Approaching the End of Life

Hospice by the Bay

SERVING THE COUNTIES OF MARIN, SAN FRANCISCO, SAN MATEO, SONOMA & THE CITIES OF AMERICAN CANYON, NAPA AND VALLEJO
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The process of dying is one of transition. As life comes to a close, many changes are experienced by the dying person and by those close to that individual.

It is important for family members and caregivers to remember that each person meets death in his or her own way. Dying is a natural process, but when faced with death we often feel helpless. It is not unusual to feel frightened or alone.

All of us at Hospice by the Bay are here to help you cope with those feelings during this time. We find that the dying process is less painful for loved ones when you are aware of some of the signs of death’s approach.

We hope this booklet offers education, support and advice, while answering many of the questions you may have. We urge you to write down your concerns and thoughts and talk them over with your Hospice by the Bay Team.

Please contact us by phone anytime – a nurse is on-call 24 hours a day, seven days a week, and available to visit. For general information, visit our website at www.hospicebythebay.org.

We’re here to support you and your loved one.

Sincerely,

Hospice by the Bay

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
First, Take Care of Yourself

For family members and caregivers, the most important thing to remember is: In order to care for someone who is dying, you must also take care of yourself.

Just as your loved one will experience changes during this time, be aware of changes within yourself. If you feel frightened or anxious, find a quiet place and breathe slowly and deeply for a few minutes. We also recommend that you rest often, eat healthy foods and drink plenty of water.

Call on friends for support. Friends often want to help, but may not know what to do for you and your family. It can be a gift to allow them to cook, come by for a visit or provide companionship for your loved one so you can have a period of rest and respite.

Talking about your feelings and concerns with friends can help ease stress. Ask your friend to just listen without offering advice or trying to make things better.

Remember: Your Hospice by the Bay Team is a phone call away, day or night, for support, companionship and assistance.

What to Expect at the End of Life

This is a painful time of letting go. It is important to know that someone with a terminal illness may die suddenly. More commonly, however, a person moves gradually through the physical and mental stages explained in this booklet. We need to anticipate these and be prepared for them.

During the final months, weeks or days, your loved one may...
experience a predictable and progressive physical decline. The person may also lose the mental ability to relate to caregivers, family and friends.

**Eating and Drinking**
The desire for food and liquids will decrease. It can be difficult to accept that your loved one no longer wishes to eat, but when the body is weak and ill, it naturally rejects food. Forcing food may increase discomfort and make the person feel worse.

Know that it is all right to stop feeding your loved one when they no longer show any interest in food. As the body systems begin to falter, the body can no longer deal efficiently with food or fluids. The kidneys become less able to filter blood and eliminate urine. Fluid begins to build up in the body and can cause lung congestion, vomiting and swelling.

When your loved one can no longer drink from a cup or use a straw, your Hospice by the Bay Team can show you how to give small amounts of fluid by teaspoon or syringe, or by placing a finger over the end of a straw and gently allowing the liquid to run into the mouth. Small, sponge-tipped swabs can be moistened and used to relieve dry mouth.

When your loved one cannot swallow, it is all right to stop giving fluids by mouth as dehydration is part of the natural dying process. Secretions from the mouth can be removed with a warm, damp cloth. Medication may be given in a different way if necessary. Discuss medications and methods of administration with your Hospice by the Bay nurse.

**Bowel and Bladder**
As food and fluid intake decreases, so does urine and stool output. It is important to know that the body can continue to produce stool even after your loved one has stopped eating, so you may need to continue bowel medications to prevent constipation.
Neurological Changes
As the neurological system shuts down, two processes may occur. The more common is an increase from sleepiness, through non-responsiveness, toward death. Less common is a more agitated state that can include restlessness, confusion and uncontrolled movement. **If this occurs, call Hospice by the Bay immediately.** We will advise you how to keep your loved one safe and comfortable, or send a nurse to make a visit.

There may also come a time when your loved one has visions or conversations with people who have died. This experience is common, and may be comforting to your loved one. It is part of the dying process and needs to be respected.

As your loved one moves closer to the time of death, a sudden increase in alertness, movement or speaking can occur that may have been absent or minimal. This state of alertness is temporary.

Circulation and Temperature
Your loved one’s heartbeat may become rapid or very slow. It may be hard to feel a pulse. Body temperature may change dramatically. Hands and feet may become discolored, cool or even cold. These are natural occurrences, and your loved one usually is not uncomfortable with these changes. Use loose coverings, or no coverings, if that is what your loved one wants. **Do not** use electric blankets, as they can cause burning and discomfort.

Perspiration can increase when the body becomes cool. Cotton bath blankets help absorb perspiration and keep the person dry. Use light, loose coverings. Too much cover can cause increased restlessness. Lukewarm water and face cloths can be used to sponge the face and arms. Frequent changes of bedclothes may be desirable for comfort.

Breathing
Changes in breathing are a natural response to decreased circulation. Breathing may become irregular – shallow or deep,
fast or slow. There may be periods of no breathing, called apnea, which may last for seconds or even minutes. Keep the person’s head elevated and slightly turned to help secretions drain from the mouth.

You may hear gurgling or rattling in the person’s throat or lungs. This is caused by muscle weakness and the decreased ability to cough. There may be congestion in the lungs due to a slowing of normal fluid circulation. Your Hospice by the Bay Team can show you how to offer frequent mouth care during this time.

**Turning Inward**

As death approaches, your loved one may withdraw physically and emotionally. Interest in the outside world may lessen. Often he or she will not want to have visitors. We should honor those wishes and support their requests.

You may see physical changes related to turning inward, such as increased sleeping, less energy for ordinary conversation and tasks, and increased fatigue.

Your gentle touch at this time can often be more important for your loved one than words.

**Communication**

Hearing is the last of the senses we lose. We encourage you to continue touching and talking with your loved one. Continue speaking in a normal voice – you may not get a response, but you are being heard. This includes honestly expressing feelings you wish to share. Telling a person it is okay to let go, if that feels comfortable, can be appropriate.

Occasionally, some people have a brief period of energy and alertness prior to progressing into unresponsiveness.
What is an Emergency?

Some distress can be part of the natural dying process, and the changes that occur can be frightening and make us feel helpless. You may think of calling 911. However, please make Hospice by the Bay your first phone call if you feel concerned about your loved one.

A nurse is available to talk through your concerns 24 hours a day, seven days a week, and to make a visit if needed.

To help ease your concerns, talk with your Hospice by the Bay Team early in your loved one’s care. Discuss what you would consider an emergency and what possible situations worry you. We can help you prepare for these circumstances and support you if they occur.

Before Your Loved One Dies

Prior to the emotional time after a loved one’s death, you may wish to make the following arrangements. Some things you’ll want to discuss with your loved one. Remember that your Hospice by the Bay Team is here to support you.

• Ask a friend or family member to be on call to be with you, day or night, at the time of death or shortly afterward.

• Determine which family members or friends want to be called so they can be present at the time of death. Ask your loved one who he or she would like there.

• Make a list of necessary phone numbers, and post it in plain sight for those who need to know.
• For spiritual support and comfort, talk with our interfaith Spiritual Support Counselor or someone from your own spiritual community. Ask your loved one if a spiritual counselor’s visit would be helpful.

• Make arrangements with a mortuary for when your loved one dies. This allows you time to explore options and make decisions about a memorial or funeral. Your loved one may already have documented her or his wishes.

• If you have questions about funeral arrangements or special requests, such as body or organ donation, your Hospice by the Bay team members can discuss the options.

• Our Spiritual Support Counselors can help plan a funeral or memorial service, and officiate if you wish.

**When Your Loved One Dies**

As death nears, your loved one may be unresponsive. The last breaths may have long spaces between them. The final out-breath signals the end of life.

No matter how prepared you may feel, it’s normal to experience feelings of shock, sadness, disorientation, confusion, fear, numbness, anger, significant emotional pain and/or a sense of relief at the time of death. You may find it difficult to make decisions. Be gentle with yourself.

It’s important to be aware that death may occur in a moment when the dying person is alone. There is no need to feel guilty if your loved one dies when you are not present. It is sometimes difficult for a person to die with someone in the room, particularly those most loved.
If your loved one dies in your absence, his or her body may be rigid, discolored and cold to the touch. You may or may not wish to be with the body after death, or in the room when the body is removed. Do what feels right for you.

For support in your loved one’s final hours or at the time of death, we encourage you to arrange for a close friend or relative to be with you or to call Hospice by the Bay to request a visit.

**What to Do at the Time of Death**

To help you through this difficult time, you can follow the suggestions listed below.

- Notify Hospice by the Bay. Whether at home or in a care facility or hospital, if a Hospice by the Bay team member is not present when your loved one dies, call the office near you so we can send someone for support and assistance. **We are available day or night at the phone numbers on the back cover.**

- Call a family member or friend to be with you for support.

- Hospice by the Bay will call the mortuary service when you feel ready. If you know in advance that you will want time with your loved one’s body before the mortuary service arrives, please discuss this early with your Hospice by the Bay Team so your wishes will be honored.

- Hospice by the Bay will call your loved one’s physician to let them know about the death.

- Let us know how else we can help you or your family.
Grief Counseling & Support at Hospice by the Bay

You do not need to be alone in your grief. Hospice by the Bay is here for you and your family members. Our counselors will continue to support you with grief counseling services and support activities.

Because the first year of mourning can be so painful, some counseling is free of charge for family members and caregivers whose loved one was in our care. Our grief support services are also open to anyone in the community anticipating or coping with the loss of someone significant in their lives. We accept Medicare Part B and offer a sliding-fee scale for those who qualify.

Public programs include annual community Service of Remembrance gatherings to honor and remember loved ones held in Marin, San Francisco and Sonoma counties. For ages 7-17, we host a grief support summer camp weekend. By the Bay Camp is free of charge to campers.

Please contact us to learn how we can support you, your family or someone you know.

For details about individual and family grief counseling, upcoming support groups and programs, visit Hospice by the Bay’s website, email us or call our grief support line near you.

Hospice by the Bay

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www.hospicebythebay.org

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