Generation CARE
PEOPLE. CARE. ALWAYS.

PATIENT & FAMILY RESOURCE

Hospice *Handbook*

A guide to your care, your rights, and the support available to you and your family, every step of the way.

24/7 SUPPORT
(805) 496-0044

EMAIL
info@generationcareinc.com

ONLINE
generationcareinc.com

Generation CARE
PEOPLE. CARE. ALWAYS.

I — WELCOME

Care that feels *personal.*

The Lighthouse Model of Care

A lighthouse is a structure with powerful light providing a beacon of navigation in the darkest moments. This structure symbolizes the care and support provided by Generation Care to every single patient in a difficult and dark time. With the entire Hospice interdisciplinary team working together to provide comfort care, the patient is guided through a difficult time with ease. At Generation Care we are committed to making every patient's experience as soothing as possible.

How Generation Care Is Different

Each patient at Generation Care is a family member. We are on call 24 hours a day, 7 days a week to ensure that our patients are always comfortable. With compassion and warmth, the team provides care management and symptom control according to the wishes of the patient and family. We work together to provide the necessary medical services as well as other additional comfort measures for a more meaningful experience.

> *"We meet complexity with calm, and uncertainty with experience."*

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EMAIL
info@generationcareinc.com

OFFICE
516 Pennsfield Pl., Suite 109
Thousand Oaks, CA 91360

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Keep this handbook somewhere easy to find. Your hospice team will review it with you, and you can call us any time, day or night, with questions.

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Questions at any hour? Call (805) 496-0044. A hospice nurse is available 24 hours a day, 7 days a week.

PART I

Your *Hospice Care*

What your hospice benefit includes, how our team supports you around the clock, and how care works when needs change.

01 Your Hospice Services

02 Hospital Care, Treatment & Benefit Periods

01 CHAPTER 01

Your Hospice Services

Pharmacy

All drugs related to the patient's certifying terminal diagnosis will be covered by the Medicare hospice benefit and will be delivered to the patient's home. Any pharmacist who dispenses any of the prescription drugs may select a drug product that is generically equivalent to the brand prescribed by the physician, unless a written request for a brand name product is made to Generation Care. The hospice provides prescription medication that pertains to the terminal illness. The terminal illness is the illness for which the patient was placed in the program. It will be the patient's responsibility to pay for any other medications.

Medical Equipment

The hospice will provide standard medical equipment needed for the patient's comfort, such as electric hospital bed, wheelchair, walker, and commode. Only equipment provided through contracted vendor companies may be used. The caregivers are responsible for proper care and use of equipment.

24/7 On-Call Service

The hospice offers services 24 hours a day, 7 days a week. All patients and families are encouraged to contact the hospice to report any changes in the patient's status. The on-call nurse will advise patients and caregivers about methods to manage the change that has occurred. The nurse may make a home visit if this is necessary. Generally, change in the patient's condition is expected and the nurse will explain why certain symptoms are occurring. It is easier to care for the patient when the caregiver understands what is happening and has learned measures to provide needed relief and comfort. Hospice staff can be reached from 8:30 am to 5:00 pm weekdays at (805) 496-0044. Routine questions are best handled during business hours.

Volunteers

Volunteers are an important part of the hospice team. They are available to provide companionship and support to patients and their families. They are available to provide friendly visits, assist with errands, read to patients, write letters, play games, or just be good listeners.

The hospice nurse will inform you that volunteers are part of the hospice team and will ask if you would like to have volunteer services provided. She will facilitate this, if you so desire.

02 — CHAPTER 02

Hospital Care, Treatment & Benefit Periods

Hospital Emergency Rooms

Please contact the hospice first whenever you feel the patient needs emergency assistance. Often their situations can be resolved fairly easily, and the hospice can continue to assist you to care for the patient at home. If the patient does need to be admitted for further medical assistance, the hospice will make an arrangement for admission to a contracted in-patient unit. Admissions are arranged by the hospice team when medically necessary 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 acute 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 except for respite care, which is five days in each benefit period. In circumstances other than respite care, a patient's length of stay is determined by symptoms and the medical management needed to alleviate the symptoms.

Aggressive Treatment

Aggressive treatment is any form of treatment, like chemotherapy or surgery that is done for the purpose of curing the disease. If the patient, once admitted to the hospice, chooses to receive any kind of aggressive treatment, he/she can no longer remain on the hospice program. At this time, either the hospice may discharge the patient, or the patient may revoke the hospice benefits. The patient should be aware that should they decide to discontinue this treatment or should they complete the treatment, they might 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 and requesting discharge and benefit revocation. The patient and caregiver should know that as soon as a patient does revoke the hospice benefit, he/she gives up the remainder of that benefit period. Should the patient ever come back on a hospice program, he/she will enter the program in the next benefit period. These periods are as follows:

- **First benefit period:** 90 days
- **Second benefit period:** 90 days
- Unlimited 60-day benefit periods thereafter. At the end of each benefit period, the patient must be medically certified as appropriate for the hospice program.

A patient may transfer to another hospice program once during each benefit period. If the patient/family chooses to admit the patient to a hospital, the hospice Medicare benefit must be revoked, as the hospice would no longer be coordinating the patient's care.

Payment for Services Not in the Hospice Plan of Care

The hospice is not required to pay for services that are outside the hospice plan of care or for services that have not received the prior approval of the hospice interdisciplinary team. A patient may utilize outside services, but the patient will be financially responsible for these services even if they are related to the terminal illness. The hospice or the Medicare hospice benefit will not cover the expenses.

WE'RE HERE FOR YOU

Have a question about *any of this?*

Your hospice team is available 24 hours a day, 7 days a week. No question is too small, and you never have to wait until morning.

(805) 496-0044

PART II

Your Rights *& Protections*

Your rights as a patient, what you will and will not pay, advance directives, privacy, and how to raise a concern.

03 Patient Rights & Responsibilities

04 Notice of Patient Financial Responsibility

05 Advance Directives

06 Complaint & Grievance Process

07 Confidentiality of Information

08 Patient Privacy Rights

09 Notice of Privacy Practices

03 — CHAPTER 03

Patient Rights & Responsibilities

As a home care patient, you have the right to be informed of your rights and responsibilities before the initiation of care/service. If/when a patient has been judged incompetent, the patient's family or guardian may exercise these rights as described below. As they relate to:

Patient Rights

You have the right:

01 To receive services appropriate to your needs and expect the home care organization to provide safe, professional care at the level of intensity needed, without unlawful restriction by reason of age, sex, race, creed, color, national origin, religion, or disability.

02 To have access to necessary professional services 24 hours a day, 7 days a week.

03 To have your pain management needs recognized and addressed as appropriate.

04 To be informed of services available.

05 To be informed of the ownership and control of the organization.

06 To be told on request if the organization's liability insurance will cover injuries to employees when they are in your home, and if it will cover theft or property damage that occurs while you are being treated.

Patient Care

You have the right:

01 To be involved in your care planning, including education of the same, from admission to discharge, and to be informed in a reasonable time of anticipated termination and/or transfer of service.

02 To receive reasonable continuity of care.

03 To be informed of your rights and responsibilities in advance concerning care and treatment you will receive, including any changes, the frequency of care/service, and by whom (disciplines) services will be provided.

04 To be informed of the nature and purpose of any technical procedure that will be performed, including information about the potential benefits and burdens as well as who will perform the procedure.

05 To receive care/service from staff that are qualified through education and/or experience to carry out the duties for which they are assigned.

06 To be referred to other agencies and/or organizations when appropriate and be informed of any financial benefit to the referring agency.

Respect and Confidentiality

You have the right:

01 To be treated with consideration, respect, and dignity, including the provision of privacy during care.

02 To have your property treated with respect.

03 To have staff communicate in a language or form you can reasonably be expected to understand and when possible, the organization assists with or may provide special devices, interpreters, or other aids to facilitate communication.

04 To maintain confidentiality of your clinical records in accordance with legal requirements and to anticipate the organization will release information only with your authorization or as required by law.

05 To be informed of the organization's policies and procedures for disclosure of your clinical record.

Financial Aspects of Care

You have the right:

01 To be informed of the extent to which payment for the home care services may be expected from Medicare, Medicaid, or any other payer.

02 To be informed of charges not covered by Medicare and/or responsibility for any payment(s) that you may have to make.

03 To receive this information orally and in writing before care is initiated and within 30 calendar days of the date the organization becomes aware of any changes.

Self-Determination

You have the right:

01 To refuse all or part of your care/treatment to the extent permitted by law and to be informed of the expected consequences of said action.

02 To be informed in writing of rights under state law to formulate advance directives.

03 To have the organization comply with advance directives as permitted by state law and state requirements.

04 To be informed of the organization's policies and procedures for implementing advance directives.

05 To receive care whether or not you have one or more advance directives in place, as well as not to be discriminated against whether or not you have executed any advance directives.

06 To be informed regarding the organization's policies for withholding of resuscitative services and the withdrawal of life-sustaining treatment, as appropriate.

07 To not participate in research or not receive experimental treatment unless you give documented voluntary informed consent.

08 To be informed of what to do in an emergency.

09 To participate in consideration of ethical issues that may arise in your care.

Complaints

You have the right:

01 To voice concerns about patient care or safety to the organization's management.

02 To voice complaints about care or treatment, or lack of respect for property without reprisal or discrimination, and to be informed of the procedure for voicing complaints.

03 Complaints or questions may be registered with Amy Belilove by phone, in person, or in writing. The address and phone number are 516 Pennsfield Pl. #109 Thousand Oaks CA 91360 and (805) 496-0044.

04 The organization will investigate the complaint and resolution of same.

05 To be informed of the toll-free state hotline. The Department of Health also has a state hotline for complaints or questions about local home care agencies as well as for consumers to voice concerns regarding advance directives. The state hotline number is (800) 228-1019.

Patient Responsibilities

As a home care patient, you have the responsibility:

01 To provide complete and accurate information about illness, hospitalizations, medications, pain, and other matters pertinent to your health; any changes in address, phone, or insurance/payment information; and changes made to advance directives.

02 To inform the organization when you will not be able to keep your home care appointment.

03 To treat the staff with respect and consideration.

04 To participate in and follow your plan of care.

05 To provide a safe environment for care to be given.

06 To cooperate with staff and ask questions if you do not understand instructions or information given to you.

07 To assist the organization with billing and/or payment issues to help with processing third party payments.

08 To inform the organization of any problems (including issues with following the plan of care), dissatisfaction with services, or recommendations for improvement.

04 — CHAPTER 04

Notice of Patient Financial Responsibility

You have the right to know, before care begins, exactly what you will and will not be asked to pay. This notice states your out-of-pocket responsibility for every hospice service we provide. Please keep it with your admission papers.

Your Cost for Hospice Services at a Glance

If you are a Medicare or Medi-Cal beneficiary, your cost for the hospice services below is:

SERVICE	YOUR COST	WHAT THIS COVERS
Routine home care	$0	Nursing, aide, social work, chaplain, physician, volunteer, and therapy visits under your plan of care
Continuous home care	$0	Extended nursing care in your home during a medical crisis
General inpatient care	$0	Short-term inpatient stays for symptoms that cannot be managed at home
Inpatient respite care	$0	Up to 5 days of inpatient care so your caregiver can rest. Medicare permits a 5% coinsurance; Generation Care, Inc. does not charge it.
Medications for pain and symptom management	$0	Per prescription, when related to your terminal illness. Medicare permits a copayment of up to $5 per prescription; Generation Care, Inc. does not charge it.
Medical equipment and supplies	$0	Hospital bed, oxygen, wheelchair, wound care, and other items in your plan of care
Bereavement support	$0	Grief support for your family, up to 13 months after death

In plain terms: Your out-of-pocket cost for the hospice services in your plan of care is zero dollars ($0).

Costs That Are Not Part of the Hospice Benefit

- **Room and board**: If you live in a nursing home, assisted living, or board-and-care facility, your hospice benefit does not pay your rent or facility fees. You (or Medi-Cal, if you qualify) remain responsible for room and board.

- **Unrelated conditions**: Care for conditions our medical director determines are unrelated to your terminal illness is not covered by hospice, but it remains covered by your regular Medicare, Medi-Cal, or other insurance, subject to that coverage's usual deductibles and copayments.
- **Services we did not pre-approve**: Emergency room visits, hospital admissions, chemotherapy or radiation, outpatient services, and physician services from doctors other than your attending physician or our Medical Director must be pre-approved by us. If you obtain these without our pre-approval and they relate to your terminal illness, you may be responsible for the provider's charges. Call us first, any time, day or night: (805) 496-0044.
- **Curative treatment**: If you choose treatment intended to cure your terminal illness, it is not covered while you are on hospice. You may revoke hospice at any time to return to your regular Medicare coverage.

Our Contracted Providers: No Cost to You

We contract with the following providers for covered items. When we arrange your medications and equipment through them, you pay nothing:

- American Care Pharmacy: (747) 788-7887
- Select Pharmacy: (310) 341-3455
- Montgomery DME: (562) 777-7088

If you obtain items from a pharmacy or supplier that is not contracted with us and not arranged by us, you may be responsible for those charges.

Your Right to a Written, Personalized List

At any time, you may request in writing the "Patient Notification of Hospice Non-Covered Items, Services, and Drugs," a personalized list of anything we have determined is unrelated to your terminal illness and not covered by us, with a plain-language explanation. If you request it at the start of care, we will provide it within 5 days; if you request it during care, within 72 hours.

If You Have Private Insurance

Private plans vary. Before admission, we will verify your benefits and give you a written statement of any deductible, copayment, or coinsurance your plan requires. If your plan requires no cost-sharing, your statement will say $0. You will never be denied hospice care based on ability to pay.

Questions About Coverage or a Bill

If you receive any bill you did not expect, from us or anyone else, call us before paying it: (805) 496-0044, available 24/7.

- BFCC-QIO Immediate Advocacy (Medicare), Livanta: 1-877-588-1123 / TTY 1-855-887-6668
- DHCS Managed Care Ombudsman (Medi-Cal): 1-888-452-8609 / MMCDOmbudsman@dhcs.ca.gov
- California Department of Public Health 24-hour hotline: 1-800-228-1019
- The Joint Commission: 1-800-994-6610 / complaint@jointcommission.org

05 — CHAPTER 05

POLICY NO. 1-004.1

Advance Directives

PURPOSE

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

POLICY

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

DEFINITIONS

01 **Adult:** A person 18 years or older, or a person legally capable of consenting to his/her own medical treatment.

02 **Advance Directives:** A document in which a person states choices for medical treatment.

03 **Attending Physician:** The physician who is primarily responsible for the medical care of a patient receiving hospice care services.

04 **DNR (Do Not Resuscitate):** A medical order to refrain from cardiopulmonary resuscitation if the patient's heart stops beating.

05 **Patient Representative:** A person appointed to make decisions for someone else. He/she may be formally appointed (as in a Durable Power of Attorney for health care) or, in the absence of a formal appointment, may be recognized by virtue of a relationship with the patient (such as the patient's next of kin).

06 **Patient Self-Determination Act:** A federal statute enacted as part of the 1990 Omnibus Budget Reconciliation Act (OBRA) (PL 101-508) which requires, among other things, that health care facilities provide information regarding the right to formulate Advance Directives concerning health care decisions.

07 **Terminal Condition:** An incurable condition caused by an injury, disease, or illness, which, regardless of the application of life-sustaining procedures, would within reasonable medical judgment produce death, and where the application of life-sustaining procedures only postpones the moment of death of the patient.

08 **POLST:** Physician Orders for Life Sustaining Treatment is an order that helps give seriously ill patients more control over their end-of-life care. It does not replace an Advance Directive. There are a number of states which have established a POLST program.

PROCEDURE

01 Upon admission, the clinician will provide information regarding a patient's rights to make decisions concerning healthcare, which include the right to accept or refuse medical or surgical treatment, even if the treatment is life-sustaining. Written information designed for this purpose will be provided to the adult patient. The clinician will document in the clinical record that the information was provided and record all discussions concerning Advance Directives.

02 If the patient lacks decision-making capacity, the admitting clinician will provide information and direct inquiry about Advance Directives to the patient's representative. The clinician will document that the patient representative received information, and his/her name and responses will be noted in the clinical record.

03 If conditions are such that it is not practical to provide information to the patient and/or his/her representative at the time of admission, such information will be provided as soon as feasible after admission.

04 During the admission/evaluation visit, the admitting clinician will ask the patient whether or not he/she has completed an Advance Directive, Durable Power of Attorney (DPOA), living will, or DNR order. If an Advance Directive has been completed, the admitting clinician will ask for a copy of the Advance Directive so it may be placed in the clinical record. If a copy is not immediately available, the patient will be informed that it is his/her responsibility to provide a copy of the Advance Directive to the hospice personnel as soon as possible.

- A Verify that the photocopy is an exact copy of the original and mark the top of the copy ("Copy From Original"). Document in the clinical record the date of the request and to whom the request was given.
- B On the last page of the document, indicate "Provided By" and record the name of the person who is presenting the document to you. Document in the clinical record the date of the request and to whom the request was given.
- C Indicate "Received By" and sign and date the document. Document in the clinical record the date of the request and to whom the request was given.

05 If a copy of the patient's Advance Directive is not available to the organization, the clinician will discuss the contents of the Advance Directive with the patient and/or patient representative, document the contents of the Advance Directive in the clinical record and communicate the contents to other hospice care providers.

06 The admitting clinician will document on the clinical record and will notify the attending physician verbally and on a physician's (or other authorized licensed independent practitioner's) order if the patient has executed an Advance Directive.

07 The patient will be encouraged to participate in all aspects of decision-making regarding hospice care and treatment. Statements by a competent patient regarding his/her desire to accept or refuse treatment will be documented in the patient's clinical record.

08 The patient will be informed of any limitations Generation Care, Inc. has in respecting the patient's Advance Directive.

09 All clinicians providing care for the patient will:

- A Review the Advance Directive and report any discrepancies between the Directive and current treatment plan to the attending physician, Clinical Supervisor, and the patient.
- B Utilize available educational materials to answer the patient's questions about Advance Directives, Durable Power of Attorney or living wills.
- C Encourage the patient to discuss questions and concerns with appropriate individuals such as the physician, family/caregiver and his/her selected advocate.
- D Assist the patient who wants to develop an Advance Directive by obtaining a form and by accommodating the outside individuals necessary to execute the directive.

10 An Advance Directive will be implemented as follows:

- A The Durable Power of Attorney for an Advance Directive is effective only when the patient is unable to participate in his/her own medical treatment decisions.
- B The attending physician and another physician or licensed psychologist must document in the patient's clinical record that the patient is unable to participate in medical treatment decisions.
- C The patient's designated advocate can then make medical treatment choices based on the Advance Directive. The patient advocate may make a decision to withhold or withdraw treatment that allows the patient to die. This is done only if the patient expressed, in a clear and convincing manner, that the advocate is authorized to make such a decision, and acknowledges that such a decision would or could allow the patient's death.
- D Executing and implementing an Advance Directive is a process, not a one-time event. On an ongoing basis, the clinical staff will keep the patient, family/caregiver, and patient's representative up to date concerning the patient's medical condition. They will discuss the patient's preferred course of treatment as his/her condition changes. The discussions will be documented in the clinical record.

11 Educational information about Advance Directives and Generation Care, Inc.'s policies and procedures regarding Advance Directives will be provided to the medical, nursing, allied health professionals, and hospice non-clinical personnel and volunteers during the orientation period.

12 In order to educate the community about Advance Directives, Generation Care, Inc. will participate in community forums, as appropriate, and make available written materials regarding Advance Directives.

13 The organization will utilize POLST specific forms and guidelines.

06 — CHAPTER 06

POLICY NO. 1-010.1 – 1-010.2

Complaint & Grievance Process

PURPOSE

To set forth guidelines for the resolution of patient concerns, dissatisfaction, or complaints and to protect patient and family rights.

POLICY

Patients can freely voice complaints and recommend changes without being subject to coercion, discrimination, reprisal, or unreasonable interruption of care, treatment, and services.

Any difference of opinion, dispute, or controversy between a patient or family/caregiver or patient representative and Generation Care, Inc. concerning any aspect of services or the application of policies or procedures will be considered a grievance.

The Executive Director/Administrator will be informed of situations that may become detrimental to good patient relations, and will be committed to maintaining a consistently high level of patient relations. This grievance procedure will be included in the Patient Bill of Rights document given to each patient upon admission.

PROCEDURE

01 The organization personnel receiving the complaint will discuss, verbally and in writing, the grievance with the Clinical Supervisor within five (5) days of the alleged grievance. The Clinical Supervisor will investigate the grievance within five (5) days after receipt of such grievance and will make every effort to resolve the grievance to the patient's satisfaction. Response to the patient regarding the complaint will occur within ten (10) days of receipt.

02 If the grievance cannot be resolved to the patient's satisfaction, the patient or his/her representative is to notify, verbally or in writing, the Executive Director/Administrator. The grievance must state the problem or action alleged and the date the Clinical Supervisor was notified. The Executive Director/Administrator or designee will then investigate the grievance and contact the patient or his/her representative regarding the grievance in an attempt to resolve the differences. The Executive Director/Administrator will respond to the patient within ten (10) days of notification of failure to resolve the complaint.

03 If the patient feels his/her grievance has not been resolved after working with Generation Care, Inc. personnel, he/she will be informed of his/her right to notify the state via the respective toll-free telephone numbers, or other methods such as ombudsman, legal services, or adult protective services. The written admission guidelines, provided to the patient upon admission, list sources of assistance for complaint resolution.

04 Complaints and any action taken will be documented on a complaint form.

05 Corrective action will be specific and related to the complaint.

06 Resolution information will be communicated in writing to the patient or his/her representative filing the complaint.

07 Risk management personnel will be notified of any complaints that may involve litigation by the clinician involved completing an organization incident report or unusual occurrence form and forwarding a copy to the Risk Management Department.

08 Complaints received on patient satisfaction surveys (mail) will be documented on a complaint form and addressed as outlined above.

09 All complaints from patients who believe their privacy rights have been violated will be forwarded for review to the designated organization personnel or office specified in the organization's Notice of Privacy Practices.

10 All complaints will be logged, tracked, trended, and filed in the performance improvement office.

11 The Performance Improvement Coordinator will prepare a quarterly report summarizing all complaints received that quarter.

12 Reports may include:

- A Number of complaints received
- B Types of complaints received
- C Action and resolution of complaints

13 The Performance Improvement Committee will review patient grievance trends on a quarterly basis. Identified trends will be followed through the established performance improvement process.

14 All organization personnel (clinical and non-clinical) will be informed of this process during a formal orientation process.

07 — CHAPTER 07

POLICY NO. 1015.1 – 1015.2

Confidentiality of Information

PURPOSE

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

POLICY

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

PROCEDURE

01 On the first day during the orientation process, this Confidentiality Policy will be reviewed by hospice personnel.

02 All hospice personnel will be required to sign a Confidentiality Agreement at the time of hire.

03 Hospice personnel will have access to the minimum necessary protected health information of patients needed to carry out their duties.

04 Use and disclosure of protected health information will be carried out according to accepted policies and procedures. (See "Uses and Disclosures of PHI" Policy No 5-017.)

05 Patients will not be discussed by clinical or nonclinical personnel outside of the context of professional conversation regarding those patients' conditions and care.

06 Comments and conversations relating to patients made by physicians, nurses, or other hospice personnel will be made in confidential settings. It will be standard, acceptable, and necessary practice to share information with other members of the care team. The decision to share information can be aided by considering the intent of the discussion.

07 An agreement and consent for services form will be signed by the patient upon admission.

08 Valid authorizations for use and disclosure of information will be obtained, as required. (See "Authorizations for Use or Disclosure of PHI" Policy No. 5-018.)

09 Copies of clinical records, or excerpts of same, cannot be removed from the Hospice except by subpoena, where statutory law requires it, or on written authorization of the Hospice. This confidential information will only be mailed in an envelope designated "confidential."

10 Patients will be allowed access to their protected health information. (See "Patient Requests for Access to PHI" Policy No 5-022.)

11 The organization respects the safety and security of patients and their property.

12 All clinical records will be kept in a locked cabinet/room when not being utilized. The Clinical Supervisor or designee will be responsible for the key. No unauthorized individual will be allowed access to clinical records.

13 The following patient information will be secured after business hours:

- A Clinical records
- B Field clinical records
- C Patient intake information
- D Minutes of patient care meetings
- E Performance improvement data
- F Clinical notes prior to filing in clinical record
- G Signed physician (or other authorized licensed independent practitioner) orders

14 Information contained in performance improvement reports will not contain individual patient or personnel information.

15 Generation Care, Inc. will apply appropriate sanctions against any Hospice personnel who fail to comply with its privacy policies and procedures.

08 — CHAPTER 08

POLICY NO. 1016.1 – 1016.2

Patient Privacy Rights

PURPOSE

To encourage awareness of patient privacy rights, Generation Care, Inc.'s legal duties with respect to these rights, and the use and disclosure of protected health information (PHI).

POLICY

Generation Care, Inc. will respect and safeguard all protected health information about the patients it serves.

Each patient will be provided with information about his/her privacy rights at the time of admission to Generation Care, Inc.

To assist with fully understanding patient privacy rights and responsibilities, all policies will be available to organization personnel, patients, and their representatives, as well as to other organizations and the interested public.

PROCEDURE

01 The patient will be provided with information about his/her privacy rights in the organization's Notice of Privacy Practices, which will be given to the patient during the admission visit. The patient's privacy rights include:

- A A right to adequate notice of the uses and disclosures of protected health information that may be made by Generation Care, Inc. (See "Notice of Privacy Practices" Addendum 1-016.A.)
- B A right to request privacy protection for protected health information. (See "Patient Requests for Privacy Restrictions" Policy No. 1-018 and "Patient Requests for Confidential Communications" Policy No. 1-019.)
- C A right of access to inspect and retain a copy of his/her protected health information. (See "Patient Requests for Access to PHI" Policy No. 5-022.)
- D A right to request that the organization amend protected health information or a record about the individual in a designated record set for as long as the protected health information is maintained in the designated record set. (See "Patient Requests to Amend PHI" Policy No. 5-023.)
- E A right to receive an accounting of disclosures of protected health information made by Generation Care, Inc. in the six years prior to the date on which the accounting is requested. (See "Patient Requests for Accounting of PHI Disclosures" Policy No. 5-024.)

02 Generation Care, Inc. will make a good faith effort to obtain the patient's written acknowledgement of receipt of this notice. A separate signature/initials line for this acknowledgement may be located on the consent form. If an acknowledgement cannot be obtained, the admitting clinician will document his/her efforts to obtain the acknowledgement and the reason why it was not obtained in the clinical note.

03 The notice will be promptly revised and distributed whenever there is a material change to the uses or disclosures, the individual's rights, organization's legal duties, or other privacy practices stated in the notice. A material change to any term of the notice will not be implemented prior to the effective date of the revised notice, unless required by law.

04 Generation Care, Inc. will prominently post the notice and make the notice available through its website.

05 The patient's legal representative may exercise the patient's rights when a patient is incompetent or a minor.

06 When a patient has questions about his/her privacy rights, requests additional information, or would like to exercise one of these rights, he/she will be referred to the appropriate individual or office designated by Generation Care, Inc. on the Notice of Privacy Practices.

09 — CHAPTER 09

Notice of Privacy Practices

> **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.**

Use and Disclosure of Health Information

Generation Care, Inc. may use your health information, information that constitutes protected health information as defined in the Privacy Rule of the Administrative Simplification provisions of the Health Insurance Portability and Accountability Act of 1996, for purposes of providing you treatment, obtaining payment for your care, and conducting health care operations. The Hospice has established policies to guard against unnecessary disclosure of your health information.

TO PROVIDE TREATMENT

The Hospice may use information to coordinate care with others involved in your care, such as your attending physician and other health care professionals who have agreed to assist the Hospice in coordinating care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. The Hospice also may disclose your health information to individuals outside of the Hospice involved in your care including pharmacists, suppliers of medical equipment, or other health professionals.

TO OBTAIN PAYMENT

The Hospice may include your health information in invoices to collect payment from third parties for the care you receive from the Hospice. For example, the Hospice may be required by your health insurer to provide information regarding your health care status so the insurer will reimburse you or the Hospice. The Hospice also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for private duty care and the services that will be provided to you.

TO CONDUCT HEALTH CARE OPERATIONS

The Hospice may use and disclose health information for its own operations in order to facilitate the function of the Agency and as necessary to provide quality care to all of the Hospice's patients. Health care operations include such activities as:

- Quality assessment and improvement activities
- Activities designed to improve health or reduce health care costs
- Protocol development, case management, and care coordination

- Contacting health care providers and clients with information about treatment alternatives and other related functions that do not include treatment
- Professional review and performance evaluation
- Training programs including those in which students, trainees, or practitioners in health care learn under supervision
- Training of non-health care professionals
- Accreditation, certification, licensing or credentialing activities
- Review and auditing, including compliance reviews, medical reviews, legal services, and compliance programs
- Business planning and development including cost management and planning related analysis and formulary development
- Business management and general administrative activities of the Hospice
- Fundraising for the benefit of the Hospice

For example, the Hospice may use your health information to evaluate its staff performance, combine your health information with other Hospice patients in evaluating how to more effectively serve all Hospice patients, disclose your health information to Hospice staff and contracted personnel for training purposes, use your health information to contact you for visit reminders, or contact you as a part of a general fundraising and community information mailing (unless you tell us you do not want to be contacted.)

FOR FUNDRAISING ACTIVITIES

The Hospice may use information about you including your name, address, phone number, and the dates you received care in order to contact you to raise money for the Hospice. The Hospice may also release this information to a related Hospice foundation. If you do not want the Agency to contact you, notify our office at (805) 496-0044.

FOR APPOINTMENT REMINDERS

The Hospice may use and disclose your health information to contact you as a reminder that you have an appointment for a home visit.

FOR TREATMENT ALTERNATIVES

The Hospice may use and disclose your health information to tell you about or recommend possible treatment options or alternatives that may be of interest to you.

> **The following is a summary of the circumstances under which and purposes for which your health information may also be used and disclosed.**

WHEN LEGALLY REQUIRED

The Hospice will disclose your health information when it is required by any federal, state or local law.

WHEN THERE ARE RISKS TO PUBLIC HEALTH

The Hospice may disclose your health information for public activities and purposes in order to:

- Prevent or control disease, injury, or disability; report disease, injury, vital events such as birth or death, and the conduct of public health surveillance, investigations, and interventions.
- Report adverse events or product defects, track products or enable product recalls, repairs, and replacements, and conduct postmarketing surveillance and compliance with requirements of the FDA.
- Notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.
- Notify an employer about an individual who is a member of the workforce as legally required.

TO REPORT ABUSE, NEGLECT, OR DOMESTIC VIOLENCE

The Hospice is allowed to notify government authorities if the Hospice believes a client is the victim of abuse, neglect, or domestic violence. The Hospice will make this disclosure only when specifically required or authorized by law or when the client agrees to the disclosure.

TO CONDUCT HEALTH OVERSIGHT ACTIVITIES

The Hospice may disclose your health information to a health oversight agency for activities including audits, civil administration, or criminal investigations, inspections, licensure, or disciplinary action. The Hospice, however, may not disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits.

IN CONNECTION WITH JUDICIAL AND ADMINISTRATIVE PROCEEDINGS

The Hospice may disclose your health information in the course of any judicial or administrative proceeding in response to an order of the court or administrative tribunal as expressly authorized by such order or in response to a subpoena, discovery request, or other lawful process, but only when the Hospice makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

FOR LAW ENFORCEMENT PURPOSES

As permitted or required by State law, the Hospice may disclose your health information to a law enforcement official for certain law enforcement purposes as follows:

- As required by law for reporting of certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena, or summons or similar process.
- For the purpose of identifying or locating a suspect, fugitive, material witness, or missing person.
- Under certain limited circumstances, when you are the victim of a crime.

- To a law enforcement official if the Hospice has a suspicion that your death was the result of criminal conduct including criminal conduct at the Hospice Agency.
- In an emergency in order to report a crime.

TO CORONERS AND MEDICAL EXAMINERS

The Hospice may disclose information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

TO FUNERAL DIRECTORS

The Hospice may disclose your health information to funeral directors consistent with applicable law and if necessary, to carry out their duties, with respect to your funeral arrangements. If necessary to carry out their duties, the Hospice Agency may disclose your health information prior to and in reasonable anticipation of your death.

FOR ORGAN, EYE, OR TISSUE DONATION

The Hospice may use or disclose your health information to organ procurement organizations or other entities engaged in the procurement, banking, or transplantation of organs, eyes, or tissue for the purpose of facilitating the donation and transplantation.

FOR RESEARCH PURPOSES

The Hospice may, under very select circumstances, use your health information for research. Before the Hospice discloses any of your health information for such research purposes, the project will be subject to an extensive approval process.

IN THE EVENT OF A SERIOUS THREAT TO HEALTH OR SAFETY

The Hospice may, consistent with applicable law and ethical standards of conduct, disclose your health information if the Hospice, in good faith, believes that such disclosure is necessary to prevent or lessen a serious and imminent threat to your health or safety or to the health and safety of the public.

FOR SPECIFIED GOVERNMENT FUNCTIONS

In certain circumstances, the federal regulations may authorize the Hospice Agency to use or disclose your health information to facilitate specified government functions relating to military and veterans, national security and intelligence activities, protective services for the president and others medical suitability determinations, and inmates and law enforcement custody.

FOR WORKER'S COMPENSATION

The Hospice may release your health information for worker's compensation or similar programs.

Authorization to Use or Disclose Health Information

Other than is stated above, the Hospice will not disclose your health information other than with your written authorization. If you or your representative authorizes the Hospice to use or disclose your health information, you may revoke that authorization in writing at any time.

Your Rights with Respect to Your Health Information

You have the following rights regarding your health information that the Hospice maintains:

RIGHT TO REQUEST RESTRICTIONS

You may request restrictions on certain uses and disclosures of your health information. You have the right to request a limit on the Hospice's disclosure of your health information to someone who is involved in your care or the payment of your care. However, the Hospice is not required to agree to your request. If you wish to make a request for restrictions, please contact the Privacy Official.

RIGHT TO RECEIVE CONFIDENTIAL COMMUNICATIONS

You have the right to request that the Hospice communicate with you in a certain way. For example, you may ask that the Hospice only conduct communications pertaining to your health information with you privately, with no other family members present. If you wish to receive confidential communications, please contact the Privacy Official. The Hospice will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.

RIGHT TO INSPECT AND COPY YOUR HEALTH INFORMATION

You have the right to inspect and copy your health information, including billing records. A request to inspect and copy records containing your health information may be made to the Privacy Official at (805) 496-0044. If you request a copy of your health information, the Hospice may charge a reasonable fee for copying and assembling costs associated with your request.

RIGHT TO AMEND HEALTH CARE INFORMATION

You or your representative have the right to request that the Hospice amend your records, if you believe that your health information is incorrect or incomplete. That request may be made as long as the information is maintained by the Hospice. A request for an amendment of records must be made in writing to the Privacy Official. The Hospice may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by the Hospice, if the records you are requesting are not part of the Hospice's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of the Hospice, the records containing your health information are accurate and complete.

RIGHT TO AN ACCOUNTING

You or your representative have the right to request an accounting of disclosures of your health information made by the Hospice for certain reasons, including reasons related to public purposes authorized by law and certain research. The request for an accounting must be made in writing to the Privacy Official at 516 Pennsfield Pl. #109 Thousand Oaks CA 91360. The request should specify the time period for the accounting starting on or after 12/11/2011. Accounting requests may not be made for periods of time in excess of six (6) years. The Hospice would provide the first accounting you request during any 12 month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

RIGHT TO A PAPER COPY OF THIS NOTICE

You or your representative have a right to a separate paper copy of this notice at any time, even if you or your representative have received this notice previously. To obtain a separate paper copy, please contact the Privacy Official at (805) 496-0044.

Duties of the Hospice

The Hospice is required by law to maintain the privacy of your health information and to provide you and your representative this notice of its duties and privacy practices. The Hospice is required to abide by the terms of this notice as may be amended from time to time. The Hospice reserves the right to change the terms of its notice and to make the new notice provisions effective for all health information that it maintains. If the Hospice changes its notice, the Hospice will provide a copy of the revised notice to you or your appointed representative. You or your personal representative has the right to express complaints to the Hospice and to the Secretary of DHHS if you or your representative believe that your privacy rights have been violated. Any complaints to the Hospice should be made in writing to the Privacy Official at 516 Pennsfield Pl. #109 Thousand Oaks CA 91360. The Hospice encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

Contact Person

The Hospice has designated the Privacy Official as its contact person for all issues regarding client privacy and your rights under the federal privacy standards. You may contact this person at (805) 496-0044.

III

PART III

Your *Medications*

How to give medications safely, how controlled substances are handled at home, and how to dispose of unused medicines.

10 Medication Management

11 Home Use & Disposal of Controlled Substances

12 Disposal of Unused Medicines

10 CHAPTER 10

Medication Management

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 any allergies you have to either medicines or food.
- About all medications you are presently taking including non-prescription (over the counter) medicines, herbs, and home remedies you are taking (this includes any eye drops, vitamins, creams, ointments, and laxatives).

THINGS YOU SHOULD KNOW BEFORE ADMINISTERING MEDICATIONS

Medicines play an important role in treating many conditions and diseases. It is important that we teach you how to safely administer these medications. During the initial visit and at every subsequent visit the nurses will discuss your medications with you. It is important for you to be able to:

01 State the rationale for administering each medication as ordered.

02 State times and frequency of when medications should be administered.

03 State two side effects of each medication that is administered, as well as to follow up with MD or RN if these side effects occur.

04 Demonstrate safe administration of medications, including having patient in upright position, adequate liquid to swallow, administer medications slowly without rushing the patient.

05 Determine when the patient needs more medications and proper procedure to take to order the medications prescribed.

06 Demonstrate ability to pre-pour medications correctly, specific to frequency and dosage ordered.

07 Store or destroy discontinued narcotic medications.

11 — CHAPTER 11

POLICY NO. 3-005.1

Home Use & Disposal of Controlled Substances

PURPOSE

To ensure the appropriate use and disposal of controlled substances, in accordance with applicable state and federal regulations.

POLICY

Generation Care, Inc. voluntarily adheres to a controlled drug reporting process.

PROCEDURE

01 Controlled substances will be distributed directly to the patient or his/her representative. (See "List of Controlled Substances Available" Addendum 3 005.A.) The interdisciplinary group will be responsible for monitoring the amount of drug issued and the length of time between renewals.

02 The Case Manager will provide a copy of the written policies and procedures on the management and disposal of controlled drugs to the patient/representative and family. The Case Manager will verbally discuss this policy in a language and manner that they understand to ensure the safe use and disposal of controlled drugs.

03 The Case Manager will outline an informal documentation procedure for the patient and family/caregiver when hospice personnel are not present in the home.

04 In cases where hospice personnel are in the home 24 hours a day, a drug count will be made by licensed personnel at the time of shift change.

05 Controlled drugs will be accounted for on a narcotic count record, which will be maintained as a part of the clinical record.

06 When a hospice patient no longer has a need for a controlled substance, the Case Manager will instruct the patient and family/caregiver regarding proper disposal of the drugs in accordance with federal, state, and local law/regulation.

07 The Case Manager will document in the clinical record that the patient and family/caregiver were given the written policy and procedure for managing controlled drugs and discussed the disposal or medications and they took responsibility to do so.

08 The hospice nurse, social worker, or chaplain attending the death of a hospice patient will inform the family/caregivers of their responsibility to dispose of all the patient's prescribed medications and will document this instruction in a clinical note.

09 Hospice personnel will not dispose of any patient medications.

12 CHAPTER 12

Disposal of Unused Medicines

OVERVIEW

Medicines play an important role in treating many conditions and diseases, but when they are no longer needed it's important to dispose of them properly to avoid harm to others. Below, we list some disposal options and some special disposal instructions for you to consider when throwing out expired, unwanted, or unused medicines.

MEDICINE TAKE-BACK PROGRAMS

Medicine take-back programs for disposal are a good way to remove expired, unwanted, or unused medicines from the home and reduce the chance that others may accidentally take the medicine. Contact your city or county government's household trash and recycling service to see if there is a medicine take-back program in your community and learn about any special rules regarding which medicines can be taken back. You can also talk to your pharmacist to see if he or she knows of other medicine disposal programs in your area.

DISPOSAL IN HOUSEHOLD TRASH

If no medicine take-back program is available in your area, consumers can also follow these simple steps to dispose of most medicines in the household trash:

- Mix medicines (do **not** crush tablets or capsules) with an unpalatable substance such as kitty litter or used coffee grounds;
- Place the mixture in a container such as a sealed plastic bag; and
- Throw the container in your household trash.

FLUSHING OF CERTAIN MEDICINES

There is a small number of medicines that may be especially harmful and, in some cases, fatal in a single dose if they are used by someone other than the person the medicine was prescribed for. For this reason, a few medicines have specific disposal instructions that indicate they should be flushed down the sink or toilet when they are no longer needed and when they cannot be disposed of through a drug take-back program. When you dispose of these medicines in the sink or toilet, they cannot be accidentally used by children, pets, or anyone else.

You may have also received disposal directions for these medicines when you picked up your prescription. If your medicine **is** on this list, and you did not receive information containing disposal instructions along with your dispensed prescription, you can find instructions on how to dispose of the medicines at Daily Med by searching by drug name, and then looking in one of the following sections of the prescribing information:

- Information for patient and caregivers
- Patient information
- Patient counseling information
- Safety and handling instructions
- Medication guide The FDA remains committed to working with other federal agencies and medicine manufacturers to develop alternative, safe disposal policies. Below is some additional information about flushing medicine that is no longer needed. If you have additional questions about disposing of your medicine, please contact the FDA at 1-888-INFO-FDA (1-888-463-6332).

Medicines Recommended for Disposal by Flushing

Due to security concerns, the U.S. Food and Drug Administration lists a small number of drugs that it recommends flushing including Oxycodone, Duragesic (Fentanyl) patch, Demerol, Methadone, Morphine, and Percocet. These medications have generic versions available or are only available in generic formulations.

ADDITIONAL RESOURCES

- Cal Recycle
- DEA nationwide Prescription Drug Take-Back initiative
- New FDA Web Page Lists Disposal Instructions for Select Medicines
- How to Dispose of Unused Medicines
- California Guidelines for Proper Disposal of Drugs
- Environmental Protection Agency

CONTACT CAL RECYCLE

1-800-Recycle (732-9253)

Source: U.S. Department of Health & Human Services

IV

PART IV

Safety *at Home*

Practical guidance for a safer home, including oxygen safety, fall prevention, and emergency preparedness.

13 Basic Home Safety

14 Home Oxygen Safety

15 Fall Prevention

13 CHAPTER 13

Basic Home Safety

These Home Safety Instructions are provided to assist you in identifying safety hazards in your home. You are responsible for correcting any safety hazards identified.

General Safety

- Keep in touch with others. If you live alone, ask a neighbor, friend, or family member to check on you each day.
- Get up slowly from chair or bed and turn your head slowly to avoid dizziness.
- Don't hurry. Many accidents happen because people try to do things too quickly. Take time to be safe.
- When carrying objects ensure your walkway is unobstructed, get a firm grip, lift with your legs (knees bent, back straight), and walk slowly. Get help for heavy awkward objects.
- Use a solid step stool or ladder, not a chair or box, if you must climb to reach a high place.
- Check hot water temperatures to prevent burns. Experts suggest setting hot water at 100 degrees F or lower.

Environmental Safety

WALKWAYS

- Remove rugs from walkways to prevent tripping, or use rugs with non-slip padding.
- Fix torn carpeting to prevent tripping.
- Make the transition between types of flooring as even as possible.
- Avoid waxed floors or slippery surfaces, which can lead to slipping.
- Do not wear socks or smooth-soled shoes or slippers on uncarpeted floors.
- Wipe up spills immediately.
- Mark sliding glass doors with stickers to prevent someone walking through them.

STAIRS

- The height of steps should be no more than 5 inches.
- Ensure that handrails are properly secured.
- Non-slip treads can be placed on wooden stairs to prevent slipping.
- Ensure that the carpeting is secure.

FURNITURE LAYOUT

- Arrange furniture in a manner that keeps walkways clear.
- Tables and chairs must be strong enough to support the weight of a person leaning or sitting on them.
- Avoid using furniture with sharp edges; furniture with sharp edges can be padded.

LIGHTING

- Be sure there is sufficient lighting to avoid falling.
- Light switches should be easily accessible in the room.

Bathroom Safety

BATHTUB

- Install skid resistant rubberized mat in tub.
- Install grab bars on the side of the tub or shower for balance.
- Use bath seat to prevent falling.
- **Do not** use a soap dish or towel bars for balance, these can pull out of wall.

TOILET

- Use an elevated toilet seat or commode if you need support getting on and off the toilet.
- Install handrails around the toilet to prevent falling.

DOORS

- Do not lock bathroom doors or only use locks that can be opened from both sides when you may need assistance in the bathroom.

Kitchen Safety

- Mark “On” and “Off” positions clearly on stove dial switches.
- Use front burners of the stove to avoid reaching over the stove. If there are children in the home, keep them out of the kitchen while cooking or use back burners.
- Ensure that pot and pan handles are turned inward and not facing outward to prevent spillages.
- Do not pick up heavy pots and pans; slide them across the stove if they need to be moved.
- Keep a fire extinguisher and baking soda easily accessible to put out any fire that might occur.
- Avoid wearing baggy and loose clothing while cooking.

Electrical Safety

- Keep appliances away from water. Spilling water on an appliance can lead to electrocution.

- Use appliances in good condition.
- Inspect cords to guarantee proper condition.
- Use grounded plugs or 3-prong adapters for medical equipment.
- Keep extension cords out of pathways to prevent falling.
- Avoid plugging too many plugs into an outlet to prevent overheating.

Fire Prevention and Response

- Smoke detectors are recommended in each bedroom, hallway and in the kitchen.
- An (ABC) type fire extinguisher should be installed in an easily accessible location.
- **Do not smoke in bed** or while sleepy.
- Have an evacuation plan.
- If a fire is to occur, a person that is bedbound must be removed from the bed and evacuated via a wheelchair or placed on a blanket and dragged out.
- Keep a hospital bed as close to an exit as possible.
- Plan to evacuate an ill person if they are not on the first floor.
- Keep space heaters away from flammable objects such as curtains, cords, furniture and high traffic areas.
- Everyone in the home should be able to call 911 in case of an emergency.
- Notify the Fire Department if you are on oxygen in case of an outage.

Earthquake Preparedness

BEFORE

- Store a 1-2 week supply of non-perishable food and medication in stock in case of an earthquake. Place in a water-proof container.
- Know the procedure to follow if you are using medical equipment that runs on electricity and there is a power failure (ventilators, IV pumps, feeding pumps).
- Keep a flashlight and portable radio handy. These are helpful if the lights go out or for an emergency.
- Check the condition and charge on batteries, especially for special medical equipment.
- Block or lock wheels of beds, wheel chairs, commodes, and refrigerators.
- Persons who live alone should appoint an official “buddy” who will check on them after an earthquake.
- Anchor tall furniture to the wall and remove heavy items from the top shelves.

DURING

- If you are inside, stay inside and take cover under a heavy desk, table, or doorway away from windows or objects that might fall.
- Drag or wheelchair a bedbound patient to a safe area.
- Lock the wheels of the wheelchair after moving to a safe area.
- If outside, stand clear of trees, electrical lines, and buildings.
- Follow your evacuation plan.

AFTER

- Home infusion patients should go to the nearest hospital emergency room if you run out of medication, supplies, or solutions and are not able to contact Generation Care.
- If necessary, use Ambu bag for a ventilator dependent patient until you can resume electrical power.
- Turn off gas if the smell or sound of hissing gas is detected. **Do not light any matches** if a gas leak is suspected.
- Assess for injuries and be prepared to administer first aid.
- Tune into a local radio station for instructions from public safety.

14 CHAPTER 14

Home Oxygen Safety

OXYGEN

Oxygen is not flammable; however, it can cause other materials that burn to ignite more rapidly. This can result in a fire that would be similar to an explosion. Oxygen is a great tool for those in need of oxygen therapy, but it must always be handled with extreme caution due to the potential hazards. Do not use individual compressed oxygen cylinders that exceed 250 cubic feet at normal temperature and pressure.

SAFETY

- Smoking is prohibited while using oxygen.
- Visitors should also be notified that smoking is prohibited. This can be achieved with a no smoking sign.
- If a portable oxygen tank is taken to a restaurant, it should be placed at least 5 feet away from open flames such as candles, fireplaces, or stoves.
- Oxygen cylinders should be kept in a well-ventilated area (not in closets or behind curtains).
- Oxygen cylinders left in a confined space can cause an accumulation of oxygen gas and if not properly ventilated can lead to a fire.
- Oxygen cylinders should be kept at least 8 feet away from heaters and electrical appliances.
- Oxygen cylinders should be placed in a stand or securely fastened to prevent falling.
- Oxygen cylinders should always be placed upright.
- To avoid fire hazards, operate oxygen cylinder valves slowly.
- The cylinder valve must be shut off when it is not in use.
- Only a properly grounded wall outlet should be used to operate an oxygen concentrator.
- Do not use extension cords for oxygen compressors.
- Electrical wiring or oxygen tubing should not be placed under rugs or furniture.
- Do not use flammable liquids such as cleaning fluids, paint thinner, or aerosol spray while using the oxygen.
- Oxygen may even react with natural materials, especially petroleum products, grease, and oil, causing a fire hazard.
- Do not use petroleum-based lotions or lubricants.
- Do not use bedding or clothing made of wool, nylon, or synthetic fabrics as materials like these can cause static electricity, which is a fire hazard near oxygen. Instead use materials such as cotton.
- Children or unqualified individuals are not allowed to operate oxygen equipment.
- Always have your gas supplier's number accessible.
- An all-purpose fire extinguisher should be kept in an easily accessible area and you should familiarize yourself with how to operate it.

15 — CHAPTER 15

Fall Prevention

Falls are a common occurrence in the older population. Falls may lead to fractures, hospitalization, rehabilitation, and long-term care. Most falls happen between the hours of 6:00 a.m. and 10:00 a.m. and between 4:00 p.m. and 8:00 p.m. These guidelines have been provided to help reduce the risk of falling. No one is free from the risk of a fall. It can happen to you! Please read the following tips and follow them. We need your cooperation to keep you safe!

- Call for assistance when you need to get up from your chair or bed, or when doing activities that you know you cannot do alone.
- Sit at the edge of the bed for a few minutes before standing to reduce dizziness.
- Take your time when moving around. Do not rush! Use your walker or cane as recommended by your physician.
- Keep the items you use most often at arm's reach (such as the TV remote, light, telephone, water, etc.)
- Remove the clutter in your living space that may create a hazard (such as scatter rugs, excessive furniture, electrical cords on the floor, etc.) Stand with one foot forward for a wider base of support and stability.
- Bend your knees, squat, and use your thigh muscles.

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 room.
- Do not walk on slippery surfaces.
- Check the rubber tips for wear and tear.

Standing with Your Walker

- The walker is at the right height for you if when standing with arms at your sides, the walker handgrips should be at the level of your wrist.
- Keep the walker in front of you with your weight on the stronger leg.
- In rest position, your elbow should be at a 30 degree bend when your hands are on the handgrip.

Walking with Your Walker

- Pick up the walker and place it one foot ahead of you.
- Place your weaker leg ahead of your stronger leg.
- Push down with your hands and bring your stronger leg forward.
- 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.
- **Range of motion exercises (if appropriate)**: This is good for the patient's overall health. And, it helps them become stronger and less likely to fall.
- **Changes to the 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 patients and 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 the patient 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 to see if they need to use the bathroom facilities, and assist them. A bedside commode may also be helpful.
- **Alarms**: These include hand bells that let the caretaker know when a patient needs attention, a buzzer or bell that sounds when a restricted door opens, or a baby monitor.

PART V

Comfort *& Care*

Managing pain, understanding the changes of the final days, and supporting nutrition and comfort.

16 Pain Management

17 Understanding the Final Days

18 Nutrition

16 CHAPTER 16

Pain Management

WHAT CAUSES PAIN?

Pain appears to have a physical cause, meaning that some part of the disease is causing pain messages to be sent to the brain where pain is realized. It is important to try and discover the cause of the pain but not always possible. This does not mean however, that the pain is not real.

TYPES OF PAIN MEDICINE

There are two types of pain medicines: over-the-counter (for mild pain) and prescription (for more severe pain). The most common over-the-counter pain medicines are ibuprofen (such as Advil® and Motrin®) and acetaminophen (such as Tylenol® and Datril®).

Usually, hospice patients require the use of a prescription pain medicine to control their pain. Prescription pain medication can be used alone or in combination with over-the-counter medicines to relieve pain. There are many different kinds of prescription pain medicines and they are currently available as pills, liquids, rectal suppositories and injections. The doctor will decide the amount and type of medication the patient should take after talking with the patient and the hospice nurse. It is important that the patient tells the doctor about the relief received or not received from the pain medicine. Your hospice nurse may ask you and the patient to keep a written pain record between visits. This record will help in making necessary adjustments in the pain management plan.

There are other ways to help lessen the patient's pain. These may be used along with the pain medications. Some methods include: distractions, massage, relaxation exercises, and application of the heat or cold near the pained area.

THINGS TO REMEMBER ABOUT OVER-THE-COUNTER PAIN MEDICINES

- Take aspirin with food or antacids to lessen stomach upset.
- Take acetaminophen on an empty stomach to improve absorption
- Helpful for mild pain only.
- Both of these medicines are available in liquid and suppository form for the patients who have problem swallowing tablets.

THINGS TO REMEMBER ABOUT PRESCRIPTION PAIN MEDICINES

- Not all prescription pain medicines are available in all forms.
- If the patient needs to have injections, your hospice nurse will teach you how to do this.

- Recently, prescription medication such as morphine has been available in controlled-release tablets (a longer-acting form of the medicine). The patient can have prolonged pain relief and does not have to take medicines as often.
- Whatever pain medicine the patient is taking, if the underlying pain increases, the patient may need to increase either the amount of pain medication they take or how often they take it. This is normal.
- Fear that the patient will become addicted to the medicines should not be exaggerated. Prescription pain medicines are known to have potential to produce dependence and may sometimes be abused, but the hospice patient has the need for pain relief and is not seeking the drug for emotional or psychological reasons. Reducing or stopping prescription medicine doses must be done according to the schedule set by your doctor to avoid symptoms of withdrawal.
- Most patients find that the best pain control occurs when pain medicines are taken on a regular schedule. This way they stay on top of their pain and don't wait until it becomes severe before taking another dose of their pain medicine.

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Have a question about *any of this?*

Your hospice team is available 24 hours a day, 7 days a week. No question is too small, and you never have to wait until morning.

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17 CHAPTER 17

Understanding the Final Days

How Fluid Deprivation Affects the Terminally Ill

Many physicians routinely order IV fluids for terminally ill patients to prevent what they believe to be the agonizing effects of dehydration and electrolyte imbalance. Many nurses, particularly those who work with the dying, believe otherwise. In a recent survey, eight out of ten hospice nurses agreed that dehydration is not painful; more than half of them said that it is beneficial. Clinical studies back up both assertions.

As death approaches, dehydration occurs naturally from inadequate oral intake, gastrointestinal and renal loss, and the loss of secretions from the skin and lungs. Transitory thirst, dry mouth, and changes in mental status have been found to develop, but the headaches, nausea, vomiting or cramps frequently associated with water deprivation rarely occur. The mental changes, while upsetting to relatives, bring relief to the patient by lessening the awareness of suffering. This effect stems from the production of ketones, which calorie deprivation stimulates. Serum levels of gamma-hydroxybutyrate, a substance with anesthetic properties that is believed to dull consciousness, also rise.

The administration of IV fluids may produce a feeling of well-being, but it is usually a fleeting sensation. In time, artificial hydration is likely to heighten the discomfort of the terminally ill patient and often exacerbates underlying symptoms. Unless renal function has declined, IV fluids increase urine output, often creating the need for an indwelling catheter. Fluid deprivation eliminates the frequent use of a urinal or bedpan and the discomfort that goes along with it.

Pharyngeal and pulmonary secretions increase, causing cough, dyspnea, and often pulmonary edema. If pneumonia is present, IV fluids make it worse. Dehydration relieves congestion and the symptoms associated with it.

An increase in gastrointestinal fluids would result in more symptoms of nausea and vomiting, particularly for patients with intestinal obstructions or neoplasms. Dehydration makes such painful symptoms unlikely.

Signs and Symptoms of Decline

- Loss of bowel and bladder control as the nervous system changes.
- The skin becomes cold, particularly in the arms and legs; and may feel clammy damp or appear blue - Use warm blankets to protect the patient from feeling cold. Do not use electrical blankets due to danger of burning skin
- The number of times and how deeply the patient breathes will lessen until the patient stops breathing entirely. Breathing may become noisy due to mucous collecting in the throat - Elevate the head of the bed or add extra pillows. Use cool mist humidifier and prescribed medications to lessen symptoms.

- The patient stops eating or drinking liquids. WHAT HELPS: Moisten mouth with a moist cloth. Clean oral cavity with wet Q-tips. Keep lips wet with lip balm.
- Hearing and vision will lessen as the nervous system slows. WHAT HELPS: Keep lights on in the room; **Never** assume the patient cannot hear you. **Always** talk to the patient as if hearing were intact. Explain what you are doing and show your feelings.
- The patient is restless, pulling at bed linens, or having visions. This is a result of slow circulation and less oxygen to the brain. WHAT HELPS: Stay calm, speak slowly and assuredly. You don't need to agree or disagree with their perception of reality. You can comfort with simple reminders of time, place and person.

Mouth Care

Gently swab out the mouth. This should be done every hour during the day and not at all during sleep time. If the patient is unresponsive, it is best to leave dentures out at all times.

THINGS TO REMEMBER

- Don't put the toothbrush too near the back of the patient's throat or the patient will gag.
- Do not give the patient mouth care as explained here if they are lying flat or are unable to swallow. The patient may choke on the liquid.
- If the patient cannot swish and remove the liquid from the mouth, your hospice nurse can give you special instructions for mouth care.
- If mouth soreness develops, tell your hospice nurse. She will ask your doctor for medicine to treat the sores.

Although watching their declining condition may be difficult for you, the patient is usually unconcerned about these changes. Sometimes, "active dying" occurs over a period of hours or days. Even when many of these signs are present it is difficult to predict the amount of time before death will occur. Some patients will exhibit some of these changes and then for some unexplained reason their condition may begin to improve a little. Although the family is caring and loving towards the patient, these roller-coaster changes can be emotionally and physically exhausting for the caregivers.

Usually the weeks and days prior to the death, your hospice nurse will begin to visit more often and other members of the hospice team will increase their availability and support. As the patient's condition worsens and they begin to emotionally as well as physically withdraw from this world, caregivers can suffer from feelings of helplessness. Withdrawal is normal for the dying patient as they become less concerned about their surroundings. At this time many of the tasks mentioned earlier in this booklet will no longer be appropriate. Alternative ways to keep the patient comfortable might include a sponge bath and moistening of the lips with cool water. Holding the patient's hands can be very meaningful and comforting at this time. It is important to continue to talk to the patient and offer reassurance.

18 — CHAPTER 18

Nutrition

In times of illness food intake is especially important. Food provides energy and the building blocks needed to sustain strength. For most of us, food is closely tied to life itself, but often, appetite and food intake are lessened for the hospice patient. There are many possible causes for this loss of appetite.

HOW TO HELP

- Do not force the patient to eat or constantly remind them of their decreased appetite. Although an encouraging, gentle approach may help, the choice to eat is the patient's.
- Serve the meal in a relaxed, comfortable, bright atmosphere. When feasible eat in the room with the patient. Remove unpleasant odors and do not do unpleasant procedures around mealtime.
- Give mouth care prior to meals to freshen the mouth and stimulate taste buds.
- Appetite tends to decrease as the day goes on; make the most of breakfast time.
- Give pain medicines on the schedule to reduce discomfort before and during meals. For example give pain medicine one-half hour prior to mealtime.
- Allow the patient to rest after meals, but keep the head of the bed elevated to promote digestion.
- Adjustments to the diet may have to be made if the patient can no longer wear their dentures. Soft foods or small bite-sized portions of meat, softened with gravy are recommended.
- If nausea is a problem, your hospice nurse can talk to the doctor about ordering medication to be given before meals to reduce nausea.
- Add small pieces of cooked meat to canned soup or casseroles to improve nutrient value in foods.
- Try new spices and flavorings for foods. It is common for a person's preference to change during illness. Add sauces and gravies to dry food.
- Try small frequent meals and leave a high protein snack to drink at the patient's bedside. Your hospice nurse can give you information and recipes for high protein supplements.
- Give liquids in other forms such as: Jell-O, pudding and ice cream.

VI

PART VI

Final *Arrangements*

What to do when death occurs at home, planning a funeral or memorial, and financial and veteran resources.

19 When Death Occurs at Home

20 Funeral Arrangements

21 Financial Resources & Veteran Benefits

19 CHAPTER 19

When Death Occurs at Home

HOW DO YOU KNOW DEATH HAS OCCURRED?

- Pupils are fixed and eyelids slightly open in a stare.
- No breathing or pulse.
- No response to shaking or verbal stimulation.
- There may be a loss of bowel or bladder contents (not usual).
- Relaxed jaw with mouth slightly opened.

Checklist of Things to Be Done at the Time of Death

- **Call Generation Care. Do not call 911.** A staff person from hospice will come to your home to pronounce the death, provide comfort and help you with making calls to the family, friends, etc. If you do not desire anyone to come to your home at this time, that is okay too. It is your special time with your loved one and your wishes will be honored.
- Generation Care will call the mortuary of your choice to notify them of the death. 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. Call the funeral home when you are ready to have the body moved, and identify the person as a Hospice patient. The police do not need to be called; the Hospice nurse will notify the physician.
- In the event that Mortuary service is needed and Family/Responsible Party is unavailable / unable to be contacted within a four (4) hour period, County Morgue is used as temporary Mortuary arrangement.
- The family may wish to call relatives and friends of the deceased and give them the opportunity to visit them one more time. Many families gather and spend time together, thereby eliminating viewings or visitations the next day.
- Decide on time and place of funeral or memorial service(s). Check with the mortuary representative concerning the time and date availability at mortuary and/or church facilities before finalizing the date and time.
- Call and meet with funeral/mortuary representative to make the arrangements for type of service. They will also ask for information about the deceased, including social security number, place and date of birth, parent's names and their places of birth, and most recent address of employment. The representative will also help with selection of casket, etc.
- Collect information for obituary. Include age, place of birth, cause of death, occupation, college degrees, memberships held, military service, and outstanding work, list of survivors in immediate family. Give time and place of services. Deliver in person, phone or fax to newspapers. Some mortuaries will give assistance with these arrangements. This information will have to meet newspaper deadlines.
- Make list of immediate family, close friends and employer or business colleagues. Notify each by phone.
- Decide on appropriate memorial to which gifts may be made. (for example, a church, library, school, or charity.)

20 CHAPTER 20

Funeral Arrangements

PRE-PLANNING

Making arrangements for a funeral is difficult at best and even more so when a patient and family are experiencing the impending loss of a loved one. However, planning in advance for one's own or a family member's funeral can have several positive benefits. Having these arrangements completed prior to death can be of great relief to everyone and saves the burden of making decisions at a time when one is dealing with grief and loss issues. Your hospice social worker can be of assistance during this time. He/she can provide you with funeral planning resources such as names of mortuaries, planning sheets, checklists as well as help guide you through the process, if you wish. You, the patient can begin by sharing your thoughts and wishes about your funeral arrangements with your family including them in the planning.

Name a spokesperson that will know your wishes and be able to make the necessary final arrangements. Other people who can be especially helpful in the discussion are your pastor, the director of the funeral agency you select or the memorial society you belong to. Pre-planning with your clergy and your family can help incorporate the religious and social dimensions of your life into a service that is appropriate for you and your family. Your clergy is also able to provide supportive counseling and bereavement care to your family. Belonging to a memorial society can often be helpful. A memorial society is a non-profit organization formed to obtain dignity, simplicity and economy in funeral arrangements through pre-planning. They generally charge modest membership fees and provide information and counsel. Many have helpful arrangements with funeral directors.

If cremation is a concern, you should make your thoughts known to your family members. This should be done by way of written instructions as opposed to verbal instructions. If you need information with respect to cremation of your remains, you can call a local funeral director, The Memorial Society or Cremation Society listed in your telephone directory. Pre-planning that includes the funeral director that you and your family have chosen can also be more helpful than many people realize. Your funeral director will assist in handling many matters coincident to death such as arranging for friends to gather, obtaining a cemetery plot for burial, and managing other activities necessary for burial, cremation, bequeathal to a medical school, and out-of-state transportation if necessary.

There are basically two forms: a funeral service or a memorial service. A funeral service, by definition, is one that is held in the presence of the body and sometimes includes a viewing. A memorial service is one held without the body present. It is generally less expensive. You should decide with your family which kind of service you want, taking into consideration costs, personal preferences, and cultural and religious beliefs. You may wish to request more information on costs and on the timing of burial, cremation or bequeathal, to a medical school. Either the memorial society or your funeral director will be able to give you the details on procedures required and the costs involved. Burial is generally the most expensive procedure. If you are a service veteran or spouse of a veteran, or a member of the fraternal lodge, remember to find out what death benefits are available to you.

LOW COST FUNERALS

The cost of a funeral can be considerable which many families can ill afford, especially if their resources have been drained after a lengthy illness. There are low cost, simple alternatives to the more elaborate and expensive arrangements. Funeral and Memorial Societies offer low cost funerals, memorial services, burials, or cremations. There are approximately 200 such societies in the U.S. and Canada. They are non-profit groups formed to promote dignity, simplicity, and economy in funeral arrangements through pre-planning. The Societies charge modest membership fees (approx. $25 for an individual) and provide information and advice on funeral arrangements at a reasonable cost, a savings of several hundred dollars in most cases. For more information, contact your local society or write The Continental Association of Funeral and Memorial Societies, 6900 Lost Lake Road, Egg Harbor, WI 54209-9231, (414) 868-2729.

The Federal Trade Commission (FTC) regulations require that all funeral charges must be itemized (including the details such as cost of the organist, registration book, etc.) Funeral directors may also offer the same service at the same cost as one of the Societies. You may wish to contact a local funeral home to determine this.

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21 CHAPTER 21

Financial Resources & Veteran Benefits

County Assistance. Arrangements for transportation and preparation of the body, burial or cremation in a county facility for a person determined to be indigent (without funds or responsible relatives) are made by a mortuary located in the county of legal residences and the office of Public Administrator. In some cases, the County Coroner may be called to pick up the body. Burial expenses for indigent individuals are commonly paid for by the county to the extent allowed by the County Board of Supervisors. However, the application for County Assistance must be applied for and approved by the office of the Coroner or Public Administrator prior to any funeral arrangements.

Social Security. Death benefits are available under some conditions to the survivors of persons who were covered by Social Security. These benefits must be formally applied for. Phone your local Social Security office. The spouse of the deceased may be entitled to a lump sum death benefit, provided the deceased was covered by Social Security in his or her own right. IF no spouse survives, the lump sum death benefit is not available to apply against the burial expenses. Children entitled to survivor's benefits may also be eligible for the death benefit.

Payment Plans. You may wish to establish a special account to assist with funeral expenses. This may take the form of a bank account, insurance program or other savings plan. Funeral directors can be helpful in determining costs and discussing available financial planning alternatives.

Veteran Benefits

Veterans are entitled to certain benefits at the time of death. The following is a brief description of general death benefits.

- Veterans are eligible for the free burial in a VA national cemetery to include the gravesite, opening and closing of the grave and perpetual care. Many national cemeteries have columbaria for the inurnment of cremated remains or special sections for the burial of cremated remains.
- A headstone or grave marker, and a United States flag are provided.
- Burial expenses may be reimbursed for veterans who at the time of death, were receiving or entitled to receive VA compensation or pension, or if death occurred in a VA facility. The reimbursement, however, is a limited amount.
- Additional costs for transportation of the remains may be allowed if the veteran died while hospitalized or domiciled by the VA or died in transit at VA's expense to or from a medical facility.

Complete information on the wide range of veteran's benefits administered by the VA can be obtained by telephone. VA's national toll-free information number is 1-800-827-1000. Information can also be obtained from Veterans Service Organizations.

Other death benefits are provided by trade unions, fraternal organizations, life insurance, credit unions and Workers' Compensation. It is also beneficial to list these so that families do not overlook available options.

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