HavenHealth™
Hospice Services

# Patient Resource Manual

# After Hours/On-Call Guidelines

A nurse is available 24 hours a day, 7 days a week to assist you with problems after regular office hours, on weekends or holidays. We will talk with you by phone to determine your needs. When appropriatem a nurse will come by your place of residence. We are available after regular office hours for urgent conditions.

**Do not call 911 before calling the on-call nurse.** Should you call 911, this may not be a covered hospice expense. The following is a list of reasons for which you may need to contact us after regular hours.

## Examples of After-Hours Situations

Call (562) 239-4992 at any time.

- Pain that does not respond to pain medication on hand
- Difficulty breathing
- New onset of agitation or restlessness
- Falls where possible injury has occoured
- No urine in 8 hours associated with discomfort
- Uncontrolled bleeding
- Temperature above 101° that does not respond to Tylenol
- Unable to wake patient up (new problem)
- Catheter leaking
- Chest pain
- Patient taken to the hospital
- Patient dies in the hospital
- Death

## Problems that are handled during regular office hours

Call (562) 426-7500 8:00 a.m. to 6:00 p.m., Monday - Friday.

- Narcotic Refills
- Messages for the primary nurse:
    1. Medication refills
    2. What time will the primary nurse visit?
    3. Can the primary nurse come earlier/later?
    4. I need supplies ordered (diapers, chux, etc.)
- Non-urgent calls for social worker, spiritual counselor or other hospice stuff
- Lab or bloodwork results
- Questions about the hospice aide/homemaker

Haven Health

# Notices of Non-Discrimination

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

Haven Health provides free aids and services to people with disabilities to communicate effectively with us, such as qualified sign language interpreters and written information in other formats (large print, audio, accessible electronic formats, other formats. Haven Health also provides free language services to people whose primary language is not English, such as qualified interpreters and information written in other languages. If you need these services, contact Melody Keenan.

If you believe that Haven 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: Melody Keenan, Compliance Officer 2855 Temple Ave, Ste B, Signal Hill, CA 90755 Phone: (562) 290-0558 Fax: (562) 427-8222 melody.keenan@havenhealth.org. You can file a grievance in person or by mail, fax, or email. If you need help filing a grievance, Melody Keenan, Compliance 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.

ATTENTION: Language assistance services, free of charge, are available to you.
Call 1-562-290-0558 (TTY/TDD: 711)

SPANISH
ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística.
Llame al 1-562-290-0558 (TTY/TDD: 711)

CHINESE
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 1-562-290-0558 (TTY/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
1-562-290-0558 (TTY/TDD: 711)

TAGALAG—FILIPINO
PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-562-290-0558 (TTY/TDD: 711)

KOREAN
주의: 한국어를 사용하실 경우, 언어 지원 서비스를 무료로 이용하실수있습니다. 1-562-290-0558
(TTY/TDD: 711)번호로 전화주십시오

Haven Health

# Notices of Non-Discrimination continued

ARMENIAN
ՈՒՇԱԴՐՈՒԹՅՈՒՆ՝ Եթե խոսում եք հայերեն, ապա ձեզ անվճար կարող են տրամադրվել լեզվական աջակցության ծառայություններ: Զանգահարեք 1-562-290-0558 (TTY/TDD:711)

PERSIAN—FARSI
توجه: اگر به زبان فارسی گفتگو می کنید، تسهیلات زبانی بصورت رایگان برای شما فراهم می باشد. با 1-562-290-0558 (TTY/TDD: 711)

RUSSIAN
ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-562-290-0558 (TTY/TDD: 711)

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。1-562-290-0558 (TTY/TDD: 711)

ARABIC

يلتزم بقوانين الحقوق المدنية الفدرالية المعمول بها ولا يميز على أساس
ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل
برقم 1-562-290-0558 (رقم
(TTY/TDD:711)

MON-KHMER—CAMBODIAN
ប្រយ័ត្ន៖ បើសិនជាអ្នកនិយាយ ភាសាខ្មែរ, សេវាជំនួយផ្នែកភាសា ដោយមិនគិតឈ្នួល គឺអាចមានសំរាប់បំរើអ្នក។ ចូរ ទូរស័ព្ទ 1-562-290-0558 (TTY/TDD: 711)

HMONG
LUS CEEV: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu rau 1-562-290-0558 (TTY/TDD: 711)

HINDI
ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। 1-562-290-0558 (TTY/TDD: 711)

THAI
เรียน: ถ้าคุณพูดภาษาไทยคุณสามารถใช้บริการช่วยเหลือทางภาษาได้ฟรี โทร 1-562-290-0558 (TTY/TDD: 711)

PUNJABI
ਧਿਆਨ ਦਿਓ: ਜੇ ਤੁਸੀ ਪੰਜਾਬੀ ਬੋਲਦੇ ਹੋ, ਤਾਂ ਭਾਸ਼ਾ ਵਿੱਚ ਸਹਾਇਤਾ ਸੇਵਾ ਤੁਹਾਡੇ ਲਈ ਮੁਫਤ ਉਪਲਬਧ ਹੈ। 1-562-290-0558 (TTY/TDD: 711)

# About Hospice

# Guidelines Regarding Hospice Care

## General Information about Hospice:

Historically hospice meant a way station, a place of hospitality where travelers could stop for rest and refreshment before continuing on their journey. Today hospice is not a place, but the name for an interdisciplinary program of care that provides palliation (relief from symptoms) as well as emotional and spiritual support to terminally ill people and their families and friends. Hospice assists families/friends in adjusting to the patient's illness and death. The patient and caregivers together are considered the unit of care.

The emphasis in hospice care is upon enhancing the quality of life and preserving the patient's sense of dignity and self-worth. This includes helping to provide the terminally ill person with an alert pain free existence when possible; emphasizing patients roles in decisions regarding their plan of care; and assisting them in their desire to stay at home under the care of family, friends and visiting professionals

## Hospice Medical Care

The primary focus of hospice medical care is upon pain and symptom control and other supportive measures. It is an alternative to aggressive medical regimens, which are not desired not shown to be effective any longer.

With a prognosis limited to months, the decision making process for physician and patient is altered under hospice care to focus upon enhancing the quality of the patient's remaining time. These palliative care guidelines have been prepared to assist the patient and caregivers in understanding certain medical aspects of hospice care.

Before discussing these guidelines, it should also be understood that hospice is not for everyone - either at the time of possible admission or during the course of hospice care. No one should be pressured in any way to be admitted to a hospice program or to remain in one against his/her wishes. The patient/physician decision to reactivate aggressive curative therapy or seek long-term remission through medical intervention(s) will be respected. Patients are always free to withdraw from hospice care by signing a revocation form.

Specific Guidelines for Palliative Medical Care:

- Health care procedures will be done in order to optimize the patient's physical functioning. The patient's independence will be supported to the highest degree possible.
- Medications will be administered for the control of pain and other symptoms in order to achieve maximum comfort and continuing relief.
- Diagnostic tests and other assessments will be done only when results are needed for palliation (relief) of symptoms.
- Procedures such as intravenous therapy, blood transfusions, and or antibiotics may be considered when such treatment may add to the comfort of the patient more than non-invasive alternatives, and when the patient/family have been fully informed of treatment choices.
- Continuous care is available for patients who have nursing crises. The need for this short-term service is based on severity of medical symptoms and a decision by the hospice team that continuous care is the optimum method for symptom stabilization.
- Patients who are alert and aware and capable of making their own decisions, will be given the option of signing a POLST which will be offered during the hospice program's first visit with the patient. Patients and/or responsible party are encouraged to sign a POLST to ensure Patient's end of life wishes are honored, however signing a POLST or other Advanced Directive is not required.
- The hospice program offers information on advance directives consistent with federal and state guidelines. Hospice staff will perform resuscitation when patient remains at Full Code Status.

Our hospice team meets every week to share information about each of our patients. Together with the patient and his/her family, we formulate a plan of care. This plan covers every aspect of care, the medicines for symptom management, how often the providers will visit, any information the patient/family needs to learn and how to best meet patient/family needs at this difficult time. The need for counseling, pastoral visits, friendly visits by volunteers, as well as the need for consultation visits by nutrition, occupational, physical and speech therapist are discussed and planned for during this weekly meeting.

## The Role of the Family or Friend

The patient's family or friend has the difficult and rewarding challenge of caring for the patient he/she dies at home. The family/friend is responsible for providing a safe and comfortable environment for the patient. One family member or friend is designated as the primary care person and becomes responsible for the day-to-day care of the patient. This caregiver arranges for someone to be with and care for the patient 24 hours a day when necessary. This can be done by the primary care person, other family members, friends, or privately hired caregivers. Hospice team members instruct the caregiver on how to care for the patient. Home health aides are provided by hospice on a as needed basis to assist with the patient's personal care.

As stated earlier, the patient, caregiver, and hospice team formulate the plan of care. It is the caregiver's responsibility to follow this plan of care to the best of their ability. The hospice team works closely with the family/friend providing information, counseling, and emotional support.

There is an inpatient respite benefit available to the caregiver for 5 days each benefit period. This allows for a patient's admission into the inpatient unit, even though he/she may not have acute symptoms, so that the caregiver may have some rest.

## Insurance other than Medicare / Medi-Cal

The hospice program has a contract with most major health plans. For specific information regarding any issues of hospice coverage or protocol, please call our office from Monday to Friday 8:30AM - 4:30 PM and ask for the Finance Department. Please continue to read this information even if Medicare is not the coverage involved as many of the details below apply to hospice guidelines and philosophy in general.

## The Medicare Hospice Benefit

By electing the Medicare Hospice Benefit all treatment for the patient's terminal diagnosis is provided by the hospice. Payment for services related to the terminal diagnosis will only be authorized and to the hospice.

## The Primary Physician

Upon admission to the hospice program, the patient's primary care physician will be notified of the patient's acceptance to the program, and he will take a place on the Interdisciplinary Team. If the patient's primary care physician does not want to follow the patient any longer, or the patient would prefer to have another physician, than the patient will have the option to select another physician. Patient may select the hospice Medical Director as their Primary Care Physician.

Medicare will make payment for services provided by a physician other than the hospice physician or designee. When the family arranges these services, hospice must be informed.

## Pharmacy

Drugs related to the patient's primary diagnosis will be reviewed and discussed for coverage under the Medicare hospice benefit and will be delivered to the patient's home. The hospice provides prescription medication that pertains to the terminal illness. The terminal illness is the illness for which the patient was placed on the program. Medications not related to the terminal illness can be billed to patient's insurance or paid privately.

## Medical Equipment

The hospice will provide standard medical equipment needed for the patient's comfort, i.e. electric/ semi electric hospital bed, wheelchair, walker, and commode. Only equipment provided through hospice's contracted vendor companies may be used. The Primary caregiver is responsible for proper care of the equipment. All hospice medical equipment must be returned upon termination of services.

## Respite Care

Respite Care is short term inpatient care provided to patient when necessary to relieve the family members or other persons caring for the patient at home. Respite Care will be arranged by hospice for a maximum of 5 days per benefit period.

## On-Call Service

The hospice offers 24 hours a day, 7 days a week availability of services. All patient/families are encouraged to contact the hospice to report any change in the patient's status. The on-call nurse will advise patient/caregivers about methods to manage the change that has occurred. The nurse may make a home visit if this is necessary. Generally, the change in the patient is expected and the nurse can explain why certain symptoms are occurring. It is often easier to care for the patient when the caregiver understands what is happening and has learned measures to take to provide needed relief and greater comfort.
Routine questions are best handled during business hours.

After business hours (overnight) on weekdays and during weekends and holidays, patients/families can call the same number to reach a hospice representative. If you reach the voicemail, please leave a message with the patient's name, date of birth and best call back number, your call should be returned within 10 minutes. If no return call, please call again.

Routine questions are best answered during business hours. After hours staff are available in English and Spanish.

## Hospitals/Emergency Rooms

We ask that you contact the hospice first any time that you feel the patient needs emergency assistance. Often these situations can be resolved fairly easily, and the hospice can continue to assist you to care for the patient at home. When the patient does need to be admitted for further medical assistance, the hospice will make the arrangements to admit to one of our in-patient units.

Admissions are arranged by the hospice team when medically necessary, i.e. for acute symptom management. Once the team feels the reason for admission has been resolved, the patient returns home. The inpatient unit is designed for short-term pain and symptom management. It is our aim to get patients home as soon as symptoms are stabilized. There is no predetermined length of stay for acute symptom management. A patient's length of stay is determined by symptoms and the medical management required to alleviate those symptoms.

## Aggressive Treatment

Aggressive or life prolonging treatment is any form of chemotherapy, radiotherapy, or surgery that is done for the purpose of curing the disease. If a patient, once admitted to hospice, chooses to receive any kind of aggressive treatment or life prolonging, he/she can no longer remain on the hospice program. Patients electing for aggressive or life prolonging treatment must revoke their hospice benefit. The patient should be aware that should they decide to discontinue this treatment or should they complete the treatment, they may reapply for admission back into the hospice program.

### Revocation of the Medicare Hospice Benefit

The patient may revoke the Medicare hospice benefit any time by contacting the hospice. The patient and caregiver should know that as soon as a patient revokes the hospice benefit, he/she gives up the remainder of that benefit period. All hospice equipment must be returned to hospice effective immediately.

### Hospice Transfer

A patient may transfer to another hospice program once during each benefit period. If the patient/family chooses to admit the patient to another hospice, the patient/family must notify hospice to arrange the transfer. All hospice equipment must be returned to hospice effective immediately.

### Bereavement Services

The hospice offers free bereavement services for spouses, relatives, and friends for a period of up to one year following the death. We encourage family members and friends to take advantage of these services and to contact the hospice at any time bereavement assistance is needed. These services are also open to the community for bereaved families of non-hospice clients.

## Medicare Hospice Benefit

Medicare will reimburse the cost of hospice care under your Medicare Hospital Insurance (Part A). When all requirements are met Medicare will cover the following:

| **Services Covered Provided as Appropriate Developed in the Plan of Care** | **Non-Covered Services (Notice of Medicare Non-Coverage)** |
|---|---|
| • Physician services<br>• Nursing Care<br>• Medical equipment and supplies related to terminal illness<br>• Medications for symptom management and pain relief of the terminal illness *(must be pre-approved by hospice)*<br>• Short-term inpatient care for pain and symptom control<br>• Respite Care for up to 5 days<br>• Hospice aide/homemaker services<br>• Spiritual counseling<br>• Bereavement counseling<br>• Physical therapy, occupational therapy, speech therapy<br>• Medical social services<br>• Dietary counseling<br>• Volunteer services | • Treatment for the terminal illness which is not for palliative symptom management and is not within the hospice plan of care<br>• Care provided by another hospice that was not arranged by the patient's hospice<br>• Ambulance transportation not included in the plan of care<br>• Medications that are not related to the terminal illness<br>• Visits to the emergency department without the prior approval or arrangements by hospice<br>• Inpatient care at non-contracted facilities<br>• Sitter services/hired caregivers<br>• Admission to the hospital without the prior approval or arrangements by hospice<br>• Lab studies, medical testing and/or any treatments not indicated<br>• Room and board if you are resident of a nursing home<br>• Blood or platelet transfusion unless approved by the hospice |

# Know your Rights

Haven Health

# Patient’s Bill of Rights and Responsibilities

**As a Hospice patient you have the right to:**

- Be informed of your rights and responsibilities on admission and any time thereafter as needed.
- Receive these rights in a manner that you understand, written and oral.
- Exercise your rights as a patient of the hospice, through yourself or your legal representative.
- Voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of the hospice
- Be protected from discrimination or reprisal for exercising your rights.
- Have your property and person treated with Respect and Dignity.
- Have relationships with our staff members based on honest and ethical standards.
- Participate in all healthcare decisions that will affect you and be involved in developing the care plan
- Formulate Advance Directives.
- Choose your attending physician.
- Expect confidentiality of all medical information as the law requires, and have access to or release of clinical records in accordance with State and Federal Guidelines. A copy of our policy regarding the release of medical records will be made available upon request.
- Receive effective pain management and symptom control for conditions related to the terminal illness.
- Be informed of your medical condition and be educated about it.
- Receive education about medications, treatments, procedures, etc. and have your questions answered.
- Refuse any medication, treatment, or procedure, and fully know the consequences of the refusal.
- Be free from mistreatment, neglect or verbal, mental, sexual, and physical abuse, including injuries of unknown source and misappropriation of patient property.
- Receive information about the services covered under the hospice benefit.
- Receive information about the scope of services that the hospice will provide and specific limitations
- Be informed of discharge from hospice within a reasonable timeframe as part of the Plan of Care.
- All information and education to be provided in a language or through an interpreter you understand.

**Patients have the responsibility to:**

- Remain under a physician’s care while in our hospice program.
- Render as complete as possible all healthcare information requested to aid in your care.
- Tell us of any changes in your condition, pain, or any other symptoms, including changes in your Advance Directive.
- Provide financial and insurance information as needed by the hospice for billing, as well as notify hospice of any changes in financial or insurance information.
- Sign or have the legal representative sign all consents needed for medical and billing purposes.
- Allow us to bill and file appeals with Medicare or any insurance you are using to cover hospice.
- Notify Haven Health of any changes in medication, treatment, or procedures ordered by your doctor.
- Obtain medications, supplies and equipment ordered by the patient’s physician if they cannot be obtained or supplied by the program.
- Participate as much as possible in creating the Plan of Care.
- Ask questions about any, and all concerns, medications, treatments, and or procedures.
- Advise the program of any problems or dissatisfaction with patient care or personnel.
- Let us know when you are available for visits by the care team.
- Please call if you are not going to be available for a scheduled visit.
- Treat us with the same respect and dignity that we extend to you.
- Accept the consequences of any/all refused medications, treatments, and or procedures.
- Provide Haven Health team members with a safe environment to work in.
- Lastly, please cooperate with the caregivers, staff, and physicians in your care.

If you have any concerns about the quality or safety of our services, please contact us directly at:

**(562) 426-7500 ask for the Administrator**

If you are not satisfied with our response to your concerns you have the right to bring your complaints to the following regulatory agencies:

**THE JOINT COMMISSION AT: (800) 994-6610**

**OR**

**LOS ANGELES COUNTY DEPARTMENT OF HEALTH SERVICES AT: (800) 228-1019**

# Problems and Complaints About Hospice

**What To Do:**
While we all hope that you won't encounter any problems in hospice care, the reality is that problems can and do occur. Any problems you encounter which arise out of the hospice care being provided should be mentioned promptly to your RN case manager. Clear communication about what the problem is can go far to resolve many problems. Our hospice staff is extremely dedicated to providing quality care to all our patients. In the event the care being provided does not meet your needs in any way, we want to hear about it.

Please call us to discuss your complaint by asking for the Administrator or Director of Patient Care Services to discuss your complaint at 562-426-7500.

If you are not satisfied with the response from our agency or you have concerns over the safety and quality of care being provided, you have the right to voice or make a written complaint to The State of California or with The Joint Commission. Below is the contact information to file a complaint with either agency.

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**The Joint Commission**
One Renaissance Boulevard
Oakbrook Terrace, Illinois 60181

email:
patientsafetyreport@jointcommission.org
phone: (800) 994-6610
fax: 630-792-5636
mail: Office of Quality and Patient Safety

OR

**The California Department of Health**
CLHF/Home Health/Hospice
Health Facilities Inspection Division
3400 Aerojet Avenue, Suite 323
El Monte, California 91731

Toll Free: 1-800-228-1019
Fax: 562-406-8801

U.S. Department of Health & Human Services

# Your Information.
# Your Rights.
# Our Responsibilities.

This notice 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** | • 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.<br>• We will provide a copy or a summary of your health information, usually within 30 days of your request. We may charge a reasonable, cost-based fee. |
| **Ask us to correct your medical record** | • You can ask us to correct health information about you that you think is incorrect or incomplete. Ask us how to do this.<br>• We may say "no" to your request, but we'll tell you why in writing within 60 days. |
| **Request confidential communications** | • You can ask us to contact you in a specific way (for example, home or office phone) or to send mail to a different address.<br>• We will say "yes" to all reasonable requests. |

## Your Rights
continued

| | |
|---|---|
| **Ask us to limit what we use or share** | • You can ask us not to use or share certain health information for treatment, payment, or our operations.<br>• We are not required to agree to your request, and we may say "no" if it would affect your care.<br>• 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.<br>• We will say "yes" unless a law requires us to share that information. |
| **Get a list of those with whom we've shared information** | • You can ask for a list (accounting) of the times we've shared your health information for six years prior to the date you ask, who we shared it with, and why.<br>• 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** | • You can ask for a paper copy of this notice at any time, even if you have agreed to receive the notice electronically. We will provide you with a paper copy promptly. |
| **Choose someone to act for you** | • If you have given someone medical power of attorney or if someone is your legal guardian, that person can exercise your rights and make choices about your health information.<br>• 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** | • You can complain if you feel we have violated your rights by contacting us using the information on the back page.<br>• You can file a complaint with the U.S. Department<br>• of Health and Human Services Office for Civil Rights by sending a letter to 200 Independence Avenue, S.W., Washington, D.C. 20201, calling 1-877-696-6775, or visiting **www.hhs.gov/ocr/privacy/hipaa/complaints/**.<br>• We will not retaliate against you for filing a complaint. |

## Your Choices

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

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

## Our Uses and Disclosures

### 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. | ***Example:*** *A doctor treating you for an injury asks another doctor about your overall health condition.* |
| **Run our organization** | • We can use and share your health information to run our practice, improve your care, and contact you when necessary. | ***Example:*** *We use health information about you to manage your treatment and services.* |

## Our Uses and Disclosures
continued

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

### How else can we use or share your health information?

We are allowed or required to share your information in other ways – usually in ways that contribute to the public good, such as public health and research.We have to meet many conditions in the law before we can share your information for these purposes. For more information see: **www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/index.html.**

| | |
|---|---|
| **Help with public health and safety issues** | We can share health information about you for certain situations such as:<br>• Preventing disease<br>• Helping with product recalls<br>• Reporting adverse reactions to medications<br>• Reporting suspected abuse, neglect, or domestic violence<br>• 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. |

## Our Uses and Disclosures
continued

**Address workers' compensation, law enforcement, and other government requests**

- We can use or share health information about you:
  - For workers' compensation claims
  - For law enforcement purposes or with a law enforcement official
  - With health oversight agencies for activities authorized by law
  - For special government functions such as military, national security, and presidential protective services

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**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 see:**
**www.hhs.gov/ocr/privacy/hipaa/understanding/consumers/noticepp.html.**

### Changes to the Terms of This Notice

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

# What to expect

# What May Happen

## Introduction

Haven Health realizes that this period of time is certainly the most difficult for friends, family members, and loved ones. We wish to be honest, straightforward, and as helpful as possible, so we share this information to prepare you to anticipate the changes which can indicate approaching death. The Haven Health staff is available to answer any questions you may have about this information. We will tell you what to expect, as well as what you can do to make your loved one more comfortable at this time. These changes are how your loved one's body prepares itself for the final stages of life. Not all of these changes appear with each person, nor do they occur in any prescribed order. You may notice some or all of these changes over a period of hours or days.

## Common Physical Changes

### Temperature Changes

As the body's heating regulating system fails, the person's extremities may become increasingly cool to the touch, and at the same time the skin may become pale or bluish in color. This is a normal indication that the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs. Your loved one's blood pressure will also gradually lower and blood flow to the hands and feet will decrease. Keep the person warm with a blanket, but do not use one that is electric. In some instances, your loved one may feel feverish and appear flushed. You can use tepid wash cloths, applied to the armpits and groins, to reduce body temperature. You can also to use these cloths to sponge him or her off. Your Hospice team can instruct you on further cooling measures.

### Alertness and Sleep changes

Some people are alert and mentally clear until the moment of death. Others are confused, restless, sleep a lot, may be difficult to rouse, or may go in and out of consciousness. Speech can become confused or difficult to understand. Even if your loved one cannot communicate with you in words, do not assume that they cannot hear you, feel your touch, or sense your presence. Hearing is believed to be the last of the senses to be lost, so talking to your loved one, maintaining gentle physical contact or playing soothing music is encouraged. Do not talk about the person in the person's presence. Speak to him or her directly as you normally would, even though there may be no response. Familiar sounds, voices and touch continue to bring comfort and security to your loved one.

### Disorientation and Unusual Communication

As your loved one's oxygen levels decreases and metabolism changes they may become confused about the time, place, and identity of people surrounding them including close and familiar people. Your loved one may also make seemingly out of character or illogical statements, gestures, or requests. Communicate clearly by identifying yourself by name before you speak rather than asking the person to guess who you are. Speak softly, clearly, and truthfully when you need to communicate something important.

### Incontinence

The person may lose control of urine and/or bowel matter as the muscles in that area begin to relax. Discuss with your Hospice nurse what can be done to keep your loved one clean and comfortable.

### Liquid and Food Decrease

As your loved one steadily declines, they may have a decrease in appetite and thirst, wanting little to no food or liquids. This is the body's natural way of conserving energy that is normally used for digestion. Do not try to force food or drink into your loved; doing so will makes the person uncomfortable. Instead, offer small chips of ice, frozen Gatorade or juice as instructed by your Hospice Nurse. If the person is able to swallow, fluids may be given in small amounts by syringe (ask the Hospice nurse for guidance). Glycerin swabs may help keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also increase physical comfort.

**Urine Decrease**

As the amount of your loved one's fluid intake and circulation through the kidney's decreases, there will be less urine output. The urine may also become more concentrated and tea colored. Please notify your Hospice nurse with any changes in urine color or odor.

**Congestion**

Congestion is a normal change due to the decrease of fluid intake and an inability to cough up secretions. You may hear gurgling; which can sound unsettling, but usually does not cause any discomfort to the person. Gently turn the person's head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. The sound of the congestion does not indicate the onset of severe or new pain. Your Hospice nurse will be able to evaluate the need for medication to help reduce these secretions as death becomes near.

**Breathing Changes**

Your loved one may experience difficulty with breathing, and you may notice changes in their breathing pattern. A particular pattern consists of breathing irregularly, i.e., shallow breaths with periods of no breathing of five to thirty seconds and up to a full minute. This is called "Cheyne-Stokes" breathing. Your loved one may also experience periods of rapid shallow pant-like breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Elevating the head, and/or turning the person onto his or her side may bring comfort. Using oxygen may be helpful and necessary; your Hospice nurse will provide instructions regarding the use of oxygen and any other comfort medications.

**Restlessness**

You may notice your loved one making restless and repetitive motions such as pulling at bed linen or clothing. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolism changes. This could also indicate that something still unresolved or unfinished is disturbing the person and preventing them from letting go. Do not interfere with or try to restrain such motions. Please notify your Hospice team as they will assist you in identifying what may be happening as well as guide you on utilizing effective calming techniques. You may find the following calming techniques helpful:

- Speak calm and quietly
- Lightly massage the forehead
- Read something comforting
- Play soothing music
- Give assurance that it is OK to let go
- Apply Oxygen
- Raise head of bed

**Vision-like experiences**

Hallucinations and vision like experiences may result from physical changes in the body and/or spiritual origins. Physical changes in the body due to disease process, medication and infection may cause your loved one to behave or see things that are not characteristic of them. These same experiences may also be indicative of your loved preparing for death. It is common for people who are dying to see or speak to persons who have already died. When such symptoms arise please notify your Hospice team for support and clinical assessment.

# What May Happen Cont...

**Pain Changes**

Some people die without experiencing any pain at all. Others may already be taking doses of pain medication around the clock. Your loved one will need to continue taking their pain medication so it is important to keep him or her on their prescribed medication schedule. Even if your loved one cannot communicate with you, rest assured that you will be able to tell if he or she is experiencing pain. Some non-verbal signs of pain are grimacing, moaning, increasing irritability, restlessness, interrupted sleep, and changes in breathing. Report any of these changes to your Hospice nurse, who can provide instructions and consult your Physician to make or change medication orders if needed.

**Saying Good-bye**

Everyone dies differently and as they need to. Some people die fighting, others are accepting, and still others may die without acknowledgment of what is happening. Allow your loved ones to face their final moments as they wish to. Remember there is no right or wrong way to die. Dying can be very different from our expectations. Don't mold the reality of the moment into a romantic idea of what it should be. Despite how difficult it is, be there and remain real!

When the person is ready to die and you are able to let go, then is the time to say "Goodbye." Saying "Goodbye" is your final gift of love to the loved one, for it achieves closure and makes the final release possible. It may be helpful to lie in bed with the person and hold him or her, or to take the hand and say everything that you need to say so that afterward you never ask yourself, "Why didn't I say this or that to him or her?" It may be as simple as saying "I love you." It may include recounting favorite memories, places and activities you shared. It may include saying, "I'm sorry for whatever I contributed to add tensions or difficulties in our relationship." It may also include saying, "Thank you for..."

Tears are a normal and natural part of saying, "Goodbye." Tears do not need to be hidden from your loved one or apologized for. Tears express your love and help you to let go.

Dying people still have hope: hope of not suffering any more, hope of being remembered, hope of an afterlife. Support that hope. They may not have anything else to hold on to at this time. The dying have special needs. Sometimes they need to plan their own funerals or make other arrangements. Talk to your loved one, find out whether you could be helpful in carrying out these last wishes.

Sometimes a dying person needs to give away things that he or she has cherished in the hope of helping keep their memory alive.

It is not uncommon for the dying to want to hold on for others and address unsettled issues. Give permission to your loved one to let go and reassure them that you will be okay.

Giving permission to your loved one to let go without making him or her feel guilty for leaving or trying to keep him or her with you to meet your own needs can be difficult. A dying person will normally try to hold on, even though it brings prolonged discomfort, in order to be sure that those who are going to be left behind will be all right. Therefore, your ability to release the dying person from this concern and give him or her assurance that it's all right to let go whenever he or she is ready is one of the greatest gifts you have to give your loved one at this time.

Offer to assist your loved one with any unfinished business. This could mean calling a estranged family member, friends or completing spiritual/religious ritual or rite.

As your loved one gets closure to dying, they may call out for their parents, or people who are not present or no longer alive. If the person is alive try to establish contact so your loved one can talk to them. If they have passed on, do not correct them, instead be a calming presence, listen to them and be flexible. You can try holding and gently stroking their hand.

We understand how difficult this time may be for you and your family, and we are here to help. Please contact your hospice team for additional support.

**Signs of Death**

Although you may be prepared for the death process, you may not be prepared for the actual death moment. It may be helpful for you and your family to think about and discuss what you would do if you were the one present at the death moment. Please contact your Hospice team so they can assist you. The body does not have to be moved until you are ready. If the family wants to assist in preparing the body by bathing or dressing, that may be done. Hospice can help you call the funeral home when you are ready to have the body moved. Normally the police do not need to be called. The Hospice nurse will notify the physician. The signs of death include such things as no breathing, no heartbeat, release of bowel and bladder, no response, eyelids slightly open, pupils enlarged, eyes fixed on a certain spot, no blinking, jaw relaxed and mouth slightly open. A hospice nurse will come to assist you if needed or desired. If not, phone support is available.

**Signs indicating death has occoured are:**

- Breathing has ceased. Chest and abdomen no longer rise or fall. Air flow cannot be felt with hand on face at patient's nose or mouth.
- Pulse is absent. Check pulse at neck and wrist.
- Patient is motionless, without speech or response.
- Patient's eyelids are slightly open; eyes fixed on a certain spot; no blinking.
- At the moment of death or shortly afterword, some patients experience bowel or bladder incontinence due to the relaxing of the muscles that control unriation and defication.

**Procedure at the time of Death**

You have been receiving care at home by the hospice staff, under the orders of your physician. There is no need for the Medical Examiner or police to visit the home at the time of death, nor for an autopsy unless you or family members specifically request it.

- At the time of death please call the hospice team at (562) 426-7500. The nurse will return your call and will notify the physician, notify the medical examiner, and contact the funeral home of your choice.
- If you choose the nurse will come to the home to assist and support the family.
- Any medical equipment in the home will be picked up within two days.

# Resources

# Helpful Medication Hints

Medications are used to prevent and/or relieve physical discomfort .To use medication in a safe and effective way the following guidelines should be observed:

**Please Tell The Hospice Doctor Or Nurse:**

- About all medications you are presently taking.
- About non – prescription (off the shelf) medicines and home remedies you are taking.
- About eye drops, vitamins, creams, ointments, and laxatives you are taking.
- About any allergies you have to either medicine or food.

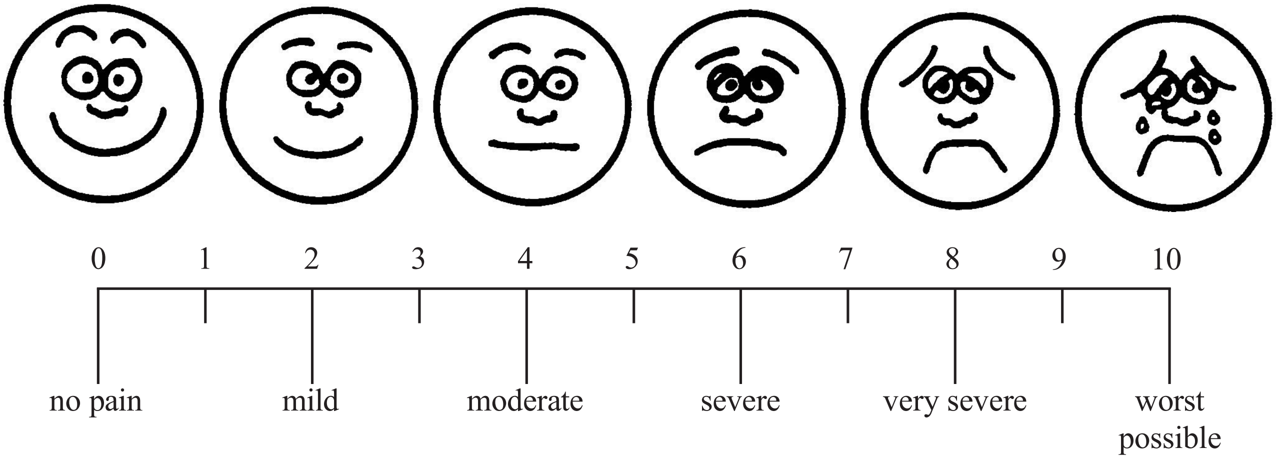
**Remember:**

- Use all medications as prescribed by the doctor. Medications are the most effective when taken as ordered.
- If you stop taking any medications for any reason, inform the hospice doctor or nurse.
- Never use medications that belong to someone else.
- Read the label on each bottle of medicine before taking. If in doubt, call hospice.
- Keep all medicines out of the reach of children.
- All medications that have been discontinued must be disposed of via hospice policy.
- Advise hospice immediately if you suspect any adverse reaction

# Pain Management Information

**Ways to describe your pain to the hospice doctor or nurse:**

- Where is the pain located?
- When did pain begin?
- What does it feel like?
- Is the pain continuous or does it occur on and off?
- Does the pain stay in one area or move around?
- Is the pain mild or severe?



# Questions About Narcotics

**Why Are Narcotics Prescribed?**

- The level of pain has moved to moderate or severe.

- Non – narcotics medication no longer works.

**What About Addiction?**

- When properly prescribed and taken as directed the risk of physical addiction is extremely low.

**What About Side Effects?**

**Not everyone experiences side effects. The most common side effects are:**

- Drowsiness (sedation) – This may occur during the first two days after starting a narcotic and will soon lessen.

- Constipation – This may occur and can be prevented or relieved by taking a laxative

- Nausea – this may be present during the first two or three days after starting a narcotic. Medication can help relieve this.

# Patient Education Fall Prevention Program

In order to prevent falls and injuries at home, we have outlined for you some important precautions and measures to follow at home:

- Assistance when you need to get up from your chair or bed, or when doing activities that you know cannot do alone.
- Sit at the edge of the bed before standing to reduce dizziness
- Do not attempt to climb up/down stairs without assistance and/or without holding on to hand rails.
- If you have poor vision, please make sure you have adequate light in the house. Do not attempt to walk in the dark.
- If you are taking Hypnotics or sleeping pills and feel drowsy, do not attempt to do activities unassisted. If you live alone, do not do activities until your drowsiness wears off.
- Make sure that rooms that you spend a lot of time in are uncluttered, and furniture is out of your way.
- Remove the clutter in your living space that may create a hazard (i.e. scatter rugs, excessive furniture, electrical cords on the floor, etc.)
- Take your time when moving around; do not rush! Use walker, cane or wheelchair as recommended by your physician.
- Keep most of the items that you need often within easy reach, such as: Medications, telephone, and personal items.
- Do not attempt to get into the shower unassisted.
- Wear supportive shoes and properly fitting clothing.
- Wear hearing aids or glasses while you are awake, if ordered by your physician.
- If you are walking and suddenly you feel very weak and unable to go any further, stay calm and slowly lower yourself onto the floor until you feel stronger.
- Know your own limitations! Discuss your concerns with your health care provider and your family.
- (IHSS/PCG) If patient is confused/disoriented, do not leave patient unattended if they are up and about.

## Lower Extremeties

### *Hip*

- Supporting leg at ankle and knee, raise leg toward ceiling keeping knees straight. Raise leg approximately six to ten inches off bed.
- Again lift leg approximately four inches off bed and bring the leg outwards toward you (sideways).

### *Knee*

- Support leg at knee and cup heel in other hand. Lift the leg, bending at the hip. Continue to move the leg as far as it will go (other leg should remain flat on bed).

### *Ankle*

- Cup patient's heel with one hand with forearm resting against the ball of foot. Steady the ankle by placing your other hand on the same leg just above the ankle.

- Press arm against the ball of foot bringing the foot up. At the same time, pull the heel of the foot.

- Slide your hand up to the top of the foot up. At the same time, pull the heel of the foot.

- Slide your hand up to the top foot pressing the forefoot down. At the same time, push against the heel with cupping hand.

## A Few Helpful Reminders

- The patient needs to be in comfortable position before starting these exercises.

- Before or after a bath is a nice time to perform exercises.

- These exercises can be an opportunity to provide the comfort that touch can provide to seriously ill patient.

## Helping The Patient With Passive Range Of motion Exercises (PROM)

Unless medically contraindicated, range–of-motion exercises can enhance circulation and help to prevent the complications that sometimes arise from extended bed rest.

Range-of-motion exercises are defined as the movement of an individual's joints through all their natural movements. In passive range of motion exercises, a person (family member/ home health aide) assists the patient through the movements.

- The patient will be most comfortable in bed.

- The joint is moved only to point f resistance / discomfort.

- Each joint should move through its free motion smoothly and rhythmically three to five times daily.

- Always discontinue immediately if pain is felt.

## Upper Extremeties

### *Shoulder – Two Movements At Joint*

- Bring patient's arm up overhead, supporting at wrist and elbow.

- Bring patient's arm outward away from the body with palm of hand facing up.

### *Elbow*

- Bend wrist elbow and bring hand as close to shoulder as possible. Then straighten elbow to rest arm on bed.

### *WRIST*

- Bend wrist forward as far as possible. Bend wrist as far back possible.

- Bend wrist in direction of little finger as far as possible. Bend wrist in direction of thumb as far as possible.

## Helping the patient move from bed to wheelchair / commode

- Moving the patient toward the edge of the bed.
  1. Move the patient's head and shoulders.
  2. Move the patient's legs.
  3. Slide your arms well under the patient's hips.
  4. Slide your back muscles tightened and in good alignment, move back as one unit, moving the patient's hips toward the edge of the bed.

- Helping the patient to sit up in bed.
  5. If the patient's has a hospital bed, elevate the bed.
  6. If no hospital bed, place one arm under the patient's shoulder.
  7. Instruct the patient to push their elbow into the bed while lifting.
  8. With the other hand, assist the patient to swing their legs over the edge of the bed, moving the patient to sitting position.

- Helping the patient to stand, then sit.
  9. Position your feet well under the patient.
  10. While facing the patient, firmly grasp each side of the patient's rib cage and push one of your knees against one of your patient's knees.
  11. Rock the patient forward until the patient is bearing weight, make sure the patient locks the knees for stability and strength.
  12. Observe the patient for pallor and ask about dizziness.
  13. Give the patient a moment to feel balanced before providing assistance in pivoting to chair or commode.

## Proper Body Mechanics – Basic Principles

### *Use Your Mind, Then Your Muscles*

- Set up work area, and clear obstacles.

- Tell your patient what you intend to do, so as to enlist their help as appropriate.

## Helping The Patient With Passive Range of Motion Exercises (PROM) cont...

- If you need help, get people and tell them your plan (one person in charge)

- Complete transfer, and again tell patient what to do, step by step, as you proceed.

### *Practice Good Body Mechanics*

- Carry any objects close to your body; stay well balanced, and avoid stretching or leaning.

- Work at comfortable height.

- Lift with legs/hips, not your back.

- Keep back straight; do not twist or turn. (If possible, better to roll, drag, push or pull).

- Stand with one foot forward for a wider base of support and stability.

- Bend your knees, squat and use your thigh muscles.

### *Using proper body mechanics for lifting*

An important aspect is the knowledge and proper use of body mechanics. Correct body mechanics allows patients and caregivers to use their bodies in a way that makes activities easier. In most activities related to patient care, the four basic principles of body mechanics are:

- Keep your back straight.
- Bend your knees, squat, and use your thigh muscles.
- Hold object as close to you as possible.
- Keep a wide base of support by placing one foot in front of the other or sideways.

## What are restraints?

Restraints are things that prevent or hinder movement of any part of the body. They can be:

- Physical – such as hand mitts, wrist or ankle straps, vest restraints or side rails are acceptable if ordered by the hospice doctor for patient mobility in bed.

- Chemical – drugs that control mood, mental condition or behavior, such as tranquilizers, sedatives and antidepressants.

## Why limit the use of restraints?

### *Because doing so benefits the patient.*

- Being able to move about freely is important for a patient's health and sense of dignity.

- It also allows the organization to comply with laws and meet accepted care standards.

### *Sometimes restraints can be useful.*

- Putting side-rails up on a hospital bed is considered a restraint, but allows weak patients to move around in bed more independently. A patient may ask to have side-rails up for this purpose.

- The restraint will be evaluated within 72 hours of emergency use by the hospice team for further use.

- Specific time for restraint release will be discussed and reinforced with the patient's primary caregiver on an ongoing basis.

### *Consider alternatives to restraints.*

- Exercise (if appropriate) – This is good for patient's overall health. And, it helps them become stronger and less likely to fall.

- Changes to patient's surroundings – Remove area rugs, improve lighting, lower mattresses, or make other changes to reduce the risk of slips and falls; decrease noise or light that can agitate patient's place often-used items within easy reach.

- Supportive Devices – These help improve posture and prevent falls, For example, for patients who might fall out of chairs, try using wedge cushions, or footrests.

- Activity – Staying involved can help keep patients from becoming restless or agitated. Try to give patients small chores to do. If appropriate, make reading materials, books on tape and games available; arrange group activities; use volunteers, friends or family members to provide companionship.

- Frequent toilet checking – Unstable patients may fall trying to get to the bathroom on their own. Instead of restraining them, check often to see if they need to use the bathroom facilities, and assist them. A bedside commode may also be helpful.

- Alarm – These include: hand bells that let caretakers know when a patient needs attention; buzzers or bells that sound when restricted doors open; or baby monitors.

## Safety Tips for Hospital Beds and Wheelchairs

### Electric Hospital Beds

- Never operate your electric bed if the unit has a damaged cord or plug.
- Keep the cord away from wet or heated surfaces.
- Make sure the side rails are properly in place.
- Do not use side rails as push handles if you are moving the bed.
- Do not lean on the side rails heavily when sitting bedside the bed.
- Lock the brake (located on the wheels) when the patient is in bed or being transferred out of the bed to a chair or commode.

## Wheelchairs

- Never force a wheelchair to open or close.
- Never push out on the arms of the wheelchair.
- Lock the brake whenever the patient is being transferred in or out of the chair.
- The patient should wear non-slip slippers or supportive shoes when transferring to and from the wheelchair.

## Using your Walker

- Lift up – do not slide your walker
- Do not pull on the walker when standing up.
- Remove all throw rugs in your home.
- Do not walk on slippery surfaces.
- Check the rubber tips for wear and tear.

### Standing with Your Walker

- When standing with arms at your sides, the walker handgrips should be at wrist level.
- In rest position, keep up the walker in front of you with your weight on the good (or stronger) leg and hands.
- In rest position your elbow should be at a 30 – degree bend when your hands are on the handgrip.

### Walking Your Walker

- Pick up the walker and place it one foot ahead of you.
- Place your affected (weaker) leg ahead of your unaffected (or stronger) leg.
- Push down with your hands and bring forward your unaffected (or stronger) leg.
- Keep repeating sequence.
- Always walk with the assistance of another person if you feel weak or unsteady. If you suddenly feel as if you might fall, have the person assisting you gently lower you to the floor.

# Diabetic Management for Hospice Patients

**Symptoms of Uncontrolled Diabetes:**

- Excessive thirst
- Frequent urination
- Extreme fatigue
- Unexplained loss of weight
- Restlessness
- Blurred vision
- Drowsiness

**Basic Facts about Diabetes**

- Different foods (e.g., sugars) and certain medications (e.g., prednisone) along with the advanced disease process can raise or lower your blood sugar.
- If the doctor orders a fasting blood sugar lab test, do not eat prior to the test. If you are thirsty, drink water while awaiting the laboratory technician's visit to your home.
- If your appetite decreases consult the hospice. Your oral medication or insulin may be decreased or eliminated to prevent unpleasant side effects.
- Diabetics are at increased risk for infection.
- Remember to wash and dry your feet well; especially between your toes.
- Uncontrolled diabetics are encouraged to consult with their podiatrist.
- Frequent small portions and snacks before bed may be beneficial for uncontrolled diabetics and per- sons with advanced illnesses.

**The Hospice team can:**

- Offer written information about diabetes.
- Assist with dietary counseling.
- Assist you in learning proper blood glucose (sugar) finger stick monitoring when needed.

The diet guidelines for diabetic patients on our program are based on the needs of the individual in consultation with our nutritionist, nurse and physician. Based on the patient's diabetic needs and overall condition, the hospice team may order specific dietary supplements.

# Oxygen Safety Tips and Helpful Hints

## Because oxygen can be easily ignited:

- Do not use near open flames.
- Post provided Oxygen in Use sign on outside door or window
- No smoking while oxygen is in use, do not allow anyone to smoke near patient while in use.
- Store oxygen cylinders in a cool, dry, ventilated place and upright in holder to prevent tipping
- Ensure you have working smoke detectors in the home.
- Do not use near petroleum products such as grease, oil, or Vaseline.
- Do not use wool blankets on the patient’s bed to avoid dangers from static electricity.

## What to do if:

1. **My oxygen concentrator will not turn on:**
    - Check to see that the power cord is plugged into outlet.
    - Check to see that the concentrator is turned to the “on position”.
2. **I do not feel the oxygen flowing:**
    - Place the nasal prongs in a clear glass with water. You should see “ bubbling” coming from the prongs.
    - If no “ bubbling “ make sure the oxygen tubing is not twisted or bent.
3. **How often do I change the water in the oxygen concentrator humidifier bottle?**
    - Water in the humidifier bottle should be changed daily.
    - The humidifier bottle should be changed daily.
    - Once a week, the humidifier bottle should be cleaned with (1) teaspoon of vinegar mixed with (3) teaspoons of water.

# Key Earthquake Safety Tips for People with Disabilities and Others with Access and Functional Needs

## During earthquake shaking, protect yourself from falling objects.

### IF POSSIBLE:

**DROP** where you are, onto your hands and knees. This position protects you from being knocked down and also allows you to stay low and crawl to shelter if nearby.

**COVER** your head and neck with one arm and hand

- If a sturdy table or desk is nearby, crawl underneath it
- If no shelter is nearby, crawl next to an interior wall
- Stay on your knees; bend over to protect vital organs

**HOLD ON** until the shaking stops.

- Under shelter: hold on to it with one hand; be ready to move with your shelter if it shifts
- No shelter: hold on to your head and neck with both arms and hands.

### ADAPT FOR YOUR SITUATION:

If you have difficulty getting onto the ground, or cannot get back up again without the help of a caregiver, then follow these recommendations:

- If you are in a recliner or bed: Cover your head and neck with your arms or a pillow until the shaking stops.
- If you use a cane: Drop, Cover, and Hold On or sit on a chair, bed, etc. and cover your head and neck with both hands. Keep your cane near you so it can be used when the shaking stops.
- If you use a walker or wheelchair: **LOCK** your wheels (if applicable). If using a walker carefully get as low as possible.
- Bend over and **COVER** your head/neck with your arms, a book, or a pillow. Then **HOLD ON** until shaking stops.

**Learn more at www.EarthquakeCountry.org/step5.**

# Key Earthquake Safety Tips for People with Disabilities and Others with Access and Functional Needs cont...

## People who are Deaf or Hard of Hearing:

Prior to an earthquake, identify and test multiple ways to receive warnings and evacuation information.

## People who are Blind or have Low Vision:

Earthquakes can cause items to fall and furniture to shift. Regular sound clues may not be available afterwards. Move with caution.

## People with Developmental/Cognitive/Intellectual Disabilities:

If you have difficulty understanding, remembering, or learning, keep a simple list of what to do and important information with you and in your kits. Practice your plan in advance. If you use augmentative communication supports, include these in your planning.

## Additional Disaster Preparedness Recommendations:

- Develop or update your individual and family plans, including your communication plans and important contacts.
- Make emergency go kits for your home, car, and office. Remember to make kits for service animals and pets too. Store extra batteries and any needed supplies in your kits.
- Label adaptive equipment or other devices with your contact information in case they are separated from you.
- Create safe spaces by securing heavy furniture and other items that could fall, injure you, or block your way out.
- Build a Personal Support Team (PST) to check on you in case you need assistance. Include them in all phases of your planning.
- Get involved! Volunteer with your local Community Emergency Response Team (CERT) or similar organizations in your area.
- If you live near or visit the beach, be aware of tsunami evacuation routes and learn what to do to protect yourself. Practice tsunami evacuations with your care provider or support team.
- Hold drills at home, work, and in your community regularly. Invite your PST and care providers to join you.

# Bio-Hazardous Waste

In the past it was legal for patients using injectables at home to dispose of these by placing them in an empty coffee can or milk container, taping it shut and writing on the outside "Used Needles."

As of 9/1/2008 this is no longer allowed.

- All used needles will need to be placed in a red needle disposal container (Sharps Container) that is approved by the Department of Health.
- If a sharps container is not available, then they should be packaged as they were before and delivered to a drop site.
- The families will have to pay to have them pickied up by a bio-hazardous waste company such as Stericycle.

Since the majority of our clients will not have the resources to pay for this service, it is our responsibility to make them aware of drop off locations in their area. The following information is information regarding drop off spots. Please visit http://www.lacitysan.org/ or http://oclandfills.com/hazardous/ for more information.

## Examples of Waste:

**Motor oil, oil filters, brake fluid**
**Used antifreeze**
**Paint, paint thinner, turpentine**
**Cleaners with acid or lye**
**Pesticides or herbicides**
**Household batteries or car batteries**
**Pool chemicals**
**CRTs, old TVs, misc. electronics**
**Mercury thermometers or thermostats**
**Used Needles or Sharps (In a Sharps container or sturdy box labeled "SHARPS")**

## Drop off Locations

### Orange County

**Anaheim Collection Center**
**1071 N. Blue Gum Street**
**Anaheim, CA 92806**

**Huntington Beach Collection Center**
**17121 Nichols Street**
**Huntington Beach, CA 92647**

**Irvine Collection Center**
**6411 Oak Canyon**
**Irvine, CA 92618**

**San Juan Capistrano Collection Center**
**32250 La Pata Avenue**
**San Juan Capistrano, CA 92675**

### LA County

**Northridge: Nicole Bernson SAFE Collection Center**
**10241 N. Balboa Blvd.**
**Northridge, CA 91325**

**San Pedro: GAFFEY STREET**
**1400 N. Gaffey St.**
**San Pedro, CA 90731**

**Los Angeles: LOS ANGELES-GLENDALE TREATMENT PLANT**
**4600 Colorado Blvd.**
**Los Angeles, CA 90039**

**HYPERION TREATMENT PLANT**
**7660 West Imperial Highway, Gate B**
**Playa Del Rey, CA 90293**

**West Los Angeles: UCLA**
**550 Charles E. Young Dr. West**
**Los Angeles, CA 90025**

# Disposal of Medical Household Waste

How to Dispose of Medical Household Waste:
Medical household waste is any disposable item used when providing patient care in the home that has been soiled by the blood, body fluids and or body waste (i.e., urine, feces, vomit, blood). Examples are used gauze bandages, dressings, disposable diapers, under pads, tissues and disposable gloves.

- Use gloves when providing patient care or handling items soiled with blood/body fluids.
- Household waste is disposed of in the regular garbage and not recycled.
- Always keep a waste container near the patient's bed.
- For disposal of soiled bandages, dressings, diapers, under-pads, tissues, or other disposable equipment (except needles, syringes, and sharps.) Use two plastic bags to line the waste container and when full, close securely and place in the regular garbage.
- Always dispose of feces, urine and vomit in the toilet and flush.

***Remember: Always wash your hands before and after patient care, after removal of gloves, after toileting and before eating.***

# Disposal of Controlled Drugs in the Home

## Policy:

When a patient dies at home, all controlled drugs listed in Schedules II, III, or IV in the home are to be disposed of in accordance with State and Federal regulations.

Procedure:

1. The hospice nurse will inform the responsible family member or other responsible person that the controlled drugs are to be disposed of and will provide education on the proper ways to do so.

2. Follow specific disposal instructions on the drug label or patient information that accompanies the medication. Do not flush prescription drugs down the toilet unless the information specifically instructs you to do so.

3. If no instructions are given on the drug label:

   a. Take medications out of their containers, crush and mix them with an undesirable substance, such as used coffee grounds or kitty litter. The medication will be less appealing to children and pets, and unrecognizable to people who intentionally go through your trash.
   b. Put them in a sealable bag, empty can, or other container to prevent the medication from leaking or breaking out of a garbage bag.
   c. Before throwing out a medicine container, scratch out all identifying information on the prescription label to make it unreadable.

4. Hospice staff must document a Controlled Drug Disposal Record.
   a. Identifying the controlled drug and the approximate amount disposed of or left in the home or SNF
      I. SNF patients: the drugs may be left at the SNF for disposal per SNF protocol. A form will be complete to not the approximate amount left at the SNF.

# Home Health Aide Information

Haven Health provides certified home health aides to assist in the process of meeting care needs.The following guidelines should be reviewed in order to enable you and/or your loved one to gain the most from this type of assistance. If at anytime you have questions regarding the home health aide assigned to you, please call us at (562) 426-7500.

- The home health aide is to come to your home promptly. However, the first day of service or during inclement weather, please allow additional time for travel.

- The home health aide is required to wear identification from the agency and be well groomed in appearance at all times.

- The home health aide has already been given information on the care needs of your loved one. If for any reason you are not confident in the care being provided please call our office immediately.

- The home health aide is NOT permitted to use the telephone other than to call his/her agency.

- The home health aide does NOT do heavy household cleaning.There are light housekeeping duties the nurse will discuss and clarify if there are any questions.

- The home health aide is NOT permitted to leave your loved one unattended at the end of his/her shift. If you or another caregiver are out and are not able to be back home for the home health aide to leave, please call our office so that we can authorize extra time.

- If you have any pets, please tell our nurse and use discretion in keeping them safely out of the home health aide's work area.

# Volunteer Help

**Could you use some volunteer help?**

Haven Health has dedicated volunteers who will come to your home to assist you.

- Our Volunteers can:
- Provide friendly visits to patients and their family
- Assist with light errands
- Read to patients, write letters, exchange stories or perhaps play cards
- OR... just be good listener

# Advance Directives and POLST

These procedures are intended to enable Haven Health to comply with the Patients self-determination Act (“ACT contained in the Omnibus Budget Reconciliation Act of 1990”). The purpose of the Act is to protect each adult patient’s right to participate in health care decision making to the maximum extent of his or her ability and to prevent discrimination based on whether the patient has executed an advance directive for health care. (RI.1.1.4)

Haven Health supports a patient’s right to participate in health care decision making to the maximum extent of his/her ability and within state law. Through education and inquiry about advance directives, the Company will encourage patients to communicate their health care preferences and values to others. Such communication will guide others in health care decision making for the patient if the patient is incapacitated, Haven Health will not discriminate against a patient based on his/her execution of an advanced directive. Education:

Educational information about advance directives and Haven Health’s policies regarding advance directives will be provided to health professionals and ancillary staff.

**Procedure:**

1. As part of the admission process, the health professional who conducts the patient’s initial assessment shall provide the patient with the information regarding the patient’s rights to make decisions concerning health care, which includes the right to accept or refuse medical surgical treatment (even if that treatment is life sustaining), to appoint an agent or proxy for health care decision making, and to formulate an advance written directive per state law. This information will be provided in the Patient Information with the admit pack.

2. During the initial visit, or as soon thereafter as reasonably possible, the nurse who conducts the visit will ask the patient or family whether he/she had completed advance directives including a Durable Power of Attorney for Healthcare and a Physician Orders for Life-Sustaining Treatment (POSLT). If an advance directive and/or POLST has been completed, the nurse will ask for a copy so that it can be placed in the hospice patient medical record. If a copy is not immediately available, the patient will be informed that it is his/her responsibility to provide Haven Health with a copy of the directive as soon as possible. If an advance directive has not been completed or the patient is unfamiliar with advance directives, the nurse making the initial visit will ask the patient whether he/she would like to receive further information on advance directives. If so, the patient should be directed to the appropriate identified resources, including a hospice MSW who can assist with the completion of a Durable Power of Attorney for Healthcare. If no POLST has been completed at the time of admission, the admitting nurse will discuss patient’s wishes for cardiopulmonary resuscitation, medical interventions, and artificially administered nutrition, and assist them in completing the POLST form. If the patient does not have decision making ability at the time of discussion, the admitting nurse will communicate with the Durable Power of Attorney or Next of Kin regarding the completion of the POLST form. Another member of the IDT, such as a visiting nurse, social worker, or chaplain, can also assist in the completion of the POLST form.

3. The person who documents the patient’s admission visit shall note in the patient’s medical record:

    a. That the patient has received information outlined in steps 1 and 2.
    b. Whether or not the patient has an advance directive or POLST form and obtain a copy for the patient’s medical record.

## Advance Directives and POLST cont...

4. Code status, medical intervention instructions, and decision maker assignments are to be documented in the patient's chart and communicated to the IDT.

5. When Haven Health begins treatment of a patient who is in such condition that it is not practical to provide them information regarding advance directives at the time of admission, this information will be provided as soon as feasible after admission.

6. When the patient who lacks personal decision making capacity for health care (as determined by admitting physician in consultation with family members and/or close friends of the patient) is under the care of Haven Health, the nurse admitting the patient will provide information regarding advance directives and the POLST to a relative or next of kin in the patient's home, if such a person is present. If no such person is present, information on advance directives and the POLST inquiry into existence of an advance directive will be directed to the patient's surrogate decision-maker, once the maker is identified.

7. It is the responsibility of the Administrator and DOPCS to be informed about the applicable state laws regarding living will, durable power of attorneys, health care proxies, the POLST, and other related documents. The Administrator and DOPCS should also be informed about agencies within the state that can provide further information to staff or patients. NHPCO and Joint Commission can be used as a resource.

# Mortuary & Burial Resources (Los Angeles)

**Mountain View Mortuary**
2400 Fair Oaks Ave
Altadena, CA 91001
626-794-7133
www.mtn-view.com

**Cremation Society of Los Angeles**
6427 S. Eastern Avenue
Bell Gardens, CA 90201
800- 615-5501
www.cremationsociety.to

**Southern California Funeral Service**
12964 Central Ave
Chino CA 91710
909-628-2634
www.socalfuneral.com

**Custer Christiansen Mortuary**
124 S. Citrus Ave
Covina, CA 91723
626-331-8231

**Forest Lawn**
1712 S. Glendale Avenue
Glendale, CA 91205
800-204-3131
www.forestlawn.com

**Inglewood Park Cemetery**
720 E Florence Avenue
Inglewood, CA 90301
310-412-6500
www.inglewoodparkcemetery.com

**Simpsons Mortuary**
5443 Long Beach Blvd
Long Beach, CA 90808
562-513-1210
www.simpsonfamilycares.com

**Affordable Burial & Cremation**
6510 Cherry Avenue
Long Beach, CA 90805
888-932-3286
www.affordableburial.net

**Stricklin & Snively Mortuary**
1952 Long Beach Blvd
Long Beach, CA 90806
562-426-3365
www.stricklinsnivelycares.com

**All Souls Mourtuary and Cemetery**
4400 Cherry Avenue
Long Beach,CA 90806
562-424-8601
www.allsoulsmortuary.com

**Los Angeles Funeral Home**
301 E. 84th St
Los Angeles, CA 90003
323-541-9835

**White's Funeral Home**
404 E. Foothill Blvd
Azuza, CA 91702
626-334-2921
www.whitesfuneralhome.com

**Funeria del Angel-Bellflower**
10333 Alondra Blvd
Bellflower, CA 90706
562-867-1778
www.funerariasdelangel.com

**Montecito Memorial Park & Mortuary**
24145 Barton Rd
Colton, CA 92324
909-825-3024
www.dignitymemorial.com

**Holy Cross Mortuary**
5835 W. Slauson Avenue
Culver City,CA 90230
310-836-5500
www.holycrossmortuary.com

**Arrowhead Aftercare**
27007 5th St
Highland, CA 92346
909-425-2920
www.arrowheadaftercare.com

**McCormick Mortuary**
653 S. Praire Ave
Inglewood, CA 90301
310-792-7580
www.lafuneral.com

**Long Beach Colonial Mortuary**
638 Atlantic Avenue
Long Beach, CA 90802
562-436-1601
www.longbeachcolonial.com

**Spongeberg Mortuary**
495 E Market Street
Long Beach, CA 90805
562-423-1495

**Luyben Family Mortuary**
5161 E. Arbor Road
Long Beach, CA 90808
562-425-6401
www.dignitymemorial.com

**Guerra-Gutierrez Mortuary**
5800 E. Beverly Blvd
Los Angeles CA 90022
323-722-1900
www.guerragutierrez.com

**Armstrong Family Malloy-Mitten**
931 Venice Blvd.
Los Angeles, CA 90015
213-747-9121
www.armstrongmortuary.com

**Allen-English & Estrada**
6435 S. Eastern Avenue
Bell Gardens, CA 90201
323-773-3547

**Whites Funeral Home**
9903 E Flower St
Bellflower, CA 90706
562-867-2741

**Robert L Adams Mortuary**
501 Palmer Ave
Compton, CA 90221
323-636-9864

**Roosevelt Memorial Park**
18255 S.Vermont Ave
Gardena, CA 90248
310-329-1113
www.rooseveltmemorialparkandmortuary.com

**Guerra Cunningham Bagues**
6351 Seville Ave.
Hungtington Park, CA 90255
323-581-8109

**Inglewood Cementary Mortuary**
3801 W. Manchester Blvd
Inglewood, CA 90305
310-412-6811
www.inglewoodcementarymortuary.com

**McKenzie Mortuary**
3843 East Anaheim Street
Long Beach, CA 90804
310-412-6811
www.inglewoodcementarymortuary.com

**Leggett & King Funeral Home**
1870 Atlantic Avenue
Long Beach, CA 90806
562-591-9751

**Heritage-Diadlay**
244 Redondo Avenue
Long Beach,CA 90803
562-438-1145

**Angelus Funeral Home**
3875 S. Crenshaw Blvd.
Los Angeles, 90008
800-348-3939
www.angelusfuneral.com

**Groman Mortuary. Inc**
830 W Washington Blvd
Los Angeles, CA 90015
213-748-2208

# Mortuary & Burial Resources (Los Angeles) cont...

**East Olympic Funeral Home**
4556 E. Olympic Blvd
Los Angeles, CA 90022
323-260-7995
www.eastolympic.com

**Felipe Bagues Mortuary**
1930 E. 1st St
Los Angeles, CA 90033
323-267-4599
www.baugesmortaury.net

**Bagues & Sons Mortuary**
4221 E. Ceasar Chavez Ave
Los Angeles, CA 90063
323-268-6373

**Douglas Family Mortuary**
3363 E. Imperial Highway
Lynwood, CA 90262
310-632-1171
www.douglasfamilymortuary.com

**Resurrection Catholic Cemetery & Mausoleum**
966 Potrero Grande Drive
Montebello, CA 90604
323-887-2024
www.la-archdiocese.org

**Acremation**
730 E. Katella Ave.
Orange, CA 92867
714- 288-4025
www.acreamation.com

**McNearney Family Mortuary**
130 S Willow Ave
Rialto, CA 92376
909-875-1123
www.mcnearneyfamilymortuary.com

**Sierra Memorial Chapel Mortuary**
4933 La Sierra Ave
Riverside, CA 92505
951-687-0551
www.sierramemorialchapel.com

**Queen of Heaven Mortuary**
2161 S. Fullerton Rd
Rowland Heights, 91748
626-964-1291
www.queenofheavenmortuary.com

**Neptune Society**
562 S Palos Verdes Street
San Pedro, CA 90731
888-637-8863
www.neptunesociety.com

**White Emerson Mortuary**
13304 East Philadelphia St
Whittier, CA 90601
562-698-0304
www.whiteemerson.com

**Calvary Mortuary**
4201 Whittier Blvd
Los Angeles, CA 90023
323-261-3106
www.calvarymortuary.com

**Harrison-Ross Mortuaries**
4601 S. Crenshaw Blvd
Los Angeles, CA 90043
888-905-7677
www.baugesmortaury.net

**Castaneda-Crollet**
3715 E.Cesar Chavez Ave
Los Angeles, CA 90063
323-269-8455

**Douglas & Zook Mortuary**
600 E. Foothill Blvd
Monrovia, CA 91016
626-358-3244
www.douglasandzook.com

**Risher Mortuary**
1316 Whittier Blvd
Montebello, CA 90640
323-728-1261
www.rishermourtuary.com

**Green Hills Mortuary**
27501 South Western Ave
R. Palos Verde, 90275
877-981-7755
www.greenhillsmortuary.com

**Preston & Simons Mortuary**
3358 Mission Inn Ave
Riverside, CA 92501
951- 683-7410
www.preston-simonsmortuary.com

**Rubidoux-Jurupa Valley Mortuary**
6091 Mission Blvd
Riverside, CA 92509
951- 683-2215
www.rubidouxmortuary.com

**Mountain View Mortuary & Cemetery**
570 E Highland Ave
San Bernardino, CA 92404
909- 882-2943
www.mtviewsanbernardino.com

**Midgley Gardenside Mortuary**
13450 Paramount Blvd
South Gate, 90280
800-795-0028
www.gardenside.net

**Funeraria Latino Americana**
3827 Whittier Blvd
Los Angeles, CA 90023
323-265-7016
www.agapefuneralhomeinc.com

**Manlinow & Silverman**
7366 Osage Ave
Los Angeles, CA 90045
800-710-7100
www.manlinowsilverman.com

**House of Winston**
9501 South Vermont Ave
Los Angeles,CA 90044
310- 757-2271
www.houseofwinston.com

**Turner & Stevens Live Oak Mort.**
200 E. Duarte Rd.
Monrovia, CA 91016
626-359-5311

**Chapel of Memories**
12626 Woods Ave
Norwalk, CA 90650
562-863-8731
www.chapelofmemoriesfuneralhome.com

**Cremation Society of the South Bay**
2701 182nd Street
Redondo Beach 90278
310-370-1075
www.lacremation.com

**Arlington Mortuary**
9645 Magnolia Ave
Riverside, CA 92503
800-275-4648
www.arlingtonmortuary.com

**Riverside National Cemetery**
22495 Van Buren Blvd
Riverside, CA 92518
951- 653-8417
www.cem.va.gov/cems/nchp/riverside.asp

**Aaron Cremation & Burial Services**
1525 N Waterman Ave
San Bernardino, CA 92404
800-303-3610
www.aaroncalifornia.com

**Rose Hills**
3888 S.Workman Mill Road
Whittier, CA 90601
562-699-0921
www.rosehills.com

# Mortuary & Burial Resources (Orange County)

**Funeria Del Angel Pierce Brothers Anaheim**
2425 W Lincoln Avenue
Anaheim, CA 92801
714-828-6440
www.funeriasdelangel.com

**Memory Garden Memorial Park & Mortuary**
455 W. Central Avenue
Brea CA, 92821
714-529-3961
www.memorygarden.com

**Harbor Lawn-Mount Olive Mortuary**
1625 Gisler Ave
Costa Mesa, CA 92626
714-540-5554
www.dignitymemorial.com

**McAulay & Wallace Mortuary**
902 North Harbor Boulevard
Fullerton, CA 92832
714-525-4721
www.mcaulaywallace.com

**O'Connor Mortuary**
25301 Alicia Parkway
Laguna Hills, CA 92653
949-581-4300
www.oconnormortuary.com

**Family Mortuary**
1201 North Main Street
Santa Ana, CA 92701
714-953-9045
www.familymortuary.net

**Omega Society**
2800-A S. Main St
Santa Ana, CA 92707
800-646-6342
www.omegasociety.com

**Melrose Abbey Park Memorial**
2303 S Manchester Ave
Anaheim, CA 92802
714-634-1981
www.burialplanning.com

**Rose Hills Mortuary**
11900 South St #119
Cerritos, CA 90703
562-809-7027
www.rosehills.com

**Neptune Society of Orange County**
758 W. 19th St.
Costa Mesa, CA 92627
800-225-1601
www.neptunesociety.org

**Heritage Memorial Services**
17712 Beach Blvd
Huntington Beach 92647
714-842-2400
www.heritagememorialservices.com

**Ferrarra Colonial Mortuary**
351 North Hewes Street
Orange, CA 92869
714-639-2711
www.ferrarramortuary.com

**Fairhaven Memorial Park and Mortuary**
1702 E. Fairhaven Ave
Santa Ana, CA 92705
714-633-1442
www.fairhavenmemorial.com

**Saddleback Chapel Mortuary**
220 E. Main Street
Tustin, CA 92780
714-544-1450
www.saddlebackchapel.com

**Hilgenfeld Mortuary**
120 E. Broadway
Anaheim,CA 92805
714-535-4105
www.hilgenfeldmortuary.com

**Pacific View Mortuary & Memorial Park**
3500 Pacific View Dr.
Corona del Mar CA 92625
949-644-2700
www.dignitymemorial.com

**Accu-Care Cremation**
1410 S. Acacia St.
Fullerton, CA 92831
800-323-1342
www.accucarecremationcenter.com

**Community Funeral Services**
1301 South Beach Blvd #B
La Habra, CA 90631
562-947-1960
www.communityfuneralservice.com

**Funeral & Cremation Services of OC**
351 North Hewes Street STE A
Orange, CA 92869
714-667-7991
www.californiacremationservices.com

**Brown Colonial**
204 W 17th Street
Santa Ana, CA 92706
714-542-3949
www.browncolonialmortuary.net

MAYO CLINIC
HEALTH SYSTEM

Home Health & Hospice

# *Nutrition Therapy*

## *in Hospice Care*

## Hospice Care and Nutrition

We are surrounded by food. It is vital to our well-being since the day we were born.

We need food to keep us healthy, vibrant and strong; to keep us functioning, except in the end. At the end of our life, food is not a necessity. Our bodies do not need food as they shut down. In the end, food can actually do more harm than good. Eating food when our body no longer needs it can cause pain, nausea, vomiting, diarrhea and anxiety. At the end of life, we eat for comfort and pleasure.

Eating for comfort and pleasure, what does that mean? It means it is okay to have ice cream for breakfast. It means having a piece of pie even if you are diabetic. It means allowing your loved one to eat only if they want to, not because it is time to. At the end of our life, we do not feel hunger or thirst. We are not starving even if all we had to eat is a piece of toast and some juice for the entire day. It is a natural process.

As your loved one's body begins to shut down, their need for food lessens. Their body produces substances that suppress their appetite and takes away the hunger. As death nears, the body has more difficulty handling fluids. Their lack of appetite is a natural defense against taking too much fluid. Dehydration is a pleasant feeling to them— a comforting feeling.

As your loved one takes in less fluid, they will have less fluid in their lungs and in their throat, making it easier for them to breath. They will have less stomach stimulation, so they will have less nausea. Their body will increase their production of its own endorphins, which will result in less pain and more comfort. Your loved one may experience a dry mouth. Frequent oral care with mouth swabs and lip moisturizers will manage the discomfort.

As a caregiver, support your loved one as they approach the end of their life. Do not focus on the type or amount of food they are eating. Allow them to eat what they want, when they want so as not to cause more pain or discomfort.

Hold their hand, read to them or just be with them instead of trying to get them to eat. Our bodies know when it needs food and in the end, it doesn't. Allow your loved ones to eat as they are able and desire to. Remember food is for comfort and pleasure, not for healing.

## Suggestions for Managing Nutrition

## Related Symptoms

- Offer five to six small meals or snacks each day rather than the typical three meal pattern. Offer the food during times when the person's appetite is the best.
- Involve your loved one in meal planning as much as they are able to participate. Respect their food choices. Remember the last time you had the flu and what foods helped you feel better. A favorite food before illness may no longer taste the same or be as appealing as in the past.
- Offer small portions on smaller plates or cups to make eating less overwhelming.
- Strict dietary restrictions of salt and sugar may not be needed at this time. Allowing a more relaxed diet may help increase intake. Talk to the nurse and the dietitian for guidance.
- Using plastic spoons or forks for eating may help if the person complains of a metallic taste to food.
- If foods with strong smells (especially when cooking) cause nausea or poor intake, try eating room temperature or cold foods. They will have little or no smell and will be tolerated better.
- Meat is typically the first food group that people stop eating due to taste difference and decreased ability to chew. Milk, pudding, cottage cheese, cheese, yogurt, ice cream, beans and ground meats are also good sources of protein.
- Do not replace your loved ones favorite foods with nutritional supplements such as Ensure or Boost if they are still able to eat.

- If nutritional supplements are needed, instant breakfast or homemade malts and shakes are often preferred over commercial supplements (and cheaper).
- Don’t be discouraged or show disappointment if your loved one doesn’t feel like eating. Try again in a couple of hours.
- Let your loved one be in control of their eating. It usually is one of the few things that is left that they can control.
- If your loved one experiences difficulty with chewing or swallowing, please contact your hospice nurse or dietitian for assistance.
- Pureed foods can be frozen in plastic cups or dropped onto a cookie sheet in spoon size/mouth size portions and offered as one bite meals many times a day.
- Fruits (banana, blueberries, grapes and applesauce) can be cut into bite size/mouth size pieces, frozen and offered half an hour before meals to help with nausea or given every half hour throughout the day.

## Dry Mouth

Your loved one may have a dry mouth.  This may occur from medication, dehydration, results of radiation, or the disease process to name few. Symptoms may be relieved by moist swabs, artificial saliva, misting with water or wet washcloth. Frozen popsicles or fruit juices may also be helpful.

## What causes poor appetite or weight loss?

Symptoms like pain, nausea, constipation and shortness of breath take up a lot of energy and may take away the desire to eat and drink. Treatment for weight loss or force feeding the person does not improve your loved ones survival and may prolong the dying process and increase pain. It may also cause conflict between your loved one wishing not to eat and family members.

## The Last Days of Life

During the last few days of life, your loved one will take in less food and fluid. Hunger and thirst are rare during this time and the body does not want or need food or fluids. The idea of withholding or withdrawing fluids can arouse strong emotions in family members as they struggle with the fears of dehydration. Dehydration may actually have some benefits for the terminally ill— it can be a natural analgesic. Allowing dehydration to occur at the very end of life is considered to be palliative and compassionate.

If your loved one is hungry, give small sips and bites as long as they are alert and able to swallow safely. If they are unable to swallow, wet mouth swabs or ice chips can be used to keep the mouth moist and lip balm can be used to moisten dry lips. When death is imminent, it is unkind to force foods or fluids. The only thing they need at this time is the love and comfort of family. To dying people, it doesn’t matter how much they eat or drink as long as they are comfortable and are cared for and loved.

For additional copies of *Nutrition Therapy in Hospice Care* contact:
Mayo Clinic Health System -
Home Health & Hospice
P.O. Box 2060
Eau Claire, WI 54702
800-236-8408

Or you may print directly from our website
mayoclinichealthsystem.org
Wisconsin/Eau Claire/Home Health & Hospice
Under Resources on the Hospice Services page

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# How are we doing?

# CAHPS Hospice Survey

## Sample Questions

For this survey, the <u>hospice team</u> includes all the nurses, doctors, social workers, chaplains and other people who provided hospice care to your family member. While your family member was in hospice care, did you need to contact the hospice team during evenings, weekends, or holidays for questions or help with your family member's care?

1. ☐ Yes
2. ☐ No

How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

1. ☐ Never
2. ☐ Sometimes
3. ☐ Usually
4. ☐ Always

While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?

1. ☐ Never
2. ☐ Sometimes
3. ☐ Usually
4. ☐ Always

While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?

1. ☐ Never
2. ☐ Sometimes
3. ☐ Usually
4. ☐ Always

How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?

1. ☐ Never
2. ☐ Sometimes
3. ☐ Usually
4. ☐ Always

Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?

1. ☐ Yes, definitely
2. ☐ Yes, somewhat
3. ☐ No

Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?

1. ☐ Too little
2. ☐ Right amount
3. ☐ Too much

While your family member was in hospice care, how much emotional support did you get from the hospice team?

1. ☐ Too little
2. ☐ Right amount
3. ☐ Too much

# CAHPS Hospice Survey
## Sample Questions

Para esta encuesta, el equipo del hospicio incluye a todos los doctores, enfermeras, trabajadores sociales, religiosos y demás personas que le proporcionaron cuidados paliativos a su familiar. Mientras su familiar estaba bajo los cuidados del hospicio, ¿tuvo usted que ponerse en contacto con el equipo del hospicio durante la noche, en fin de semana o en día festivo porque tenía alguna duda o necesitaba ayuda para el cuidado de su familiar?

1. ☐ Si
2. ☐ No

¿Con qué frecuencia obtuvo la ayuda que necesitaba del equipo del hospicio durante la noche, en fin de semana o en día festivo?

1. ☐ Nunca
2. ☐ A veces
3. ☐ La mayoría de las veces
4. ☐ Siempre

Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del hospicio lo mantenía a usted informado sobre el estado de su familiar?

1. ☐ Nunca
2. ☐ A veces
3. ☐ La mayoría de las veces
4. ☐ Siempre

Mientras su familiar estaba bajo los cuidados del hospicio, ¿con qué frecuencia el equipo del centro trataba a su familiar con dignidad y respeto?

1. ☐ Nunca
2. ☐ A veces
3. ☐ La mayoría de las veces
4. ☐ Siempre

¿Con qué frecuencia el equipo del hospicio lo escuchó con atención cuando usted les habló sobre problemas relacionados con los cuidados de su familiar?

1. ☐ Nunca
2. ☐ A veces
3. ☐ La mayoría de las veces
4. ☐ Siempre

¿Le dio el equipo del hospicio tanta información como usted quería sobre qué acontecimientos esperar mientras su familiar estuviera muriéndose?

1. ☐ Sí, definitivamente
2. ☐ Sí, más o menos
3. ☐ No

Apoyo respecto a sus creencias religiosas o espirituales incluye hablar, rezar, momentos de recogimiento, u otras maneras de satisfacer sus necesidades religiosas o espirituales. Mientras su familiar estaba bajo los cuidados de este hospicio, ¿cuánto apoyo recibió usted respecto a sus creencias religiosas y espirituales por parte del equipo del hospicio?

1. ☐ Demasiado poco
2. ☐ Justo el necesario
3. ☐ Demasiado

Mientras su familiar estaba bajo los cuidados de este hospicio, ¿cuánto apoyo emocional recibió usted del equipo del hospicio?

1. ☐ Demasiado poco
2. ☐ Justo el necesario
3. ☐ Demasiado