="list-style-type: none">• Sit at the edge for a few minutes of your bed before standing.
<ul style="list-style-type: none">❑ Visual impairment (twice as likely to fall)	<ul style="list-style-type: none">• Wear your glasses• See your eye doctor at least once a year for eye exams• Make sure eye glasses are clean and in good repair

Risk Factors for All Ages	Falls Prevention Tips
<input type="checkbox"/> Poor memory and/or dementia	<ul style="list-style-type: none"> • Follow a daily routine, use written reminders and calendars • Minimize distractions • Use prompts, such as bed alarms, as a reminder to call for assistance • Keep walkers and canes directly next to the bed to reduce the chance of forgetting to use them • Manage agitation, as appropriate
<input type="checkbox"/> Pets in the home	<ul style="list-style-type: none"> • Put a small bell on pet collars to alert you to their presence • Be aware of pet toys in the environment • Whenever possible, walk your dog on level terrain • Use two hands or a retractable leash when walking large or active dogs • Know what triggers your pet's startled or jumping behavior
Specific Pediatric Risk Factors (0-18 years)	Falls Prevention Tips
<input type="checkbox"/> Ambulate or transfer with assistive device <input type="checkbox"/> Ambulate with unsteady gait and no assistive device <input type="checkbox"/> Developmentally delayed <input type="checkbox"/> Disoriented <input type="checkbox"/> Needs assistance with toileting <input type="checkbox"/> Independent with urinary frequency or diarrhea <input type="checkbox"/> History of falls before and after admission <input type="checkbox"/> Anticonvulsants, opioids, diuretics, sedatives, bowel prep <input type="checkbox"/> Current use of alcohol (quantity of alcoholic beverages per day) or recreational drugs	<ul style="list-style-type: none"> • Use night lights in hallways, bedrooms and bathrooms • Remove obstacles such as electric cords and clutter • Paint the edges of steps, stairs and uneven surfaces or mark them with reflective tape • Remove throw rugs and area rugs or secure with two-sided tape • Always keep a bedside commode next to your bed for toileting. • Falls frequently occur in the bathroom and while getting out of bed, so always ask for assistance with these activities. • Always ask for help getting in and out of bed. If no one is staying in the room with you, consider using a bell or baby monitor to communicate. • Ensure items used frequently are stored within safe reach. • Always put on rubber-soled shoes or slippers when walking.

Specific Risk Factors for Adults (18-100+ years)	Falls Prevention Tips
<ul style="list-style-type: none"> <input type="checkbox"/> You are 65 years old or older <input type="checkbox"/> You have a history of falling within the past three months <input type="checkbox"/> Equipment tubing, such as oxygen, in the home <input type="checkbox"/> Weakness, as illustrated by requiring assistance with bathing and dressing <input type="checkbox"/> Depression <input type="checkbox"/> Pain <input type="checkbox"/> Musculoskeletal problems, such as osteoporosis, arthritis, fractures or bone metastases <input type="checkbox"/> Neurological impairments such as neuropathy, Parkinson's, MS, stroke, vestibular conditions (dizziness) or diabetes <input type="checkbox"/> Urgency getting to bathroom, such as due to incontinence or diarrhea <input type="checkbox"/> Current use of alcohol (quantity of alcoholic beverages per day) or recreational drugs 	<ul style="list-style-type: none"> • Use night lights in hallways, bedrooms and bathrooms • Remove obstacles such as electric cords and clutter • Paint the edges of steps, stairs and uneven surfaces or mark them with reflective tape • Remove throw rugs and area rugs or secure with two-sided tape • Always keep a bedside commode next to your bed for toileting. • Falls frequently occur in the bathroom and while getting out of bed, so always ask for assistance with these activities. • Always use an assistive device whenever ambulating: wheelchair, walker or cane • Always ask for help getting in and out of bed. If no one is staying in the room with you, consider using a bell or baby monitor to communicate. • Ensure floor surfaces are even, uncluttered, and adequately lighted. • Ensure items used frequently are stored within safe reach. • Install handrails in the bathroom. • Always put on rubber-soled shoes or slippers when walking.

IF YOU HAVE A FALL

1. Call By the Bay Health immediately at the numbers below, anytime, day or night.
2. If you need help getting up off the floor, dial 9-1-1 and ask for Non-Emergency Assist. They will call the fire department, which will send someone to help pick you up off the floor and get you back into bed.

Call the office nearest you:

Marin County: (415) 927.2273

San Francisco/San Mateo County: (415) 626.5900

Sonoma County/cities of American Canyon/Napa/Vallejo: (707) 935.7504

Infection Control

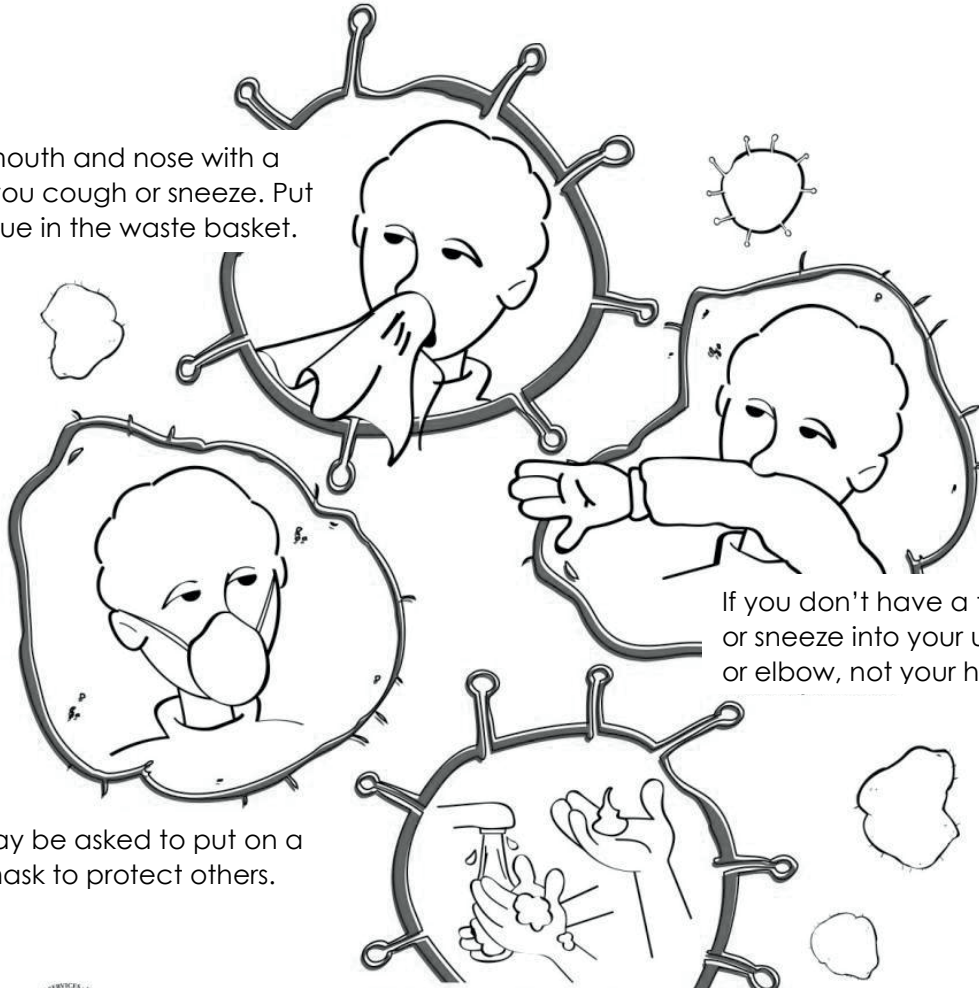
- Hand-washing is the best way to prevent infection. Wash your hands:
 - before preparing food,
 - before and after medical care,
 - after handling soiled material,
 - after going to the bathroom,
 - when they look visibly dirty.



Cover your Cough

— Stop the spread of germs that can make you and others sick! —

Cover your mouth and nose with a tissue when you cough or sneeze. Put your used tissue in the waste basket.



If you don't have a tissue, cough or sneeze into your upper sleeve or elbow, not your hands.

You may be asked to put on a face mask to protect others.



Wash hands often with soap and warm water for 20 seconds. If soap and water are not available, use an alcohol-based hand rub.

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Telephone

- A phone with enlarged or lighted number keypad can make use easier.
- Keep phone within easy reach at all times, especially if bedbound.
- Use a cordless phone or answering machine so you don't have to rush to answer.
- Post emergency numbers near the phone. Include By the Bay Health, your doctor, police, fire department, ambulance, nearest neighbor and a relative.

Bedroom

- Place a lamp and telephone near the bed.
- Keep a whistle or bell and a flashlight near the bed for use in an emergency.
- Do not fall asleep while using a heating pad.
- Never smoke in bed, when drowsy or when oxygen is in use.
- Do not use electric blankets if electrical parts are worn or broken, or the blanket is damp. Never set on the "High" setting, or cover or tuck-in the blanket.

Kitchen

- Learn and use safe food handling, preparation and storage techniques.
- Wash your hands after handling raw meats, fish or eggs.
- Maintain a clean environment where food is stored.
- Cover and refrigerate food promptly.
- Keep utensils, foods and other frequently used items at a convenient height.
- Store heavy items flat on lower shelves for easy access.
- Don't wear long sleeves or loose clothes while cooking.
- Turn pot handles toward the back of the stove.
- Keep a multi-purpose fire extinguisher nearby. Check expiration date annually.
- Cover open cuts or wounds with clean bandages.
- Store medical supplies in a clean, dry place, away from children and pets.
- Dispose of soiled dressings and incontinence supplies in sealed plastic bags.
- Store used syringes and needles in a puncture-proof container (red sharps container). Dispose of properly.
- Wash heavily soiled linens in hot soapy water.
- Wash garbage cans with hot soapy water and a cleansing solution, such as bleach.

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- Clean all areas of the bathroom with a cleansing solution, such as bleach.
 - Clean door handles weekly, with a cleansing solution, such as bleach.

Poison Prevention

- Keep products that are poisonous, such as cleaning solutions, cosmetics, gasoline and medicines, out of the reach of children and mentally-impaired adults.
- Keep chemicals in their original containers with proper handling instructions. Never put harmful substances into food or drink containers.
- Never mix cleaners with bleach. Mixing can create poisonous or noxious fumes.
- If you think someone has swallowed something poisonous, call the **Poison Control Hotline at (800) 222.1222.**

Firearms

- If there are weapons in the home, they must be unloaded and stored securely away from patient care areas.

Electrical Safety

- Check the condition of electrical appliances, cords and plugs regularly, and keep them in good repair. Throw out frayed or damaged electrical cords.
- Avoid multiple outlet adapters to prevent overload of electrical circuits.
- Do not place wires or cords beneath furniture or rugs.
- Never use nails or staples to secure wires or cords. Use duct tape to secure wires or cords to flooring.
- Replace light bulbs with the correct type and wattage.
- Never use electrical equipment in or near liquids, and keep them away from the sink, tub and shower areas. All electrical equipment should be grounded.
- Unplug appliances when not in use.
- Keep a flashlight handy in case of a blackout. Be sure the batteries are fresh.

Fire Prevention

- Keep flammable materials away from stoves, heaters or other heat sources.
 - Keep portable heaters at least three feet away from people and objects.
 - Prepare a fire escape plan that includes at least two ways out of the house from every room. Designate a meeting place outside the building for all residents. Practice the escape plan at least twice a year.
 - Inform the local fire department that an infirm patient is in the home.
 - Arrange regular, professional cleaning and maintenance for heating systems and chimneys.
 - Install smoke detectors on every level of the home. Test detectors once a month.
 - Install a carbon monoxide detector.
 - Keep a fire extinguisher in the home and check the expiration date annually.
- ➔ If you are using oxygen in the home, please review *Oxygen Use* on page 44.

Home Emergency Preparedness

In the event of an emergency/local disaster, By the Bay Health has a plan that will enable us to continue to provide care to our patients. We will contact or visit patients in the order of those that are in most need of medical attention.

To contact By the Bay Health during a disaster, please call (415) 927.2273. You can also check our website for updates at www.hospicebythebay.org.

Important Definitions

Emergency: An emergency is an unexpected or sudden event that significantly disrupts the home environment physically. Emergencies can be either human-made (such as accidental fire) or natural (such as an earthquake or a flood). Emergencies can also be a combination of both and may be mild or severe.

Disaster: A type of emergency that, due to its complexity, scope, or duration, threatens local services and requires outside assistance to keep people safe and secure.

Preparedness: Planning how to respond in case an emergency or disaster occurs and working to ensure you have supplies available, a safety plan, and an escape plan.

Watch: A watch means that there is a high possibility that a weather emergency will occur. When a severe storm watch is issued for your area, continue to listen to the radio or television for updates and pay attention to visible weather changes around you.

Warning: A warning means that a weather emergency is already happening, or will happen soon. When you hear a warning, take immediate action.

Planning for Emergencies

The delivery of health care services, such as medicine, medical supplies, and staff visits may be disrupted by natural disasters (earthquakes, floods, etc.) as well as by other types of emergency situations, such as electrical blackouts. The aim of this section is to help you prepare for a variety of possible emergencies. Hopefully, you will never need to use these emergency measures. However, by knowing what to do and preparing ahead, you can feel secure if an emergency should occur. Study the information in this section carefully and remember to keep this Hospice Care Guide in a place where you can find it easily. Leave copies of this section at your workplace, at home, with family members that do not live with you, and take one with you when you travel.

Gather Important Information

It is important to keep certain documents in one place in a waterproof container, including:

- ☐ Copy of your POLST (Physician Orders for Life Sustaining Treatment)
- ☐ Up-to-date list of your medicines and dosage (sample included on page 64)
- ☐ Paperwork about your medical condition(s)
- ☐ Completed Family Emergency Plan. There is a sample copy on page 63 of this Hospice Care Guide. Update the information often. If needed, ask your health care staff to help you complete these forms.
- ☐ Emergency phone list
- ☐ Insurance cards
- ☐ Bank statements
- ☐ Contact list for friends and family. Ask a friend or relative in another area to be your designated contact person. In an emergency, you may not be able to make telephone calls in your immediate area, but may still be able to place calls to another area. Although cell phones will often lose their signal during emergency situations, landlines often still work. Learn how to use text messaging if your cell phone has this feature. Text messaging may work when calling does not. It would be good to have a landline phone in your home.

Be Prepared

- How will you contact your family? Find out how to get local emergency alerts. Know emergency telephone numbers. Check with your local health department or emergency management agency to see how they share emergency information.
- Learn about your community's warning signals. Be able to recognize what the warning signals sound and look like, and what you should do when you hear or see them.
- Keep your car's tank at least half full with gasoline at all times.
- Know where the gas, electric and water shutoff locations are for your home. You can contact your utility company to send a technician to your home to show you how. Learn how to do this before there is an emergency.

Put Together an Emergency Supply Kit

Keep the following items in a secure place, in a water-proof container. Check for expiration and replace your supplies as needed throughout the year:

- ☐ Extra cash, maps of your area, extra set(s) of car keys, and house keys.
- ☐ Two-week supply of medicines and diet needs. Be sure to check monthly for expiration dates and replace items when needed.
- ☐ Hand-cranked or battery-powered AM/FM radio and extra batteries. Find out what the emergency broadcast radio station is in your area. This will give you up-to-date information on road conditions and emergency information, even if you have no electricity or phone service.



- Tune into one of these local radio stations: **KCBS AM 740**, **KGO AM 810**, or **KWMR FM 90.5**, **KZST FM 100.1**. You can also stream these stations on the internet at the station's website.
- ☐ Flashlights with plenty of extra batteries, or candles and matches. (To use only if emergency personnel have checked and okayed your gas line.)
 - ☐ Safety supplies such as a first-aid kit, emergency blanket, multipurpose tool (that can act as a knife, file, pliers, and screwdriver), whistle, and mirror (to reflect light if needed so safety personnel can find you), and fire extinguisher. Check regularly to make sure it is full.
 - ☐ Warm blankets, extra clothing, and shoes.
 - ☐ Prepare for loss of indoor plumbing. Basic toileting can be met by using kitty litter, fireplace ashes or sawdust and garbage bags.
 - ☐ Enough food and water for each person in the home to last 3 days or more (1 gallon of water per person per day).
 - ☐ Personal care items (soap, toothbrush, toothpaste, baby wipes for bathing, contact lenses and solution or glasses).
 - ☐ Pet care supplies. Food, water, bowls, leashes, pet carriers, pet toys, current photos of your pets (in case you become separated), manual can opener and cat litter. Make sure you have enough pet supplies to last at least 3 days or more.

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- ❑ Health and safety supplies such as face wash, dry shampoo, biodegradable soap, paper towels, plastic trash bags, household bleach.

Make a Family Emergency/Disaster Plan

Before making your emergency/disaster plan, it's important to know what types of emergencies are likely in your area and the best way to respond.

- Find the safe spots in your home for each type of disaster. For example, during an earthquake you will need to "drop, cover, and hold on" under a sturdy desk or table. For a flood you will want to go to an upper floor, etc.
- Choose multiple meeting places. Different disasters may require you to go to different places. Make sure you choose a meeting place in your neighborhood, a meeting place just outside your neighborhood, and a meeting place out of town.
- Determine the best escape routes from your home. Find two ways to get out of each room.
- Consider how to help your loved one with limited mobility escape from the home quickly. A bedbound person will need to be placed in a wheelchair and wheeled out, or wrapped in a blanket and dragged away from danger. If possible, place hospital beds close to an exit door.
- Practice, Practice, Practice. Review your plan with all members of your family. Practice your disaster plan by running drills with the whole family every six months. This would also be a good schedule for checking the contents of your Emergency Supply Kit.
- Don't forget your pets! Think about what you would do with your pets, because they may not be allowed in emergency shelters.

Types of Disasters and Special Considerations

Earthquakes

An earthquake is a sudden, rapid shaking of the ground caused by the breaking and shifting of rock beneath the earth's surface. This shaking can cause damage to buildings and bridges, disrupt gas, electric and phone service. It can sometimes lead to landslides, avalanches, flash floods, fires, and huge destructive ocean waves (tsunamis). Most earthquake-related injuries are due to collapsing walls or floors, flying glass, and falling objects as a result of the ground shaking or people trying to move more than a few feet during the shaking.

Planning:

- Make sure your furniture, potted plants and wall hangings are secured in place.

What to do during an earthquake:

- Pick a safe place (under a heavy table or desk), then drop, cover, and hold-on.
- Stay indoors; do not go outside unless it seems likely that the building is going to collapse.
- Once the initial shaking has stopped, be aware that aftershocks may occur.
- Stay away from tall objects that could fall over.

What to do after an earthquake:

- Listen to a battery-powered radio to keep up with what is going on in the area: KCBS AM 740, KGO AM 810, KWMR FM 90.5, or KZST FM 100.1.
- Know the location of the nearest hospital in a safe area that has not been affected by the earthquake.
- Make sure to wear shoes when walking in case of broken glass.
- Turn off any lighting and electrical devices.
- Do not use the telephone except in extreme emergencies.
- Locate your emergency supplies; remember to conserve supplies.
- Do not light candles or matches until emergency personnel have verified there are no gas leaks.
- If you evacuate your home, remember to take your Hospice Care Guide and other information with you, as well as your medicines and Emergency Kit.
- If you have to go to a shelter, tell the person in charge about your special needs as a hospice patient.

Floods

Floods can be serious catastrophes and they are one of the most common hazards in the United States. Floods can be caused by many things such as a sudden accumulation of rain, rising rivers, and storm surges.

Some terms to understand:

Flood Watch: Flooding is possible. Monitor your radio and TV stations for more information.

Flash Flood Watch: Flash flooding is possible. Be prepared to move to higher ground such as the top of a hill. Monitor your radio and TV stations for more information.

Flood Warning: Imminent threat. Flooding is occurring or will happen soon. If advised to evacuate, do so immediately.

Flash Flood Warning: Imminent threat. A flash flood is occurring or will happen soon. Move to higher ground, such as the top of a hill soon.

What to do during a flood:

1. Listen to your local emergency broadcast radio station for information and instructions about what to do: **KCBS AM 740, KGO AM 810, KWMR FM 90.5, or KZST FM 100.1.**
2. Move essential items to an upper floor of your house.
3. If you have to evacuate your home:
 - Stay out of already-flooded areas and areas where floods may occur, such as low-lying areas.
 - Move to high ground if you see or hear rapidly rising water.
 - Do not drive through flooded areas or cross water that may be more than knee-deep.
 - Do not walk through moving water; even a few inches can sweep you off your feet.
 - Use a stick to check the firmness of the ground in front of you.
 - Do not touch electrical equipment if you are wet or standing in water.
 - Be very careful at night when it is harder to spot flood dangers.
4. If you have to go to a shelter, remember to bring your Hospice Care Guide binder and tell the person in charge about your special needs as a hospice patient.

Wildfires

Wildfires are common disasters that can spread quickly, particularly during dry conditions. Advance planning can help protect you against the destructive impacts of wildfires.

Planning:

Having an evacuation plan in place before a wildfire occurs can help avoid confusion and prevent injuries. A thorough evacuation plan should include:

- How you know when to activate the plan (emergency alerts via text or radio)
- Emergency functions and who will perform them
- Specific evacuation procedures, including routes and exits
- Procedures for accounting for all family members and pets
- Review your plan with family members regularly

Maintain a fire safe zone ("defensible space") around your home or residence. Remove combustible materials within 30 feet of your home including dried plants, weeds, shrubs, or any other flammable material. Clear branches and shrubs that are within 15 feet of chimneys or stovepipes. In addition to the 30-foot safety zone, an additional safety zone of 70 feet is recommended. This will increase your level of protection against fire. For more information, contact the California Department of Forestry and Fire Protection, or look at the Federal Emergency Management (FEMA) website.

Power Outages:

PG&E Service Interruption: (800) 743.5002

Planning:

- Contact the local electrical utility company and local public safety agencies in advance, if lack of electricity would create an immediate threat to life or safety.
- Work with your care team and caregivers to develop a plan on what you will do if the power goes out.
- Find out what kind of telephone you have. If it is a cordless home phone or answering machine, it will not work during a power outage. Make plans to use an older telephone that plugs directly into the wall. A cellular phone that has been fully charged is also a good option.

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- Be sure you know how to open your garage door if the power goes out.
 - Make sure you have backup batteries or a generator available.
 - Keep a flashlight or lantern equipped with fresh batteries within easy reach. For people with limited reach or grasp, inexpensive battery-operated touch lamps are a good option. Such lights can be installed in areas of greatest use and are small enough to be carried in an emergency.
 - Ensure that your house numbers are readily visible from the street to expedite emergency response.
 - Keep your refrigerator and freezer doors closed. Refrigerated foods should remain safe to eat for several hours, and frozen foods should remain safe for an extended period. If in doubt about the safety of any food, throw it out.

During an Outage:

- Listen to the radio for current information on affected areas. **KCBS AM 740, KGO AM 810, KWMR FM 90.5, or KZST FM 100.1.** Have a battery-operated radio available with an extra set of batteries.
- Turn off all appliances, computers and all lights except one. That light will indicate when power has been restored.
- Be careful using candles for heat or light, as they can be a fire hazard.

Terrorist Attack:

The Department of Homeland Security www.dhs.gov; (202) 282.8001 has up-to-date information on preparedness for a terrorist attack.



Family Emergency/Disaster Plan

Important Phone Numbers:

Fire / Police / Ambulance: 9-1-1

Poison Control: (800) 222.1222

American Red Cross Disaster Assistance: (800) 733.2767 (RED.CROSS)

City or County Office of Emergency Services: _____

Medical Numbers:

Local Hospital: _____ Phone: _____

Local Pharmacy: _____ Phone: _____

Medical Insurance Carrier: _____ Phone: _____

Medical Insurance Numbers:

Person: _____ No.: _____

Person: _____ No.: _____

Person: _____ No.: _____

Personal Contacts:

Family Member/Friend: _____ Phone: _____

Contact Person Outside Area: _____ Phone: _____

Local Services:

Plumber: _____ Phone: _____

Electrician/Electric Co.: _____ Phone: _____

Taxi/Ride Share: _____ Phone: _____

Telephone Repair Service: 6-1-1

Resources:

American Red Cross: www.redcross.org; (202) 303.4498

Disaster Response and Recovery: www.fema.gov; (800) 621.3362; (800) 462.7585 (TTY)

National Weather Service: www.weather.gov

Nearest Evacuation Shelter: www.redcross.org/get-help/disaster-relief-and-recovery-services/find-an-open-shelter

Public Health Emergency (US Dept. of Health and Human Services):
www.phe.gov

CDC Emergency Preparedness and Response: www.emergency.cdc.gov

Patient Information

Complete the following information and keep it with you. Keep a copy with your emergency supplies. If you need to go to the hospital or be seen by another hospice, you will need to have this information available. Also, make copies of your insurance ID cards and keep them with your emergency supplies.

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ Cell Phone: _____

Your BTBH Medical Number: _____

Other Insurance Carrier: _____

Policy Number: _____

Emergency Contact/Legally Authorized Person

Name: _____

Relationship to You: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: _____ Cell Phone: _____

By the Bay Health Toll-Free Phone: (888) 834.7367

Nurse Case Manager: _____

Your Attending Physician: _____

Your Attending Physician Phone: _____

Sample Medicine List:

Medicine Name	Number of Times per Day	Quantity per Dose	Times Taken	Special Instructions

Support for Patients, Family Members & Caregivers

People cope with serious, life threatening illness in many ways and there is no “right” way to cope with the end of life. Your hospice social worker is specially trained in helping patients and family members deal with the many emotions that arise when you or your loved one are facing a terminal prognosis.

Anticipating the end of life is one of the most difficult times any of us will encounter. Many patients and family members feel relieved to be able to discuss some of their more difficult family and interpersonal relationships with their hospice social worker. Receiving emotional support from a qualified social worker can help in a variety of ways.

Our social workers assist patients, families and caregivers with emotional support and practical preparation for the days ahead. Information can include:

- The benefits of By the Bay Health services, including grief counseling and other programs
- Options for home care resources you may need in addition to our care team visits
- Identifying additional help available through local community resources
- Legal and financial choices and resources, including advance health care planning or insurance, finances and legal arrangements
- Creating a plan for support at the patient's time of death
- Help with planning funeral and memorial services

Support for Caregivers

Caregivers do so much to care for their loved one. The physical and emotional demands can cause “caregiver fatigue,” so it's essential that you take care of your physical, emotional and spiritual health. Self-care allows you to give the best care to your loved one. All you do — including taking care of yourself — makes a positive difference in your loved one's life.

Here are some suggestions to help you stay in balance and ease the stress that can arise:

- Balance caregiving activities with short rest periods or time away. Nourish yourself with activities that are just for you.
- Ask family members and friends to visit with the patient, cook a meal, or help with household chores, errands or shopping.

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- Ask your care team for support from our trained volunteers. A volunteer visit allows you to take a refreshing break to visit a friend or run errands.
 - Eat when you're hungry and avoid skipping meals.
 - Stay healthy with well-balanced meals, rather than fast foods.
 - Drink plenty of water or juice daily. Limit alcoholic drinks.
 - Get a good night's sleep so you'll be rested each day.
 - Several times a week, get 30 minutes or more of moderate physical activity.
 - Visit your own health care provider for checkups or as needed.
 - Watch for signs of stress, such as impatience, headaches, stomach aches, difficulty sleeping, loss of appetite and muscle tension. Ask for help when you need it.
 - Use stress reduction techniques, such as relaxation recordings, soothing music and deep breathing.
 - Make your daily duties realistic to your energy level. Keep your "Things to Do" list do-able.
 - It's natural to feel angry, frustrated or overwhelmed at times. Write in a journal, or share feelings with family members, friends or your hospice team.
 - Ask your hospice social worker if caregiver support groups are available in your community.
 - Ask your care team for suggestions and support on smoothing communication between the patient, your family, friends and your care team.

Volunteer Help

Our carefully screened, well-trained volunteers offer support between visits by other care team members. Although volunteers cannot provide physical care for patients, they offer:

- Companionship for the patient and respite care for the caregiver, typically for 1–3 hours
- Help with errands, such as grocery shopping, or light chores, like meal preparation
- Patient transportation for appointments or short outings (talk to your social worker about availability)

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- A supportive presence during the patient's final hours

We can also suggest local complementary care options that may promote well-being, reduce stress and provide other benefits for hospice patients and their families. Contact your care team to learn more.

By the Bay Health's spiritual support counselors invite you to explore how we might support you on the journey ahead. A professional spiritual support counselor, specifically trained in end-of-life care, is available to you, your family and those caring for you. Our interfaith counselors support those with no religious affiliation, as well as those of diverse faiths. Regardless of whether you choose to utilize this service, we encourage you to reference this guide for tips and suggestions you may find useful.

What do Spiritual Support Counselors Do?

Spiritual support can include many different approaches to enhancing your quality of life and helping you cultivate a sense of peace and well-being. We offer care based on your own experiences, beliefs and questions, in whatever way is most meaningful to you. Here are some examples of the roles our spiritual support counselors can play in supporting you and your family:

- A trusted, non-judgmental confidante with whom fears and concerns that may not easily be shared with family and friends can be addressed at your discretion
- The member of the care team whose sole purpose is to help you cultivate a sense of peace. We might do this through conversation, the sharing of music, readings, your favorite hobbies or through the lens of your spiritual or religious beliefs. A review of your life and values can also help foster a sense of meaning.
- An experienced companion and guide for those who wish to explore their spiritual beliefs, questions and concerns or to address the emotional and spiritual causes of non-physical pain
- An interfaith minister for prayer and ritual, in times of need at your request and aligned with your beliefs
- A liaison with members of your own faith community. We are happy to contact any religious community on your behalf to arrange a visit or sacrament
- A source of support for your loved ones and those caring for you who may need a compassionate ear, acknowledgement and encouragement
- An officiant to help with the planning and/or conducting of a memorial service
- Another set of eyes and ears bringing valuable insights and a different perspective to your care team's plan for you

All of these services are not just included in hospice care, but valued as an essential part of supporting you through this most challenging and vulnerable time. We consider it a privilege to work with you.

Creating Sacred Space For You and Your Loved One

As illness progresses, there is often a natural turning inward when matters of heart and spirit begin to take precedence over everyday life. As a caregiver, friend or family member providing support for a loved one going through this process, you may wish to consider some suggestions for nurturing this inner journey. Bear in mind that when trusting and following your own instincts based on your deep care and concern, there is no “right or wrong.”

Supporting a loved one through the end of life is one of the most profound challenges that any of us might face. We encourage you to ask for help or guidance along the way. Be gentle with yourself, and know that your love and caring will be felt in many ways.

Readings

Being read to can be very comforting, particularly when the subject matter is familiar and/or inspiring. Even if your loved one is no longer responding, they can most likely hear you. Our sense of hearing can endure long after our other faculties have diminished. We can offer you printed readings from various faiths or inspiring quotes, passages and poetry.

Music

The power of music, whether played softly on a radio or sung quietly in your own voice, can bring a sense of comfort and familiarity, as well as a distraction from pain. Music can also be a companion at times when your loved one may be alone.

Favorite Things

Your loved one will appreciate having favorite and familiar objects or images nearby, such as pictures of family and friends or special places, symbols of faith and inspiration, a candle with a favorite scent or a special pillow, blanket or item of clothing. Simple comforts can have a big impact.

Sharing

Remembering that your loved one can hear you, keep talking with them and sharing your affection. A slow, calm pace communicates care and concern to someone who may not be fully engaged in daily life. Gentle, reassuring touch can also be a very comforting way of communicating.

Quiet Time

Sitting by the bedside and just being present with your loved one may be all that is needed. Your presence alone can communicate your love and let them know that they are not alone. You might use this time to do something soothing for yourself such as reading or doing a relaxation exercise.

Depending on personal preference, periods of quiet may be restful and necessary for someone in fragile health.

Self Care

Nourishing your spiritual, inner life is a gift not only to yourself, but also to your loved ones. Taking good care of yourself and sustaining your own well-being will help bring a calm, soothing presence to difficult situations that may arise and offer you a source of replenishment and renewal. Here are some ways to help keep you connected beyond what is happening right now:

- Spend some time in nature focusing on the sights, sounds, smells and feelings of the season. Even just a few minutes a day can be very helpful.
- Set some time aside for your own forms of prayer, meditation, ritual or reading. Choose an activity that you can designate as your “sacred” time. It could be as simple as lighting a daily candle as you reflect on your wishes for yourself and your loved ones.
- Connect with people who make you feel better and whose presence calms you.
- Allow yourself to do whatever makes your heart sing (without feeling guilty about it!).
- Engage in music, art, dance, poetry or any other artistic expression that inspires and nourishes you.
- Write down whatever you are feeling, thinking or wanting in a private journal. Don’t worry about editing yourself. Sometimes just getting our thoughts and feelings out can help relieve stress.
- Get physical if you can. Even just a little bit of movement or stretching that feels good can go a long way.
- Don’t be shy about setting boundaries with friends, relatives or staff. It is important to communicate clearly with others about what you need, what is most helpful, and what is not. Protect your precious time and energy.
- Be gentle with yourself. Rest.

5-Minute Relaxation Exercise

Try this simple yet powerful deep breathing exercise to help calm any tensions or anxiety:

1. Start from a seated, comfortable position.
2. Put one hand on your belly and the other on your chest.
3. Take a slow deep breath through your nose, allowing your stomach to rise as you do this. The hand on your chest should move very little.
4. Exhale through your mouth, pushing out as much oxygen as you can while contracting your stomach muscles. The hand on your stomach should move in as you exhale but the other hand should move very little.
5. Continue to breathe in through your nose and out through your mouth. As you inhale, feel the breath start at your abdomen and work its way to the top of your head.
6. Reverse the process as you exhale. Try to keep the breath rising and falling from your stomach rather than your chest.

People cope with serious, life threatening illness, in many ways and there is no “right” way of coping when anticipating death. The way a person grieves depends on the personality of that person and the relationship with the person who is dying. It is also affected by their experience with the illness, the way the disease progresses, the person's cultural and religious background, coping skills, mental history, support systems, and even social and financial status.

Anticipatory Grief

Anticipatory grief is the normal mourning that occurs when a patient or family is expecting a loss or death. It has many of the same signs as those experienced after a death has occurred.

It allows the family more time to slowly get used to the reality of the impending loss. Some people are able to address unfinished business between the dying person and the family, such as saying “Good-bye,” “I love you” and “I forgive you”.

Feelings of anticipatory grief may be more difficult to cope with if there is an underlying presence of depression, anxiety, a mental health diagnosis or unusual concern for the dying person. Some think that to accept a loved one's death while they are still alive is a kind of abandonment.

Anticipatory grief affects families and patients alike. When overwhelmed by feelings, it is not uncommon for people to withdraw as a way to cope. Talking with a skilled hospice social worker or spiritual support counselor can help. If you or your family are experiencing these feelings, contact your hospice social worker or spiritual support counselor for support and guidance in this process. They are skilled at assisting you with practical problem solving and anticipatory grief counseling.

Grief

Grief is the normal process of reacting to loss. Each person's grief is individual and no two people will grieve exactly alike. As a family goes through a terminal illness, many losses are experienced, and each can trigger its own mental, physical, social or emotional reactions. Emotional reactions can include **sadness, anger, guilt, anxiety and despair**. Physical reactions can include **sleeping problems, changes in appetite or illness**. Social reactions can include **withdrawal from normal activities, increased irritability or conflict with others, or even resentment of others' happiness**.

How Grief Counseling Works

Most of the support that people receive after a loss comes from friends and family. Grief counseling may also be helpful for those who are experiencing difficulty in coping. Grief counseling helps mourners work through the four tasks of grieving, which are identified by J. William Worden, PhD as:

1. Accepting the reality of the loss
2. Experiencing the pain of grief
3. Adjusting to an environment with the deceased missing
4. Withdrawing emotional energy and reinvesting it in other relationships

The goals of grief counseling include:

- Helping the bereaved to accept the loss by allowing space to talk about it
- Helping the bereaved to identify and express feelings related to the loss, such as sadness, anger, guilt, anxiety and despair
- Providing support and time to focus on grieving at important times such as birthdays and anniversaries
- Describing normal grieving and the differences in grieving from person to person
- Providing ongoing support
- Helping the bereaved to understand their methods of coping
- Helping the bereaved to separate emotionally from the person who died and to reinvest in life and other relationships

Grief counseling is also helpful for people who may have more serious reactions to grief and can be a beneficial supplement to psychotherapy. Grief counseling may allow the mourner to see that anger, guilt and other negative or uncomfortable feelings can exist at the same time as more positive feelings about the person who died.



Grief counseling services are available in individual or group settings at By the Bay Health. Please refer to the ***Grief Support*** brochure, located in the back pocket of this binder for more details about available bereavement services.

You can find a calendar of upcoming grief support groups on our website, www.hospicebythebay.org.

Patient and Family Rights and Responsibilities

By law, every patient and caregiver has rights and responsibilities. Laws protect your right to be cared for in ways that preserve your dignity and respect your wishes for care. Rights and responsibilities cover all aspects of care, including the patient's medical care, other services provided by By the Bay Health, and coverage, billing and payment procedures. We support these rights and responsibilities as part of our mission to provide compassionate, quality care.

Following this section, you will find several notices. They describe your rights and responsibilities in more detail:

- *Non-Discrimination Notice*
- *Patient and Family Bill of Rights*
- *Notice of Privacy Practices: Your Information, Your Rights, Our Responsibilities.*
- *Hospice Policies*
 - *Medication Administration, Management and Disposal*
 - *Safe/Effective Use of Medications*
 - *Medication Disposal*

Should you have questions about this information, please contact us on weekdays during our regular business hours — 8:30 a.m.–5 p.m.:

By the Bay Health

Director of Quality and Compliance

17 East Sir Francis Drake Blvd., Larkspur, CA 94939

(415) 927.2273

Patient and Family Responsibilities

Patients, family members and caregivers can help ensure their caring partnership with By the Bay Health is successful by following regulations set by the California Hospice and Palliative Care Association's Standards of Quality Hospice Care, as follows:

- To remain under a doctor's care while receiving hospice services.
- To inform By the Bay Health of any advance directives or any changes in advance directives and provide the program with a copy.
- To cooperate with the attending physician, program staff and other caregivers.
- To advise By the Bay Health of any problems or dissatisfaction with patient care.

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- To notify By the Bay Health of address or telephone number changes or when unable to keep appointments.
 - To provide a safe home environment in which care can be given. In the event that conduct occurs such that the patient's or staff's welfare or safety is threatened, service may be terminated.
 - Obtain medicines, supplies and equipment ordered by the attending physician if they cannot be obtained or supplied by By the Bay Health.
 - Treat personnel with respect and consideration.
 - Sign the required consents and releases for insurance billing and provide insurance and financial records as requested.
 - Accept the consequences for any refusal of treatment or choice of non-compliance.
 - If you have questions or concerns about the rights and responsibilities in this chapter, please contact your By the Bay Health care team.

Patient and Family Bill of Rights

By the Bay Health is committed to ensuring that each patient and their caregivers receive the highest quality services possible. To this end, every patient and caregiver has rights and responsibilities that are supported by law and agency policy. This Bill of Rights is designed to describe, protect and promote the rights of each patient to be treated with dignity and respect. These rights may be exercised by the patient or a representative.

It is our desire that patients and caregivers be informed participants in the care process. This includes understanding the illness, the services provided, and the billing/payment procedures.

Every patient is assured of personalized care regardless of race, religion, gender, ethnicity, age, handicap, sexual orientation, veteran status, lifestyle, or ability to pay. By the Bay Health staff provides high-quality care, which is respectful of dignity, individuality, privacy, and personal property. All staff members providing care are licensed or certified in their respective fields, and have completed additional training in hospice-specific care. By the Bay Health will not tolerate any occurrence of abuse, neglect, or exploitation of any kind by anyone, including our staff. The patient and family should be free from mistreatment, neglect or verbal, mental, sexual and physical abuse, including injuries of unknown source and misappropriation of patient property.

Additionally, every patient is guaranteed that they will not receive any experimental treatment without expressed consent and a full understanding of all information.

Right to Be Fully Informed

The patient and caregivers have the right and are encouraged to be informed and active participants in the care process. The By the Bay Health staff is available to answer questions and interpret complicated medical procedures.

Involvement in the development of the Plan of Care, which is tailored to each patient's needs and circumstances, is a very important way to participate. The patient and caregivers are encouraged to be informed decision makers in the development, change and updating of the Plan of Care. The goals and objectives of the Plan of Care reflect the physical, psychological, spiritual, and social needs of the patient, caregivers and family.

All By the Bay Health patients are assured of receiving the best possible care, including pain and symptom management. Every patient may also be assured of the right to refuse care or medicine. Our staff will provide

information to the patient and/or caregivers of the potential result and risks of a decision to stop care or medicine.

By the Bay Health prides itself on more than 40 years of quality hospice care, but if the patient's needs are not being met, or in order to best serve the patient's needs, it may become necessary to consider alternative levels of care or referral to another agency.

By the Bay Health staff will provide necessary and helpful information to assist in the decision-making process and will facilitate transfer to another agency.

Rights to Services

By the Bay Health provides all necessary and physician-ordered equipment and services. This includes: nursing, physician, hospice aides, spiritual, counseling and social services. If necessary, dietary, physical and speech therapy services are also available. Any additional services or equipment required for the patient's comfort and safety, which are ordered by a physician, are provided. Volunteer services may be arranged upon request.

All services are provided in a consistent and timely manner. Appointments are arranged consistent with the Plan of Care. The patient and caregivers are informed of the name and discipline of the staff member providing care and the proposed frequency of visits.

As hospice care benefits are most often paid for by private insurance or Medicare, there are certain requirements and restrictions which By the Bay Health must observe. If there is a change in the care that will be covered by insurance and/or Medicare, the patient and caregivers will be notified in advance and will be provided with an explanation of why the coverage was changed and when it will take effect.

Staff will also work with the patient and caregivers to explore treatment and/or transfer options if necessary. In the event that a patient and/or caregiver chooses to discontinue service with By the Bay Health (e.g. remission, revocation of hospice benefit, dissatisfaction with care), staff will provide education and instructions necessary for care after discharge.

Rights to Have Your Concerns Addressed

By the Bay Health is always interested in patient family feedback, suggestions or concerns regarding our services. All complaints are taken seriously, responded to and resolved in a timely manner. Be assured that if you voice a complaint, you will not be subject to coercion, discrimination, reprisal or unreasonable interruption of care for exercising your rights.

We encourage you to voice any concern or complaint to a member of your care team for prompt follow-up.

You may also contact the Department of Public Health or our accrediting organization at any time, 24 hours a day, seven days a week, to report a complaint or request information.

Patient and Family Responsibilities

By the Bay Health is pleased to be your partner in the care process. This process is best facilitated by the presence of a Primary Caregiver.

The Primary Caregiver is essential in providing quality continuous care. That person assumes the responsibility of facilitating the Plan of Care between By the Bay Health staff visits. The Primary Caregiver will normally be present during visits and should notify us if a visit needs to be rescheduled.

A Primary Caregiver is often a family member or friend who oversees arrangements for the patient's needs and assures a safe home environment in which care can be given. By the Bay Health will work with the patient to identify someone to manage in-home caregiving needs if necessary.

For More Information:

By the Bay Health
Director of Quality and Compliance
17 E. Sir Francis Drake Blvd.
Larkspur, CA 94939
Mon.–Fri., 8:30 a.m.–5 p.m.
Phone: (415) 927.2273 / Fax: (415) 925.1680

To File a Complaint:

(Complaints concerning the advance directives requirements may be filed with the State Survey and Certification Agency listed below.)

The Joint Commission (TJC)
Office of Quality and Patient Safety
One Renaissance Blvd.
Oakbrook Terrace, IL 60181
(800) 994.6610
www.jointcommission.org

In Marin, Sonoma, Napa, Solano, Alameda and Contra Costa Counties:

California Department of Public Health, Licensing and Certification
Redwood Coast/Santa Rosa District Office
2170 Northpoint Pkwy.
Santa Rosa, CA 95407
Phone: (707) 576.6775
Toll Free: (866) 784.0703
Fax: (707) 576.2037

In San Francisco and San Mateo Counties

California Department of Public Health, Licensing and Certification

San Francisco District Office

150 North Hill Dr., Suite 22

Brisbane, CA 94005

Phone: (415) 330.6353

Toll Free: (800) 554.0353

Fax: (415) 330.6350

Non-Discrimination Notice

Discrimination is Against the Law

By the Bay Health complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. By the Bay Health does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

By the Bay Health:

Provides free aids and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

Provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

If you need these services, contact Robertina Szolarova, Chief Administrative Officer.

If you believe that By the Bay Health has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance with:

Robertina Szolarova, Chief Administrative Officer
17 E. Sir Francis Drake Blvd.
Larkspur CA 94939
(415) 927.2273 TDD: 711 (California Relay Service) Fax: (888) 204-4081
Email: info@hbttb.org.

You can file a grievance in person or by mail, fax, or email. If you need help filing a grievance, Robertina Szolarova, Chief Administrative Officer, is available to help you.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights, electronically through the Office for Civil Rights Complaint Portal, available at

<https://ocrportal.hhs.gov/ocr/portal/lobby.jsf> or by mail or phone at:

U.S. Department of Health and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201
1-800-368-1019, 800-537-7697 (TDD)
Complaint forms are available at
<http://www.hhs.gov/ocr/office/file/index.html>.

Spanish- ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al (415) 927.2273, (TDD 711).

Chinese (Mandarin or Cantonese)- 注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 (415) 927.2273, (TDD 711)。

Tagalog- PAUNAWA- Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa (415) 927.2273, (TDD 711).

Vietnamese- CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số (415) 927.2273, (TDD 711).

Korean- □□ : □□□□ □□□□□ □□ , □□ □□ □□□□ □□□ □□□□ □
□□□□ . (415) 927-2273, (TDD 711). □□□ □□□ □□□□ .

Armenian- ՈՒՇԱԴՐՈՒԹՅՈՒՆ՝ Եթե խոսում եք հայերեն, ապա ձեզ անվճար կարող են տրամադրվել լեզվական աջակցության ծառայություններ:
Հանգահարեք (415) 927.2273, (TDD 711).

Persian- هجوت :رگا هب نابز يسراف وگتفگ م ينکی،د هستيتلا نابز يتروصب اريناگ ارب يامش مهارف م
تماس بگيريد. (415) 927.2273, (TDD 711). يدشاب .اب

Japanese- 注意事項：日本語を話される場合、無料の言語支援をご利用いただけます。

(415) 927.2273, (TDD 711). まで、お電話にてご連絡ください。

Russian- ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните (415) 927.2273, (телетайп TDD 711).

Hindi- ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। (415) 927.2273, (TDD 711). पर कॉल करें।

Arabic- مقرب لصتا .ناجملاب كل رفاوتت ةيوغلا ةدعاسملا تامدخ ناف ،ةغلا ركذا ثدحتت TDD 711 (مقر
تنك اذا :ةظوحلم) 415. (927.2273 :مكبلاو مصلا فتاه

Hmong- LUS CEEV: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu rau (415) 927.2273, (TDD 711).

Laotian- ໂປດຊາບ: ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອດ້ານພາສາ, ໂດຍບໍ່ເສັຽຄ່າ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ໂທ (415) 927.2273, (TDD 711).

French- ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le (415) 927.2273, (TDD 711).

Notice of Privacy Practices

Your Rights. Your Information. Our Responsibilities.

By the Bay Health Privacy Officer
17 E. Sir Francis Drake Blvd.
Larkspur, CA 94939
Phone: (415) 927.2273 / Fax: (888) 204.4081

This Notice of Privacy Practices describes how medical information about you 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	<ul style="list-style-type: none">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	<ul style="list-style-type: none">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	<ul style="list-style-type: none">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	<ul style="list-style-type: none">You can ask us not to use or share certain health information for treatment, payment, or our operations.<ul style="list-style-type: none">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. <p>We will say "yes" unless a law requires us to share that information.</p>
Get a list of those with whom we've shared information	<ul style="list-style-type: none">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 will charge a reasonable, cost-based fee if you ask for another one within 12 months.

Get a copy of this privacy notice	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> You can complain if you feel we have violated your rights by contacting us using the information on page 1. You can file a complaint with the U.S. Department of Health and Human Services Office for Civil Rights by sending a letter to: 200 Independence Avenue, SW, Washington, DC 20201, calling 1-877-696-6775, or visiting www.hhs.gov/ocr/privacy/hipaa/complaints/. We will not retaliate against you for filing a complaint.

Your Choices

<p>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.</p>	
<p>In these cases, you have both the right and choice to tell us to:</p>	<ul style="list-style-type: none"> 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 <p><i>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.</i></p>
<p>In these cases we never share your information unless you give us written permission:</p>	<ul style="list-style-type: none"> Marketing purposes Sale of your information Most sharing of psychotherapy notes
<p>In the case of fundraising:</p>	<ul style="list-style-type: none"> We may contact you for fundraising efforts, but you can tell us not to contact you again.

How do we typically use or share your health information? 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. We may also share health information about you electronically through a health information exchange that allows providers involved in your care to access some of your By the Bay Health records to coordinate services for you.	<i>Example: A doctor treating you for an injury asks another doctor about your overall health condition.</i>
Run our organization	We can use and share your health information to run our practice, improve your care, and contact you when necessary.	<i>Example: We use health information about you to manage your treatment and services.</i>
Bill for your services	We can use and share your health information to bill and get payment from health plans or other entities.	<i>Example: We give information about you to your health insurance plan so it will pay for your services.</i>
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: 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: <ul style="list-style-type: none"> • Preventing disease • Helping with product recalls • Reporting adverse reactions to medicines • 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	We can use or share health information about you: <ul style="list-style-type: none"> • For workers' compensation claims • For law enforcement purposes or with a law enforcement official 	

government requests	<ul style="list-style-type: none"> • 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 we can in writing. 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:

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 web site.

Effective date of notice: September 23, 2013.

This Notice of Privacy Practices applies to the following organization:

By the Bay Health, which operates in the counties of Marin, San Francisco, San Mateo, Sonoma, and the cities of American Canyon, Napa and Vallejo.

If you have questions, please contact

By the Bay Health Privacy Officer

17 E. Sir Francis Drake Blvd., Larkspur, CA 94939

Phone: (415) 927.2273 / Fax: (888) 204.4081

Medication Administration, Management and Disposal

Hospice Policy No. H: 2-053.1

PURPOSE

To ensure that patients, families, and caregivers receive information on the proper administration, management and disposal of medications per county guidelines.

POLICY

1. By the Bay Health (HBTB) staff follow professional practice guidelines and agency policy in administering medications and in assisting the patient to manage his/her medication regimen.
2. A medication profile is established at the initial assessment and kept current throughout the patient's service.
3. The transdisciplinary team is responsible for oversight of the patient's medication profile as part of the plan of care.
4. The patient/caregiver are provided with necessary instruction regarding medication.
5. The supervision of medication is documented in an accurate and timely manner.

PROCEDURE

1. Only legally authorized, qualified staff shall be responsible for medication administration and management.
 - A. A physician prescribes all medications.
 - B. Only registered nurses and licensed vocational nurses may administer medications.
 - a. The nurse ensures that the medications being administered to the patient are those prescribed for the patient.
 - b. The nurse instructs the patient/caregiver in the needs and administration of the medication and in the observation and reporting of any side effects or adverse reactions.
2. Initial medication orders are taken as part of the referral process on each patient.
 - A. The nurse completes a medication profile on the initial home visit.
 - a. The medications are verified with the attending physician.
 - b. The patient is assessed on his/her ability to manage medication.
 - c. The nurse records the review of medications with the patient/caregiver in the clinical record.

-
3. Documentation will include teaching regarding:
 - A. Intended therapeutic effect
 - B. Side effects
 - C. Contraindications
 - D. Adverse reactions
 - E. Storage and Disposal
 4. The nurse will record any barriers to learning.
 5. The ongoing supervision of a patient's management of self-administered medications is part of the patient's Plan of Care.
 - A. The Plan of Care includes an accurate listing of medications with the following information:
 - a. Name
 - b. Dose
 - c. Route of administration
 - d. Frequency
 - B. Skilled nursing interventions will additionally include:
 - a. On-going observation of the patient's response to treatment and side effects.
 - b. Securing signed physician orders for changes in the regimen.
 - c. Reporting to the physician the patient's response to treatment.
 - d. Assisting the patient to obtain refills on continuing medications.
 6. Patient/caregiver instructions about the medication regimen begins on the initial visit and continues throughout service as necessary.
 7. A patient's/caregiver's level of understanding of medication regime is assessed anytime there is an addition, deletion or other change in the medication regime and as often as necessary.
 - A. The assessment findings and any instruction are documented.
 8. The method of instruction should facilitate the patient's learning and may include a Patient/Caregivers Instruction sheet left in the home.
 9. When a hospice patient no longer has a need for a medication, the nurse will instruct the patient/family/caregiver about proper disposal. Written information about medication disposal is included in the admission booklet (Refer to Policy C: 4-016 Medication Disposal).

-
10. The primary nurse will document in the clinical record that the patient and family/caregiver were instructed to dispose of medications and took responsibility to do so.
 11. The hospice nurse, social worker, or chaplain attending the death of a hospice patient will inform the family/caregiver of their responsibility to dispose of all the patient's prescribed medications and will document this in a clinical note.

PURPOSE

To provide guidelines for the instruction of patients and families/caregivers regarding the safe and effective use of medication.

POLICY

Patients and families/caregivers will receive information regarding the safe and effective use of medications in accordance with applicable hospice policies.

PROCEDURE

Upon admission, the patient and family/caregiver will be assessed as to their knowledge and skill required for safe and effective use of medications.

1. The components of the medication assessment to determine patient and family/caregiver knowledge and skill related to medication administration will include, but not be limited to:
 - A. Name, dosage, route, duration, time, and usage of medication, intended use as well as expected actions of drug therapy
 - B. Preparation, self-administration, and use of medication
 - C. Safeguards against contamination
 - D. Compounding and administration techniques (if applicable)
 - E. Significant side effects, adverse reactions/interactions (including drug-to-drug and drug-food interactions) as well as contraindications and how to avoid and respond to such factors
 - F. Self-monitoring of drug therapy
 - G. Proper storage and expiration dating of medications
 - H. Refill information
 - I. Actions to take in the event of a missed dose
 - J. Proper disposal of unused or expired medications, especially controlled substances/Schedule II drugs
 - K. Administration
 - L. Control of opioids in home, hospital and other facilities
 - M. Disposal of controlled drugs in home, hospital and other facilities
 - N. Other information, as applicable

-
2. Based on the assessment, the clinician or designee will review written hospice information available to use for patient and family/caregiver instruction.
 3. Using the written information, the clinician will review the key points based on patient knowledge and skills as well as identified needs, including the patient's role in identifying and preventing medication errors.
 4. The primary nurse will include information, when appropriate, regarding poison control center numbers, allergies, pharmacy numbers, emergency actions, etc.
 5. Documentation of patient and family/caregiver instruction in the clinical record will include:
 - A. Information taught
 - B. Patient and family/caregiver understanding
 - C. Return demonstrations
 - D. Response to teaching

POLICY

Prescription medication, including controlled medications, will be disposed of in compliance with federal and state laws and the procedures of this agency.

Prescription medications no longer needed by the patient are defined as medications that have been discontinued by the physician or those remaining at the time of death.

Prescription medications are the property of the patient and are not to be removed or destroyed by hospice personnel. The responsibility of proper medication disposal belongs to the patient and/or family or facility. Hospice personnel will provide instruction on proper disposal.

Procedures for disposal of medications in the home setting will be given at the time when the medications are first ordered, including:

1. Written instructions for safe medication disposal in accordance with county-specific regulations and instructions.
2. Discussion of the procedures with the patient or representative and family in a language and manner that they understand, and
3. Documentation in the patient's medical record that the procedures were provided and discussed.

PROCEDURE

1. At the time of admission, written instructions about proper medication disposal are provided and the information is reviewed by the admission nurse.
2. When a hospice patient no longer has a need for a medication, the nurse will instruct the patient/family/caregiver about proper disposal. Written information about medication disposal is included in the admission booklet.
3. It is documented in the clinical record that the patient and family/caregiver were given instruction on proper disposal of medications.
4. Hospice nurse, social worker or chaplain attending the death of a hospice patient will inform the family/caregiver of their responsibility to properly dispose of all the patient's prescribed medications and will document this in the clinical record.
5. If the patient resides in a facility, medications that are no longer needed, or those remaining at the time of death will be disposed of by authorized facility personnel in accordance with the facility's policies and procedures.

-
6. If it is deemed unsafe to leave unneeded medication in the home, the nurse will offer the patient/family use of a deactivation kit for the medications, and will notify a supervisor that this was done. The nurse will document in the clinical record:
 - A. That the deactivation kit was used
 - B. The reason the situation was deemed unsafe.
 - C. Which medications were placed in deactivation kit
 - D. Who was present
 7. A signature from the family member/caregiver confirming their use of the deactivation kit will be obtained.
 8. If it is deemed unsafe to leave unused medications in the home, but the person(s) present refuse use of the deactivation kit, the nurse will notify a supervisor immediately, and law enforcement if indicated. A signature from the family member/caregiver confirming refusal will be obtained if possible.
 9. If a patient has died and there are no relatives or responsible parties to dispose of medications, the nurse will contact law enforcement and a supervisor.

ORGANIZATION

Rights and Responsibilities

ADVANCE CARE PLANNING

PURPOSE

To support the implementation of the Patient Self-Determination Act within the framework of state and federal law and organization policies.

POLICY

The organization recognizes that all adult persons 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 the organization to encourage individuals and their families/caregivers to participate in decisions regarding care and treatment. Valid advance health care directives will be followed to the extent permitted and required by law. In the absence of advance directives, the organization will provide appropriate care according to the plan of care or as authorized by the attending/certifying physician. The organization will not condition the provision of care or otherwise discriminate against an individual based on whether or not the individual has executed an advance health care directive or on their choice of treatment indicated in the advance health care directive.

Definitions

1. *Adult*: A person 18 years or older, or a person legally capable of consenting to his/her own medical treatment.
2. *Advance Health Care Directive*: A legal document in which a person states choices for medical treatment.
3. *Attending/Certifying Physician*: The physician who is primarily responsible for the medical care of a patient while receiving services.
4. *DNR (Do Not Resuscitate)*: A medical order to refrain from cardiopulmonary resuscitation if the patient's breathing and/or heartbeat ceases.
5. *Durable Power of Attorney for Health Care (DPAHC)*: A legally recognized document for appointing a health care agent. Generally included in an Advance Health Care Directive.
6. *Health Care Agent*: A person named in an Advance Health Care Directive or Durable Power of Attorney for Health Care to make health care decisions in the event the patient is unable to do so.
7. *Patient Self Determination Act*: A federal statute enacted as part of the 1990 Omnibus Budget Reconciliation Act (OBRA) (PL 101-508) which requires, among other things, that health care facilities provide information regarding the right to formulate advance directives concerning health care decisions.

-
8. *Patient Representative*: A person appointed to make decisions for the patient whether formally appointed (as in an advance health care directive) or in the absence of a formal appointment, one who is authorized as a legal surrogate decision maker. (See the "Informed Consent" Policy.)
 9. *Terminal Condition*: An incurable and irreversible condition which, regardless of the administration of life sustaining treatment will, within reasonable medical judgment, result in death.
 10. *POLST (Physician Orders for Life-Sustaining Treatment)*: A medical order, signed by a physician, allowing a patient to choose the level of medical intervention wanted.

PROCEDURE

1. Upon admission, the admitting clinician will provide information regarding a patient's right to make decisions concerning health care, which include: the right to accept or refuse medical or surgical treatment, even if that treatment is life sustaining, the right to execute advance health care directives, and related organization policies. The clinician will document in the clinical record that the information was provided and document all discussions concerning advance health care directives and the patient preferences concerning care and treatment options. The patient will be provided the opportunity to complete a POLST.
2. If the patient lacks a decision-making capacity, the admitting clinician will provide information and direct inquiry about advance health care directives to the patient's healthcare agent or patient representative. The clinician will document that the patient's healthcare agent or patient representative received information and his/her name and responses will be noted in the clinical record.
3. During the referral/admission process, the clinician will determine and document whether the patient has completed an advance health care directive, obtain a copy, if available, to be placed in the clinical record, or request that the patient or his/her representative provide a copy to the organization as soon as possible.
4. Organization staff cannot honor verbal assurances as evidence of advance health care directive content and assigned health care agent. Only a signed and properly executed copy of the advance health care directive, entered into the organization's patient medical record, can be honored.

-
5. The organization encourages families to share copy of advance health care directives, including DPAHC, with the primary physician.
 6. The patient will be encouraged to participate in all aspects of decision-making regarding care and treatment options. Statements by a competent patient of his/her desire to accept or refuse treatment will be documented in the patient's clinical record.
 7. All clinicians providing care for the patient will:
 - A. Review the advance health care directive and clarify any discrepancies between the directive and current treatment plan with the patient, health care agency or patient representative, the attending/certifying physician, the Team Leader/Clinical Manager, and the trans/interdisciplinary team.
 - B. Provide information to answer the patient's questions about advance health care directives.
 - C. Encourage the patient to discuss questions and concerns with appropriate individuals such as the physician, family/caregiver, and his/her health care agent.
 - D. Assist the patient who wants to complete an advance health care directive to obtain a form and access to the outside resources as necessary to execute the directive.
 8. An advance health care directive will be implemented as follows:
 - A. An advance health care directive is in effect only when the patient is determined to lack the capacity to make his/her own health care decisions unless the advance health care directive specifically states that it should go into effect immediately at time of signature.
 - B. The patient's designated health care agent can then make medical treatment choices based on the advance health care directive.
 9. Education about advance health care directives and the organization's policies and procedures regarding advance health care directives will be provided to the medical, nursing and allied health professionals and volunteers during the orientation period.
 10. In order to educate the community about advance health care directives, the organization will participate in community forums as appropriate and make written materials available regarding advance health care directives.

Care Team Visit Log

Patient Name: _____

Each time a member of your Hospice Care Team visits, they will sign in below. This will help you and your caregivers keep track of who has visited, and when.

Name/Title	Date	Comments (as needed)

Care Team Visit Log

Patient Name: _____

Each time a member of your Hospice Care Team visits, they will sign in below. This will help you and your caregivers keep track of who has visited, and when.

Name/Title	Date	Comments (as needed)

Care Team Visit Log

Patient Name: _____

Each time a member of your Hospice Care Team visits, they will sign in below. This will help you and your caregivers keep track of who has visited, and when.

Name/Title	Date	Comments (as needed)

Name/Title	Date	Comments (as needed)

Patient/Caregiver Instructions

Patient: _____ MR #: _____

Date	Instructions	Initials

If you have questions about these instructions or other concerns, please call us:

Marin County **(415) 927.2273**

San Francisco and San Mateo Counties **(415) 626.5900**

Sonoma County and the cities of American Canyon, Napa and Vallejo **(707) 935.7504**

Date	Instructions	Initials

Patient/Caregiver Instructions

Patient: _____ MR #: _____

Date	Instructions	Initials

If you have questions about these instructions or other concerns, please call us:

Marin County **(415) 927.2273**

San Francisco and San Mateo Counties **(415) 626.5900**

Sonoma County and the cities of American Canyon, Napa and Vallejo **(707) 935.7504**

Date	Instructions	Initials

Patient Name: _____ MR#: _____

[illegible]

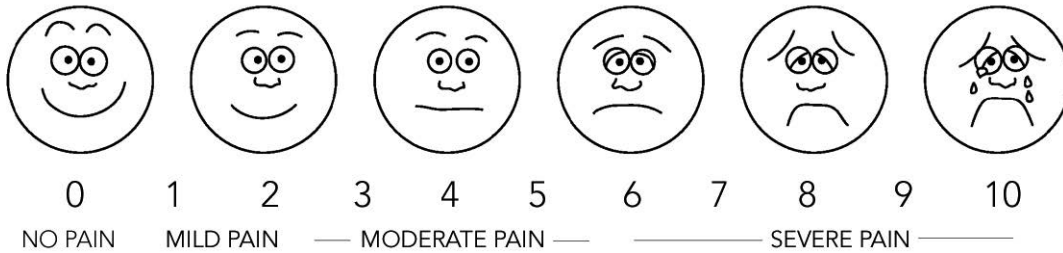
[illegible]

Patient Name: _____ MR#: _____

Remember, you can speak to a Hospice Nurse anytime, day or night, at the number indicated on the **blue “Your Care Team” sheet**, located at the front of this binder.

Nurse Instructions: _____

Rating Symptom Severity:

[illegible]

[illegible]

The following topics have been identified as common concerns expressed by hospice patients and their family members/caregivers regarding pain and pain medication. Please go over this form with a member of your Hospice Team.

A. For the Caregiver/Family Member (name): _____

Do you have concerns about:

- | | |
|--|--|
| 1. The patient becoming addicted? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 2. The patient building up a tolerance and needing higher doses? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 3. The patient being knocked out, drowsy or constipated? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 4. Being viewed as weak or a whiner? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 5. Being seen as a drug-seeker? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 6. Being a bother to others (your family or hospice staff)? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 7. Giving too much pain medication? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 8. The treatments not working? | No <input type="checkbox"/> Yes <input type="checkbox"/> |

B. For the Patient (name): _____

If patient is unable to respond, check here ☐ and skip to question C-2.

Do you have concerns about:

- | | |
|---|--|
| 1. Becoming addicted? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 2. Building up a tolerance and needing higher doses? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 3. Being knocked out, drowsy or constipated? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 4. Being viewed as weak or a whiner? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 5. Being perceived as a drug-seeker? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 6. Being a bother to others (your family or hospice staff)? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 7. Taking too much pain medication? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 8. The treatments not working? | No <input type="checkbox"/> Yes <input type="checkbox"/> |

C. For the Hospice Team (name): _____

- | | |
|--|--|
| 1. Was the brochure discussed with the patient? | No <input type="checkbox"/> Yes <input type="checkbox"/> |
| 2. Was this form discussed with the caregiver/family member? | No <input type="checkbox"/> Yes <input type="checkbox"/> |

Trouble Breathing Report

Patient Name: _____ MR#: _____

Remember, you can speak to a Hospice Nurse anytime, day or night, at the number indicated on the **blue "Your Care Team" sheet**, located at the front of this binder.

Nurse Instructions: _____

Rating Symptom Severity:

0 1 2 3 4 5 6 7 8 9 10
 No Trouble Mild Moderate Severe Worst Possible

Date/Time	Rating (See Above)	What did you do?

Nurse Instructions: _____

[illegible]

Symptom Management Report

Patient Name: _____ MR#: _____

Symptom: _____

Remember, you can speak to a Hospice Nurse anytime, day or night, at the number indicated on the **blue "Your Care Team" sheet**, located at the front of this binder.

Nurse Instructions: _____

Rating Symptom Severity:

0 1 2 3 4 5 6 7 8 9 10
 No Trouble Mild Moderate Severe Worst Possible

Date/Time	Rating (See Above)	What did you do?

Our well-trained and screened Patient and Family Support Volunteers are part of your Hospice Care Team. They receive a background check and complete numerous Medicare-mandated requirements before being allowed to assist patients/families.

This checklist may suggest ways in which you might benefit from this level of care. Please share your needs with your Social Worker, who can then arrange for a volunteer visit.

For the Patient:***Do you feel lonely or isolated?***

A volunteer can:

- ☐ Make weekly companion visits
- ☐ Discuss life experiences
- ☐ Participate with you in an activity or assist with a special project
- ☐ Play music, read or sit quietly with you
- ☐ Offer a comforting and caring presence

Are you mobile and would like more activity?

A volunteer can:

- ☐ Provide short walks or outings
- ☐ Drive you to appointments
- ☐ Help run errands
- ☐ Take you shopping

Do you miss the company of an animal?

An Animal Therapy Volunteer can:

- ☐ Make weekly animal-assisted social visits.
Animal teams are provided through a community agency. In a home setting, a Hospice Volunteer can also accompany the animal team.

Are you troubled with pain, anxiety, sleeplessness or depression?

A specially-certified volunteer can:

- ☐ Provide energy work (Reiki) to help relieve symptoms, promote well-being and increase quality of life.

For the Caregiver:***Do you need some assistance?***

A volunteer can:

- ☐ Provide 1–3 hours of relief care and allow you to leave the home
- ☐ Do shopping errands
- ☐ Prepare a simple meal 1x per week
- ☐ Complete a simple home chore

Patient Time of Death Planning Checklist

Making your wishes known for your time of death can be hard to talk about. But having the conversation now can make sure both you and your loved ones can experience as peaceful a transition as possible.

☐ I would like the room to be quiet.

☐ I would like the following music to be played:

Song: _____ Artist: _____

Song: _____ Artist: _____

Song: _____ Artist: _____

Song: _____ Artist: _____

Song: _____ Artist: _____

☐ I would like to be left alone, if possible.

☐ I would like the following person(s) to be with me:

Name: _____ Phone: _____

Name: _____ Phone: _____

Name: _____ Phone: _____

Name: _____ Phone: _____

☐ I would also like the following (e.g. gentle massage, hand-holding, being talked to, etc.)

☐ Immediately after my death, please notify the following persons:

Name: _____ Phone: _____

Name: _____ Phone: _____

Name: _____ Phone: _____

Name: _____ Phone: _____

Name: _____ Phone: _____

☐ I have arranged for the following person to take over care of my pets:

Name: _____ Phone: _____

☐ I have chosen the following mortuary:

Mortuary Name: _____ Phone: _____

☐ Burial ☐ Cremation



Dear By the Bay Health patient,

In order to ensure that your wishes for health care are known and followed, we recommend that you consider completing the attached Advance Care Planning form. We're here to support you in this process and answer any questions you might have. Please call on us.

Advance care planning is the process individuals can use to make and document decisions about the health care they wish to receive if they are unable to speak for themselves. These choices are based on one's personal values, preferences and discussions with loved ones and health care providers. Advance care planning includes selecting an individual who would make those decisions on his or her behalf.

Making decisions for loved ones can be difficult for family members, and especially if they aren't already clear about their loved ones' health care goals and wishes. It can leave family members uncomfortable or anxious, asking themselves if the decisions they made were really what their loved ones would have wanted.

Defining your wishes, values and goals for health care today can provide guidance and comfort to your loved ones in the future. It can help them advocate for you if needed, ensuring that your choices are honored.

Sincerely, Your By the Bay Health Care Team

For more copies of this form, visit: <https://ag.ca.gov/consumers/general/care>

For online information on Advance Care Planning:

- California Coalition for Compassionate Care: www.coalitionccc.org
- POLST (Physician Orders for Life-Sustaining Treatment) in several languages: www.capolst.org
- California Advance Directive form, Caring Connections: www.caringinfo.org
- Five Wishes workbook in more than 25 languages: www.agingwithdignity.org
- National Healthcare Decisions Day: www.nhdd.org
- National Hospice and Palliative Care Organization: www.nhpco.org
- Institute for Healthcare Advancement: www.iha4health.org
- Center for Health Care Decisions: www.chcd.org/what-endoflife.htm
- Caring Conversations Workbook, the Center for Practical Bioethics: www.practicalbioethics.org

Advance Health Care Directive Form Instructions

You have the right to give instructions about your own health care.

You also have the right to name someone else to make health care decisions for you.

The Advance Health Care Directive form lets you do one or both of these things. It also lets you write down your wishes about donation of organs and the selection of your primary physician. If you use the form, you may complete or change any part of it or all of it. You are free to use a different form.

INSTRUCTIONS

PART 1: POWER OF ATTORNEY

Part 1 lets you:

- **name** another person as **agent** to make health care decisions for you if you are unable to make your own decisions. You can also have your agent make decisions for you right away, even if you are still able to make your own decisions.
- **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.
- your supervising health care provider (the doctor managing your care)
- an employee of the health care institution where you are receiving care, unless your agent is related to you or is a coworker.

Your **agent** may make all health care decisions for you, unless you limit the authority of your agent. You do not need to limit the authority of your agent.

If you want to limit the authority of your agent the form includes a place where you can limit the authority of your agent.

If you choose not to limit the authority of your agent, your agent will have the right to:

- Consent or refuse consent to any care, treatment, service, or procedure to maintain, diagnose, or otherwise affect a physical or mental condition.
- Choose or discharge health care providers (i.e. choose a doctor for you) and institutions.
- Agree or disagree to diagnostic tests, surgical procedures, and medication plans.
- Agree or disagree with providing, withholding, or withdrawal of artificial feeding and fluids and all other forms of health care, including cardiopulmonary resuscitation (CPR).
- After your death make anatomical gifts (donate organs/tissues), authorize an autopsy, and make decisions about what will be done with your body.

Part 2: Instructions for Health Care

You can give specific instructions about any aspect of your health care, whether or not you appoint an agent.

There are choices provided on the form to help you write down your wishes regarding providing, withholding or withdrawal of treatment to keep you alive.

You can also add to the choices you have made or write out any additional wishes.

You do not need to fill out part 2 of this form if you want to allow your agent to make any decisions about your health care that he/she believes best for you without adding your specific instructions.

Part 3: Donation of Organs

You can write down your wishes about donating your bodily organs and tissues following your death.

Part 4: Primary Physician

You can select a physician to have primary or main responsibility for your health care.

Part 5: Signature and Witnesses

After completing the form, **sign and date it** in the section provided.

The form must be signed **by two qualified witnesses** (see the statements of the witnesses included in the form) **or** acknowledged before a notary public. **A notary is not required if the form is signed by two witnesses. The witnesses must sign the form on the same date it is signed by the person making the Advance Directive.**

See Part 6 of the form if you are a patient in a skilled nursing facility.

Part 6: Special Witness Requirement

A Patient Advocate or Ombudsman must witness the form ***if you are a patient in a skilled nursing facility*** (a health care facility that provides skilled nursing care and supportive care to patients). See Part 6 of the form.

You have the right to change or revoke your Advance Health Care Directive at any time.

If you have questions about completing the Advance Directive while in the hospital, please ask to speak to a Spiritual Support Counselor or Social Worker.

We ask that you complete this form in English so that all your caregivers can understand your directions.

Advance Health Care Directive

Name _____

Date _____

You have the right to give instructions about your own health care. You also have the right to name someone else to make health care decisions for you. This form also lets you write down your wishes regarding donation of organs and the designation of your primary physician. If you use this form, you may complete or change all or any part of it. You are free to use a different form.

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

Part 1 — POWER OF ATTORNEY FOR HEALTH CARE

(1.1) 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: _____

Relationship: _____

Address: _____

Telephone numbers: (Indicate home, work, cell) _____

ALTERNATE AGENT (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 agent: _____

Relationship: _____

Address: _____

Telephone numbers: (Indicate home, work, cell) _____

SECOND ALTERNATE AGENT (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 alternate agent: _____

Address: _____

Telephone numbers: (Indicate home, work, cell) _____

(1.2) AGENT'S AUTHORITY: My agent is authorized to 1) make all health care decisions for me, including decisions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of healthcare to keep me alive, 2) to choose a particular physician or health care facility, and 3) to receive or consent to the release of medical information and records, except as I state here (add additional sheets if needed):

(1.3) WHEN AGENT'S AUTHORITY BECOMES EFFECTIVE: My agent's authority becomes effective when my primary physician determines that I am unable to make my own health care decisions unless I initial the following line. If I initial this line, my agent's authority to make health care decisions for me takes effect immediately. ____ (initial here)

(1.4) 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 my best interest. In determining my best interest, my agent shall consider my personal values to the extent known to my agent.

(1.5) AGENT'S POST-DEATH 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):

(1.6) 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. ____ (initial here)

PART 2 — INSTRUCTIONS FOR HEALTH CARE

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

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

☐ **A)** Choice Not To Prolong: I do not want my life to be prolonged if the likely risks and burdens of treatment would outweigh the expected benefits, or if I become unconscious and, to a realistic degree of medical certainty, I will not regain consciousness, or if I have an incurable and irreversible condition that will result in my death in a relatively short time.

Or

☐ **B)** Choice To Prolong: I want my life to be prolonged as long as possible within the limits of generally accepted medical treatment standards.

(2.2) OTHER WISHES: If you have different or more specific instructions other than those marked above, such as: what you consider a reasonable quality of life, treatments you would consider burdensome or unacceptable, write them here (add additional sheets if needed):

PART 3 — DONATION OF ORGANS AT DEATH (OPTIONAL)

(3.1) Upon my death (mark applicable box):

- ☐ I give any needed organs, tissues, or parts
- ☐ I give the following organs, tissues or parts only: _____
- ☐ I do not wish to donate organs, tissues or parts.

My gift is for the following purposes (strike out any of the following you do not want):

Transplant Therapy Research Education

PART 4 — PRIMARY PHYSICIAN (OPTIONAL)

(4.1) I designate the following physician as my primary physician:

Name of Physician: _____

Address: _____

Telephone: _____

PART 5 — SIGNATURE

(5.1) EFFECT OF A COPY: A copy of this form has the same effect as the original.

(5.2) SIGNATURE: _____ Date: _____

(5.3) 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

Print Name: _____

Address: _____

Signature of Witness: _____ Date: _____

SECOND WITNESS

Print Name: _____

Address: _____

Signature of Witness: _____ Date: _____

(5.4) 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 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 on his or her death under a will now existing or by operation of law.

Signature of Witness: _____

Signature of Witness: _____

PART 6 — SPECIAL WITNESS REQUIREMENT IF IN A SKILLED NURSING FACILITY

(6.1) 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 Dept. of Aging and that I am serving as a witness as required by Section 4675 of the Probate Code:

Print Name: _____

Address: _____

Signature: _____ Date: _____

Certificate of Acknowledgement of Notary Public (not required if signed by two witnesses)

State of California, County of _____. On this _____ day of _____, _____, before me, the undersigned, a Notary Public in and for said State, personally appeared _____, personally known to me or proved to me on the basis of satisfactory evidence to be the person whose name is subscribed to the within instrument, and acknowledged to me that he/she executed it.

WITNESS my hand and official seal.

Seal

Signature _____



EMSA #111 B
(Effective 4/1/2017)*

Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: (optional)

A Check One	CARDIOPULMONARY RESUSCITATION (CPR): <i>If patient has no pulse and is not breathing.</i> <i>If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.</i>
	<input type="checkbox"/> Attempt Resuscitation/CPR (Selecting CPR in Section A <u>requires</u> selecting Full Treatment in Section B) <input type="checkbox"/> Do Not Attempt Resuscitation/DNR (Allow <u>Natural Death</u>)

B Check One	MEDICAL INTERVENTIONS: <i>If patient is found with a pulse and/or is breathing.</i>
	<input type="checkbox"/> Full Treatment – primary goal of prolonging life by all medically effective means. In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. <input type="checkbox"/> Trial Period of Full Treatment. <input type="checkbox"/> Selective Treatment – goal of treating medical conditions while avoiding burdensome measures. In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care. <input type="checkbox"/> Request transfer to hospital <u>only</u> if comfort needs cannot be met in current location. <input type="checkbox"/> Comfort-Focused Treatment – primary goal of maximizing comfort. Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. Request transfer to hospital <u>only</u> if comfort needs cannot be met in current location. Additional Orders: _____ _____

C Check One	ARTIFICIALLY ADMINISTERED NUTRITION: <i>Offer food by mouth if feasible and desired.</i>
	<input type="checkbox"/> Long-term artificial nutrition, including feeding tubes. Additional Orders: _____ <input type="checkbox"/> Trial period of artificial nutrition, including feeding tubes. _____ <input type="checkbox"/> No artificial means of nutrition, including feeding tubes. _____

D	INFORMATION AND SIGNATURES:		
	Discussed with: <input type="checkbox"/> Patient (Patient Has Capacity) <input type="checkbox"/> Legally Recognized Decisionmaker		
	<input type="checkbox"/> Advance Directive dated _____, available and reviewed → Health Care Agent if named in Advance Directive: <input type="checkbox"/> Advance Directive not available Name: _____ <input type="checkbox"/> No Advance Directive Phone: _____		
	Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)		
	My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.		
	Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert. #:
	Physician/NP/PA Signature: (required)		Date:
	Signature of Patient or Legally Recognized Decisionmaker		
	I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.		
	Print Name:		Relationship: (write self if patient)
Signature: (required)		Date:	
Mailing Address (street/city/state/zip):		Phone Number:	
Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.			

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011, 10/1/2014 or 01/01/2016 are also valid

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY**Patient Information**

Name (last, first, middle):	Date of Birth:	Gender: M F
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NP/PA's Supervising Physician

Name:

Preparer Name (if other than signing Physician/NP/PA)

Name/Title:

Phone #:

Additional Contact☐ None

Name:

Relationship to Patient:

Phone #:

Directions for Health Care Provider**Completing POLST**

- **Completing a POLST form is voluntary.** California law requires that a POLST form be followed by healthcare providers, and provides immunity to those who comply in good faith. In the hospital setting, a patient will be assessed by a physician, or a nurse practitioner (NP) or a physician assistant (PA) acting under the supervision of the physician, who will issue appropriate orders that are consistent with the patient's preferences.
- **POLST does not replace the Advance Directive.** When available, review the Advance Directive and POLST form to ensure consistency, and update forms appropriately to resolve any conflicts.
- POLST must be completed by a health care provider based on patient preferences and medical indications.
- A legally recognized decisionmaker may include a court-appointed conservator or guardian, agent designated in an Advance Directive, orally designated surrogate, spouse, registered domestic partner, parent of a minor, closest available relative, or person whom the patient's physician/NP/PA believes best knows what is in the patient's best interest and will make decisions in accordance with the patient's expressed wishes and values to the extent known.
- A legally recognized decisionmaker may execute the POLST form only if the patient lacks capacity or has designated that the decisionmaker's authority is effective immediately.
- To be valid a POLST form must be signed by (1) a physician, or by a nurse practitioner or a physician assistant acting under the supervision of a physician and within the scope of practice authorized by law and (2) the patient or decisionmaker. Verbal orders are acceptable with follow-up signature by physician/NP/PA in accordance with facility/community policy.
- If a translated form is used with patient or decisionmaker, attach it to the signed English POLST form.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid. A copy should be retained in patient's medical record, on Ultra Pink paper when possible.

Using POLST

- Any incomplete section of POLST implies full treatment for that section.

Section A:

- If found pulseless and not breathing, no defibrillator (including automated external defibrillators) or chest compressions should be used on a patient who has chosen "Do Not Attempt Resuscitation."

Section B:

- When comfort cannot be achieved in the current setting, the patient, including someone with "Comfort-Focused Treatment," should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).
- Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), bi-level positive airway pressure (BiPAP), and bag valve mask (BVM) assisted respirations.
- IV antibiotics and hydration generally are not "Comfort-Focused Treatment."
- Treatment of dehydration prolongs life. If a patient desires IV fluids, indicate "Selective Treatment" or "Full Treatment."
- Depending on local EMS protocol, "Additional Orders" written in Section B may not be implemented by EMS personnel.

Reviewing POLST

It is recommended that POLST be reviewed periodically. Review is recommended when:

- The patient is transferred from one care setting or care level to another, or
- There is a substantial change in the patient's health status, or
- The patient's treatment preferences change.

Modifying and Voiding POLST

- A patient with capacity can, at any time, request alternative treatment or revoke a POLST by any means that indicates intent to revoke. It is recommended that revocation be documented by drawing a line through Sections A through D, writing "VOID" in large letters, and signing and dating this line.
- A legally recognized decisionmaker may request to modify the orders, in collaboration with the physician/NP/PA, based on the known desires of the patient or, if unknown, the patient's best interests.

This form is approved by the California Emergency Medical Services Authority in cooperation with the statewide POLST Task Force.
For more information or a copy of the form, visit www.caPOLST.org.

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED



CPR/DNR

Being asked to make a decision about cardiopulmonary resuscitation (CPR) can be complicated. Few of us have ever seen CPR performed. Our understanding of CPR may come from what we see on TV ...where it looks easy and seems to be very successful without any complications. Unfortunately, these TV images of CPR are not completely accurate.

This brochure provides answers to some common questions about what CPR involves and what else is important to think about when making a decision about CPR.

COALITION *for* COMPASSIONATE CARE *of* CALIFORNIA

WHAT DOES CPR LOOK LIKE?

CPR is a longer process than most people realize. It is an attempt to re-start the heart when the heart has stopped beating. The person is placed on a hard board or on the ground and the center of the chest is pushed in about 2 inches (to provide 100 to 125 pounds of pressure). These chest compressions must be done 100 times each minute. Artificial respiration using a special mask and bag over the person's mouth to pump air into the lungs may be started. When the emergency team arrives, a breathing tube may be inserted into the windpipe to provide oxygen, and a number of electrical shocks may be given with paddles that are placed on the chest. An intravenous line (IV) will be placed in a vein and medications will be given through the IV line.

If the heart continues to respond to these treatments, the person is taken to the emergency department. Those who survive will then be transferred to the intensive care unit at the hospital and attached to a ventilator (breathing machine) and a heart monitor. At this stage, most persons are still unconscious.

WHO IS LEAST LIKELY TO BENEFIT FROM CPR?

Risk factors that are more frequent among older persons may contribute to lower chances of CPR survival as age increases. Most older adults do not have the type of heart rhythm that responds to CPR. Having any chronic disease that affects the heart, lungs, brain and kidneys can lower chances for survival after cardiac arrest. If a person has multiple advanced chronic illnesses, CPR survival will be even lower.

Individuals in advanced stages of dementia have CPR survival rates three times lower than those without dementia. Several studies that looked at survival of frail nursing home residents in advanced stages of illness who were dependent on others for all of their care showed CPR survival rates of 0 – 5% even if they were transferred from the nursing home to the hospital before the cardiac arrest.

continued on next page

A GUIDE FOR DECISION MAKING

A GUIDE FOR DECISION MAKING

Older adults in terminal stages of cancer had CPR survival rates 0 – 1%. Unlike younger persons whose healthy bodies may be able to withstand the shock of a cardiac arrest and respond to treatment, those at an advanced age with serious underlying health problems may be dying from progressive organ failure. Their bodies do not have enough reserve to tolerate the lack of oxygen that occurs with cardiac arrest, their hearts may not be able to pump effectively enough to respond to CPR attempts. Those with liver or kidney failure may not be able to use the emergency drugs that are given.

WHO IS MOST LIKELY TO BENEFIT FROM CPR?

The success of CPR depends on the reason the heart stopped, how healthy the person was before the heart stopped, and how long the heart has been stopped before CPR is started. It is hard to know in advance how effective CPR will be for a specific person, but many studies have shown who is most likely to benefit from CPR and who is not. In general, about 15% of all those who have CPR will survive. This number may increase for those who have no major health problems, have a sudden, unexpected collapse, have CPR started within a few minutes of when the heart stops, and have the type of heart rhythm that responds to electrical shocks.

ARE THERE ANY COMPLICATIONS FROM CPR?

On TV CPR looks fast and uncomplicated. It is different in real life situations. Serious complications are likely. The most common complications are rib fractures that have been documented in up to 97% of CPR attempts, and breastbone fractures documented in up to 43% of cases. The risk of these fractures increases with age as does the chance for multiple fractures. This may be due to a decrease in muscle mass and an increased rate of osteoporosis with age. Approximately 59% of those who have CPR will have bruising of the chest, and about 30% may have burns from the defibrillator.

Permanent brain damage may occur from lack of oxygen in up to 50% of those who have CPR attempted.

Other less frequent complications of CPR that have been identified include bleeding in the chest (0-18%), damage to the trachea or esophagus (0-20%), damage to abdominal organs (0-31%), lung damage (0-13%), and damage to lips and teeth (0-8%).

WHAT HAPPENS IF I DECIDE NOT TO HAVE CPR?

After careful consideration of all possible benefits and risks, many individuals decide that they do not want CPR attempted. However, some people are afraid that if they say they don't want CPR they won't get the kind of care they should. A decision not to have CPR applies only to the CPR process. Overall care and treatment will not be affected by choosing not to have CPR. If you do not want CPR done, an order will be written in the medical record so that CPR will not be attempted if the heart stops beating and breathing stops. The order is called a DNR (Do NOT Resuscitate) order and is used to protect a person from unnecessary attempts at CPR.

Compliments of HOSPICE BY THE BAY
17 E. Sir Francis Drake Blvd., Larkspur
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Phone: 916-489-2222 • www.CoalitionCCC.org
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Tube Feeding

"I've been asked to decide about a feeding tube..."

Making a decision about a long-term feeding tube for yourself or for someone you love may be challenging and emotional. Those who have faced a similar decision have told us that having honest answers to their questions was most helpful.

HOWEVER.....Every situation is different... what may help someone with a short term correctable eating problem may not be best for long-term use for a person who is in the final stages of a terminal illness.

COALITION *for* COMPASSIONATE CARE *of* CALIFORNIA

What is a feeding tube?

A temporary feeding tube can be inserted through the nose into the stomach (N-G tube) for short term use. A feeding tube for long term use is called a Percutaneous Endoscopic Gastrostomy (PEG) tube. A small surgical opening is cut through the skin and stomach to place the tube that allows formula to be delivered directly to the stomach.

Who is helped most by having a feeding tube?

Those who function independently but are receiving chemotherapy or radiation for certain cancers and some stroke survivors in rehabilitation whose swallowing ability is expected to return may benefit from temporary feeding tubes. Persons with ALS (Lou Gehrig's disease) may benefit because swallowing problems may occur before they reach the terminal phase of their disease.

When are feeding tubes less helpful?

When those in very late stages of dementia lose their ability to swallow, often this is not an isolated event but may represent progression of the disease to a terminal phase. In terminal stages of many diseases including advanced dementia, the gastrointestinal system shuts down and digestion becomes ineffective.

Will my loved one starve?

Some people fear that not providing a feeding tube at the end of life means they are letting their loved one "starve to death."

This is not true. Starvation occurs when a hungry person whose body needs and can use the nutrients is deprived of food. When a dying person's body begins to shut down, the body may be unable to adequately use nutrients that tube feeding would provide, and the chance for bloating and discomfort increases.

A GUIDE FOR DECISION MAKING

A GUIDE FOR DECISION MAKING

What are some possible complications related to feeding tubes?

Feeding tubes may cause no problems, but some complications have been identified such as: bleeding (1%), infection and skin irritation (1-4%), leakage around the tube (4%), vomiting or nausea (9-10%) and diarrhea or cramping (12%).

Will a feeding tube prevent pneumonia?

Findings from several recent studies of individuals with late stage dementia or advanced terminal diseases show no evidence that pneumonia is prevented with a feeding tube. In some cases, pneumonia risk may be increased with feeding tubes.

Does a feeding tube lower the risk for getting pressure ulcers or help them to heal if they are already there?

There is no evidence that a feeding tube will prevent pressure ulcers or cause them to heal for those who are in advanced stages of a terminal illness. Increased production of urine and stool from tube feedings can increase the risk of pressure ulcers.

Does a feeding tube improve comfort and prevent suffering?

For those with temporary swallowing problems from mouth or throat conditions, tube feeding may alleviate associated pain and provide short term nutritional support. In advanced dementia, the presence of a tube may cause agitation and attempts to pull it out. In some cases, this may prompt the use of restraints which decrease comfort. In the active stage of dying, continued tube feeding may cause fluid overload and make breathing more difficult.

What else should be considered when making a decision about a feeding tube?

It is hard to separate our love and respect for a person from what might be the best decision for that person. Any decision about tube feeding must be made with consideration of general health status and overall goals of care. Prevention of suffering should be a major standard for evaluating individual risks and benefits. Asking the question, "Will the benefit of a tube be significant enough to outweigh any risks and discomfort?" can be helpful.

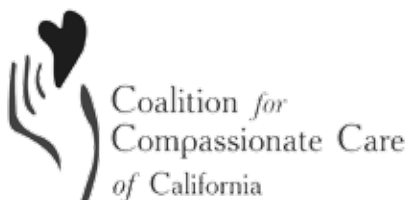
Clarification of personal, religious and cultural values in the context of overall prognosis and life expectancy may aid decision making.

What choice do I have if I decide not to have a feeding tube?

For those who still have some swallowing ability, careful hand feeding may be tried. For those who are in advanced, terminal stages of disease, maintaining excellent mouth care and providing ice chips or moist swabs will alleviate dry mouth and promote comfort.

Where can I get more information about feeding tubes?

A summary of studies, guidelines, and expert position statements are available at the Coalition for Compassionate Care of California web site: www.CoalitionCCC.org



Phone: 916-489-2222 • www.CoalitionCCC.org
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Hospice Care Guide

The logo for By the Bay Health is located to the right of the title. It features a stylized graphic of four stacked, rounded shapes in red, light blue, teal, and dark blue. To the right of this graphic, the text "By the Bay" is written in a small, light blue font, and "Health." is written in a larger, teal font with a small registered trademark symbol. A thin orange horizontal line is positioned below the word "Health."