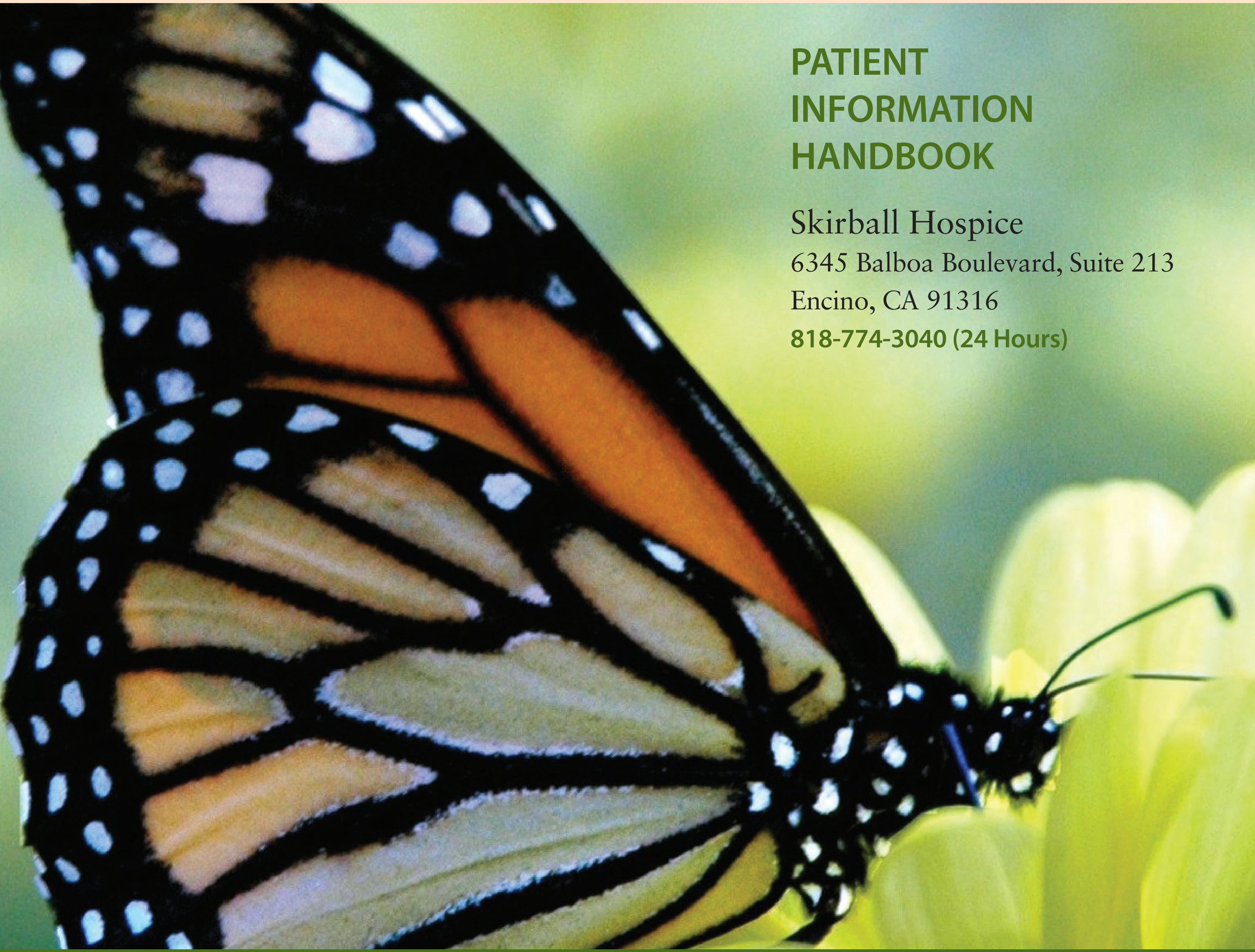
Skirball Hospice

A Program of the Los Angeles Jewish Home

SKIRBALL
HOSPICE

Committed to Quality of Life



PATIENT INFORMATION HANDBOOK

Skirball Hospice
6345 Balboa Boulevard, Suite 213
Encino, CA 91316
818-774-3040 (24 Hours)

INFORMATION HANDBOOK CONTENTS

SECTION 1: HOSPICE OVERVIEW

CRITERIA FOR ADMISSION:

- Referral from your attending physician who makes a recommendation to Hospice. Medical condition with a life expectancy of six months or less, if the illness runs its normal course.
- Agree to palliation (control) of symptoms and not cure of illness.
- Agree to follow the plan of care established and refined by you, your family, by the physician and the hospice team.
- Live within the geographic area served by Skirball Hospice.
- Have a place of residence (home, skilled nursing or residential care facility) which is a safe environment for patient, caregiver and hospice staff.
- Have a realistic plan for the provision of primary caregiving on a 24-hour basis when needed.

HOSPICE CONCEPT:

What is Hospice?

- Hospice care provides comfort and kindness to those persons nearing the end of life's journey.
- Hospice will help you make decisions about how and where you want to spend the rest of your life.
- Hospice is a special kind of caring that includes both the patient and loved ones.

Why Hospice?

- Hospice treats you, not the disease. The focus is on care, not cure. You and your family's medical, social, emotional, and spiritual needs are addressed by a team of hospice professionals and volunteers.

- Hospice considers your entire family, not just you, as the "unit of care." You and your family are included in the decision making process. Hospice will help you and your family make choices about end-of-life issues and enable you to have greater control over these choices. Bereavement counseling is provided to your family for 13 months after your death.

- Hospice offers palliative rather than curative treatment. Hospice will provide care and comfort when cure is no longer an option. Through advancing technology, pain and symptom control will enable you to live as fully and comfortably as possible.

- Hospice emphasizes quality of life. Hospice neither hastens nor postpones your death. It affirms life and regards dying as a normal process.

SERVICES:

Hospice provides the most effective care-alternative to people who have life-limiting illnesses and decreases the need for hospitalization. Skirball Hospice offers the following features for all who receive hospice care:

- 24 hours a day, 7 days a week availability of a full team of professionals.
- Case Management services.
- Aggressive pain control and symptom management.
- Extended nursing care at home during short periods of medical crisis.
- Respite services for caregiver relief.
- Staff who visit the home when the patient dies to assist the family, day or night.
- All diagnosis-related services, drugs, supplies and medical equipment are covered under the Medicare and Medicaid hospice benefit and many commercial insurance plans.
- Support for family, caregivers and other loved ones.

YOUR HOSPICE TEAM:

At Skirball Hospice, your care is provided by an interdisciplinary team of professionals in partnership with your physician. The following interdisciplinary team services are available to you:

- **A Medical Director** available for consultation and discussion of the plan of care.
- **Nursing** staff, highly trained in pain management, symptom control and supportive care.
- **Social Workers** who help relieve the emotional and social pain of patients and their families, address family financial concerns and assist with coordination of community resources and funeral pre-arrangements.
- **Spiritual counselors** who offer guidance and support to patients and their families.

- A Registered Dietician to assess the nutritional needs of patients and to provide education education and information.
- Trained volunteers who provide companionship, respite care and support to patients and their certified caregivers. (See services listed below.)
- Home health aides who provide personal care to patients.
- Physical, occupational and speech therapists who provide palliative modalities to enhance quality of life.
- Bereavement Counselors who provide grief support for hospice families and coordinate grief support groups for the general community and hospice caregivers.

REVOCATION OF THE MEDICARE HOSPICE BENEFIT:
The patient may revoke(stop) the Medicare hospice benefit any time by contacting us 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 come back on a hospice program, he/she will enter the program in the next benefit period.

TRANSFER:
A patient may transfer to another hospice program once during each benefit period. The change will be coordinated between the two hospice programs involved and Medicare will be notified.

PAYMENT FOR SERVICES NOT IN THE HOSPICE PLAN OF CARE:
Skirball Hospice does not pay for services outside the hospice plan of care (that is services for other than the admission diagnosis) or for services that have not received prior approval from us. You may utilize other outside services, but the patient will be financially responsible for these services if they are related to the terminal illness. Medicare, Medi-Cal and commercial insurance will not pay for those services. You may, however, seek medical services for issues not related to the hospice diagnosis and, based on the benefits of your insurance policy, these may be reimbursed. Always check with us or your insurance before seeking such services to ensure payment.

EMERGENCY ROOM/FACILITY ADMISSION:
We ask you to contact Skirball Hospice at: **818-774-3040** any time you feel the patient needs immediate assistance. Usually these situations can be resolved by Skirball staff, and we can continue to assist in caring for the patient at home. When the patient requires a higher level of care than can be provided in the home, we will help to make the arrangements for that care.

Admissions to a facility are arranged by the hospice team when medically necessary, e.g.: for acute symptom management. Once the team feels the reason for admission has been resolved, the patient can return home. It is our aim for patients to return home as soon as symptoms are stabilized. There is no predetermined length of stay.

RESPITE CARE:
Respite care is provided by hospice for a period of up to five days to allow a period of rest for the patient's caregiver. This care is routinely provided in a contracted facility, usually a Skilled Nursing Facility, with support from the Skirball Hospice staff. Should you need this option, we will make all arrangements, including transportation as needed.

AGGRESSIVE TREATMENT:
Aggressive treatment is any form of therapy or surgery that is done for the purpose of curing the disease. If a hospice patient chooses to receive any kind of aggressive treatment, he/she can no longer remain in the hospice program. At this time, either the hospice may discharge the patient or the patient may revoke the hospice benefit. The patient/decision-maker should know that if they decide to discontinue this curative treatment or they complete the treatment, they may apply for re-admission to Skirball Hospice.

MEDICARE HOSPICE BENEFIT

Medicare will reimburse the cost of Hospice care under your Medicare Hospice Insurance (Part A). In general, Medi-Cal covers the same benefits. Commercial insurance plans vary and we will verify your benefits when you decided to come on service. When all requirements are met, Medicare will cover the following:

Covered Services	Non-Covered Services
• Physician services	• Treatment for the terminal illness which is not for palliative symptom management and is not within the hospice plan of care
• Nursing care	• Care provided by another hospice or home health agency
• Home Health Aide	• Private caregivers/Sitter services
• Medical Social Services	
• Bereavement counseling • Spiritual counseling	
• Dietary counseling	• Dietary supplements unless directly related to terminal illness
• Volunteer Services	
• Physical Therapy, Occupational Therapy, Speech Therapy	• Services not authorized by Skirball Hospice.
• Medical equipment, services and supplies	• Ambulance transportation not included in the plan of care • Supplies not related to terminal illness
• Medications for pain and symptom management related to the terminal illness and approved by Hospice.	• Chemotherapy drugs or other drugs deemed aggressive in nature. • Medications not related to the terminal illness
• Short-term inpatient care for pain and symptom control	• Visit to the emergency department without the prior approval or inpatient care without prior authorization or at non-contracted facilities.
• Diagnostic studies	• Lab studies, medical testing and/or any treatments not authorized by Skirball Hospice.
• Respite for up to 5 days to provide relief for caregivers	

PROBLEM SOLVING PROCEDURE

Your problems and concerns are important to us. We will give full focus to any issue you bring to our attention and make every effort to resolve the issue. We assure you that you will have the opportunity to voice grievances and recommend changes in services without discrimination, coercion, or interruption of services or reprisal in any manner from us.

If you have a concern, please:

1. Notify the RN Team Leader Monday through Friday from 8:00 a.m. to 4:30 p.m. at 818-774-3040. After normal business hours and on weekends and holidays, dial the same number and ask to speak to the Administrator on Call. Most problems can be solved at this level. If the concern is not resolved, you can refer your concerns to the Director of Patient Care Services at the same number.

2. You may also submit your concern in writing to:
   Administrator
   Skirball Hospice
   6345 Balboa Boulevard, Suite 213
   Encino, CA 91316

3. You may also report complaints to the Department of Health Services, Consumer Protection Division of the Attorney General's office, the Commissioner of the State Department of Public Health or with any other person or agency.

Procedures for Making Complaints:

If you have any complaints regarding the services you have received from the Skirball Hospice program that we have not resolved to your satisfaction, the Department of Health Services operates a 24-hour, toll-free hotline you may contact at any time:

In Los Angeles County: 1-800-228-1019

The Department of Health Services office hours are M-F, 8 am – 5 pm, except holidays. You may also write to them at the following address:

Department of Health Services
5555 Ferguson Drive, Suite 320
City of Commerce, CA 90022

SECTION 2: PATIENT RIGHTS AND RESPONSIBILITIES AND NOTICE OF PRIVACY PRACTICES

PATIENT RIGHTS AND RESPONSIBILITIES

You have the right to:

1. Be informed of your rights in a manner you understand.
2. Make informed decisions regarding proposed and ongoing care and services.
3. Choose whether or not to participate in research, investigational or experimental studies or clinical trials.
4. Have your communication needs met.
5. Have complaints heard, reviewed, and if possible, resolved.
6. Confidentiality of information, privacy and security.
7. Be fully informed, as evidenced by your written acknowledgement or by that of your appointed representative, of these rights and of all rules and regulations governing patient conduct, prior to or at time of admission.
8. Be involved in the care planning process.
9. Be fully informed by a physician of your medical condition, unless medically contraindicated, and to be afforded the opportunity to actively participate in your medical treatment.
10. Formulate advance directives.
11. Have an appropriate assessment and management of your pain.
12. Keep and use personal clothing and possessions.
13. An environment that preserves dignity and contributes to a positive self-image. Unlimited contact with visitors and others.
14. Be fully informed, prior to or at time of admission, of services available through the hospice and their related charges.
15. Refuse treatment to the extent permitted by law and to be informed of the medical consequences of such refusal.
16. Be advised what hospice services are to be rendered and by what discipline, e.g., Registered Nurse, Counselor, Chaplain, Volunteer, etc.
17. Be advised in advance of any change in treatment, care, or services.
18. Be assured of confidential treatment of personal and clinical records and the right to approve or refuse their release to any individual outside the hospice, except in the case of transfer to another health facility, or as required by law or third-party payment contract.
19. Be treated with consideration, respect, and full recognition of dignity and individuality, including privacy in treatment and in care for personal needs..

20. To not be subjected to exploitation, verbal, physical or sexual abuse of any kind, and to be informed that corporal punishment is prohibited.

21. Be informed by Skirball Hospice of the provisions of the law regarding complaints and procedures for registering complaints confidentially, including, but not limited to, the address and telephone number of the local District office of the Dept. of Health Services.

22. Be informed of the provisions of the law pertaining to advanced directives, including but not limited to living wills, power or attorney for health care, withdrawal or withholding of treatment and/or life support.

23. Be assured the personnel who provide care are qualified through education and experience to carry out the services for which they are responsible.

<u>You have the responsibility to:</u>

1. Remain under a doctor's care while receiving hospice services.

2. Inform the hospice of advance directives or any changes in advance directives, and provide hospice with a copy.

3. Cooperate with your primary doctor, hospice staff and caregivers by providing information, following instructions and asking questions.

4. Advise us of any problems or dissatisfaction you have with the care provided.

5. Notify Skirball Hospice of address or telephone number changes or when you are unable to keep appointments.

6. Provide a safe home environment in which care can be given. In the event of conduct such that if the patient's or staff's welfare or safety is threatened, service may be terminated.

7. Obtain medications, supplies and equipment ordered by your physician if they cannot be obtained or supplied by the hospice.

8. Treat hospice personnel with respect and consideration.

9. Sign the required consents and releases for insurance billing, and provide insurance and financial records as requested.

10. Accept the consequences for any refusal of treatment or choice of non-compliance.

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!

1. USE AND DISCLOSURE OF HEALTH INFORMATION

Skirball Hospice may use your health information (information that constitutes protected health in- formation 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, obtain- ing payment for your care and conducting health care operations. Skirball Hospice has established policies to guard against unnecessary disclosure of your health information.

THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH THE LAW PERMITS YOUR HEALTH INFORMATION TO BE USED AND DISCLOSED:

a. **To Provide Treatment.** Skirball Hospice may use your health information to coordinate care within the Hospice such as your attending physician, members of the Hospice interdisciplinary team and other health care professionals who have agreed to assist the Hospice in coordinating care such as pharmacists and suppliers of your medical equipment and supplies. We also may disclose your health care information to individuals for whom you have given us permission to relay information including family members, caregivers and clergy.

b. **To Obtain Payment.** Skirball Hospice may use and disclose your health information to collect payment from third parties for the care you receive from the Hospice. Your health information may be used and disclosed on invoices, correspondence and other communications with your health insurer. We also may need to obtain prior approval from your insurer and may need to use and disclose health information to explain to the insurer your need for hospice care and the services that will be provided to you.

c. **To Conduct Health Care Operations.** Skirball Hospice may use and disclose health information for its own operations in order to facilitate the function of the Hospice and as necessary to provide quality care to all of the Hospice's patients.

d. **For Fundraising Activities.** Skirball Hospice may use information about you including your name, address, phone number and the dates you received care in order to contact you or your family to raise money for the Hospice. If you do not want the Hospice to contact you or your family for this purpose, notify the Administrator at 818-774-3040 and indicate that you do not wish to be contacted for this purpose.

e. **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 visit.

f. **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 YOUR HEALTH INFORMATION MAY ALSO BE USED AND DISCLOSED WITHOUT YOUR PRIOR AUTHORIZATION OR CONSENT, UNLESS SUCH DISCLOSURE IS FURTHER RESTRICTED OR LIMITED BY CALIFORNIA LAW:

a. **When Legally Required. Skirball Hospice will disclose your health information when it is required to do so by any Federal, State or local law.**

b. **When There Are Risks to Public Health. We may disclose your health information for public activities and purposes**

c. **To Report Abuse, Neglect Or Domestic Violence.** Skirball Hospice is required to notify government authorities if our staff reasonably believes a patient is the victim of abuse, neglect or domestic violence. We will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

d. **To Conduct Health Oversight Activities.** Skirball Hospice may disclose your health information to a health oversight organization for activities including audits, civil, administrative or criminal investigations, inspections, licensure or disciplinary action. We, 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.

e. **In Connection With Judicial Or Administrative Proceedings.** We may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a 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.

f. **For Law Enforcement Purposes.** As permitted or required by State law, Skirball Hospice may disclose your health information to a law enforcement official for certain law enforcement purposes.

g. **To Coroners and Medical Examiners.** We may disclose your health information to coroners and medical examiners for purposes of determining your cause of death or for other duties, as authorized by law.

h. **To Funeral Directors.** Skirball Hospice may disclose your health information to funeral directors consistent with applicable law to carry out their duties with respect to your funeral arrangements..

i. **For Organ, Eye Or Tissue Donation.** With your permission, we 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

j. **For Research Purposes.** We 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, and your permission will be obtained for that purpose.

k. **In the Event of A Serious Threat To Health Or Safety.** Skirball 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.

l. For Specified Government Functions. In certain circumstances, the Federal regulations authorize Skirball Hospice 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.

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

THE FOLLOWING IS A SUMMARY STATEMENT OF THE CIRCUMSTANCES UNDER WHICH YOUR AUTHORIZATION IS NEEDED TO USE OR DISCLOSE HEALTH INFORMATION:

Except as described and stated above, Skirball Hospice will not disclose your health information other than with your written authorization. If you or your representative authorizes us to use or disclose your health information, you may revoke that authorization in writing at any time.

1. YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION

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

a. **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 Officer at 818-774-3040.

b. **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 Officer. The Hospice will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.

c. **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 Officer. If you request a copy of your health information, the Hospice will require you to sign a release of health information and may charge a reasonable fee for copying and assembling costs associated with your request

d. **Right to amend health care information.** You or your representative has 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 Skirball Hospice. A request for an amendment of records must be made in writing to the Privacy Officer. 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 Skirball Hospice, if the records you are requesting are not part of Skirball 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.

e. **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 Administrator. The request should specify the time period for the accounting starting on or after April 14, 2003. Accounting requests may not be made for periods of time in excess of six (6) years. Skirball Hospice will provide the first accounting during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

f. **Right to a paper copy of this notice.** You or your representative has 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 Administrator.

2. DUTIES OF THE HOSPICE

Skirball Hospice is required by law to maintain the privacy of your health information and to provide to 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. Skirball 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 we change our Notice, we 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 Department of Health and Human Services who is our Administrator if you or your representative believes that your privacy rights have been violated. Any complaints to us should be made in writing to the Privacy Officer. We encourage 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.

3. CONTACT PERSON

Skirball Hospice has designated a Privacy Officer as its contact person for all issues regarding patient privacy and your rights under the Federal privacy standards.

IF YOU HAVE ANY QUESTIONS REGARDING THIS NOTICE, PLEASE CONTACT OUR ADMINISTRATOR: **818-774-3040.**

4. **EFFECTIVE DATE:** This Notice is effective April 26, 2010.

SECTION 3: YOUR RIGHT TO MAKE DECISIONS ABOUT YOUR MEDICAL TREATMENT

The following information explains your right to make healthcare decisions and how you can plan now for your medical care if you are unable to speak for yourself in the future. A federal law requires us to give you this information. We hope this information will help you increase your control over your medical treatment.

Who decides about my treatment?
Your doctors will give you information and advice about treatment. You have the right to make choices about that treatment. You can say "Yes" to treatments you want. You can say "No" to any treatment you don't want—even if the treatment might keep you alive longer.

How do I know what I want?
Your doctor must tell you about your medical condition and about what different treatments and pain management alternatives can do for you. This explanation should include both the benefits and side effects of those treatments. Sometimes, more than one treatment might help you and your doctor will tell you about those options. However, your doctor can't choose for you. That choice is yours to make and depends on what is important to you.

Can other people help with my decisions?
Yes. Patients often turn to their relatives and close friends for help in making medical decisions. These people can help you think about the choices you face. You can ask the doctors and nurses to talk with your relatives and friends. They can ask the doctors and nurses questions for you.

Can I choose a relative or friend to make healthcare decisions for me?
Yes. You may tell your doctor that you want someone else to make healthcare decisions for you. Ask the doctor to list that person as your healthcare "surrogate" in your medical record. The surrogate's control over your medical decisions is effective for the time limit you request. If you want someone to always make healthcare decisions for you, you should consider a Durable Power of Attorney For Healthcare (see discussion below.)

What if I become too sick to make my own healthcare decisions?
If you haven't named a surrogate, your doctor will ask your closest available relative or friend to help decide what is best for you. Most of the time that works. But sometimes everyone doesn't agree about what to do. That's why it is helpful if you can say in advance what you want to happen if you can't speak for yourself.

Do I have to wait until I am sick to express my wishes about health care?
No. In fact, it is better to choose before you get very sick or have to go into a hospital, nursing home, or other healthcare facility. You can use an **Advance Health Care Directive** to say *who* you want to speak for you and *what* kind of treatments you want. These documents are called "advance" because you prepare one before healthcare decisions need to be made. They are called "directives" because they state who will speak on your behalf and what should be done.

In California, the part of an advance directive you can use to appoint an agent to make healthcare deci- sions is called a **Power of Attorney for Health Care.** The part where you can express what you want done is called an **Individual Health Care Instruction.**

Who can make an advance directive?
You can if you are 18 years or older and are capable of making your own medical decisions. You do not need a lawyer.

Who can I name as my agent?
You can choose an adult relative or any other person you trust to speak for you when medical decisions must be made.

When does my agent begin making my medical decisions?
Usually, a healthcare agent will make decisions only after you lose the ability to make them yourself. But, if you wish, you can state in the Power of Attorney for Health Care that you want the agent to be- gin making decisions immediately.

How does my agent know what I would want?
After you choose your agent, talk to that person about what you want. Sometimes treatment decisions are hard to make, and it truly helps if your agent knows what you want. You can also write your wishes down in your advance directive. California now has a form called a Physician Ordered Life Sustain- ing treatment or POLST form. This allows you to be very specific about treatment you want and don't want if you are very ill or have a terminal diagnosis. Our staff can help you with either advance direc- tive form is you so wish.

What if I don't want to name an agent?
You can still write out your wishes in your advance directive, without naming an agent. You can say that you want to have your life continued as long as possible. Or you can say that you would not want treatment to continue your life. Also, you can express your wishes about the use of pain relief or any other type of medical treatment.

> Even if you have not filled out a written **Individual Health Care Instruction or Physician Orders For Life-Sustaining Treatment** (**POLST**) form, you can discuss your wishes with your doctor, and ask your doctor to list those wishes in your medical record. Or you can discuss your wishes with your family members or friends. But it will be easier to follow your wishes if you write them down.

What if I change my mind?
You can change or cancel your advance directive at any time as long as you can communicate your wishes. To change the person you want to make your healthcare decisions, you must sign a statement or tell the doctor in charge of your care.

What happens when someone else makes decisions about my treatment?
The same rules apply to anyone who makes healthcare decisions on your behalf—a healthcare agent, a surrogate whose name you gave to your doctor, or a person appointed by a court to make decisions for you. All are required to follow your **Health Care Instructions** or, if none, your general wishes about treatment, including stopping treatment. If your treatment wishes are not known, the surrogate must try to determine what is in your best interest.

The people providing your health care must follow the decisions of your agent or surrogate unless a requested treatment would be bad medical practice or ineffective in helping you. If this causes disagreement that cannot be worked out, the provider must make a reasonable effort to find another healthcare provider take over your treatment.

Will I still be treated if I don't make an advance directive?
Absolutely. You will still get medical treatment. We want you to know that if you become too sick to make decisions, someone else will have to make them for you. Remember that:

- **A Power of Attorney for Health Care** lets you name an agent to make decisions for you. Your agent can make most medical decisions—not just those about life sustaining treatment—when can't speak for yourself. You can also let you agent make decisions earlier, if you wish.

- You can create an **Individual Healthcare Instruction** by writing down your wishes about health care or by talking with your doctor and asking the doctor to record your wishes in your medical file. Or you can fill out a **POLST** form and have your doctor sign it. If you know when you would or would not want certain types of treatment, an Instruction provides a good way to make your wishes clear to your doctor and to anyone else who may be involved in deciding about treatment on your behalf.

- These two types of **Advance Healthcare Directives** may be used together or separately.

How can I get more information about making an advance directive?
Ask your doctor, nurse, social worker, or healthcare provider to get more information for you. You can have a lawyer write an advance directive for you, or you can complete an advance directive form which our staff can provide for you.

SECTION 4: BASIC HOME SAFETY INSTRUCTIONS AND INFECTION CONTROL

These safety instructions are provided to assist you in identifying safety hazards in your home and to help make your home safer.

GENERAL SAFETY

- Keep in touch with others. If you live alone, ask a neighbor, friend, or family member to check on you each day. You may want to consider a remote alert system that allows you to press a button to summon help. We can help you get one of these.
- Get up slowly. Because of certain changes in blood circulation, it is best to get up from a chair or bed slowly and to 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.
- Carrying objects—Make sure your view isn't blocked. Get a firm grip. Lift with your legs (knees bent, back straight), and walk slowly. Get help for heavy or 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 throw rugs whenever possible to avoid tripping.
- If you can't remove throw rugs, use rugs with non-skid backing to avoid slipping.
- Repair or replace torn carpeting to avoid tripping.
- Make the transition between types of flooring as even as possible and secure to prevent slipping.
- Don't walk on freshly washed or waxed floors until they are dry. Wipe up spills immediately.
- Avoid wearing socks, smooth-soled shoes or slippers on uncarpeted floors.
- Mark sliding glass doors with stickers to prevent someone from walking through.

Stairs

- Make sure handrails are well anchored on both sides of the stairway.
- Non-skid treads can be placed on wooden stairs to prevent slipping.
- Make sure carpeting is secure.

Furniture Layout

- Arrange furniture so that pathways are not cluttered.
- Chairs/tables need to be sturdy and stable enough to support a person leaning on them.
- Pad furniture that has sharp edges and corners.

Lighting

- Be sure that your lighting is ample to prevent falls and to assure that you can read medication labels and instructions easily.
- Good lighting in hallways, stairs, and bathrooms is important.

BATHROOM SAFETY

Bathtub

- Install skid-resistant strips or a rubber mat.
- Use a bath seat if it is too difficult to stand during a shower or to get out of the tub.
- Install grab bars on the side of the tub or shower for balance.
- DO NOT use the soap dish or towel bars for balance - these can pull out of the wall.

Toilet

- Use an elevated toilet seat or commode if you need support getting on and off of the toilet or you are not able to bend your hip normally.
- Install grab bars around the toilet if you need more leverage to get off the toilet.

Doors

- Avoid locking bathroom doors or use only locks that can be opened from both sides when you need assistance in the bathroom.

KITCHEN SAFETY

- Mark "ON" and "OFF" positions clearly on the dials on the stove.
- Use front burners of the stove to avoid reaching over burners. If there are children in the home, use back burners.
- Make sure pan/pot handles are not over other burners or over the edge of the stove.
- Do not wear loose or dangling sleeves while cooking - they could easily catch fire.

ELECTRICAL SAFETY

- Keep appliances away from water. Dropping water on an appliance or dropping the appliance into water (sink, tub, etc.) can cause electrocution.
- Use only appliances in good repair. Don't use lamps or appliances that appear to have a "short" when operated.
- Inspect cords. Don't use appliances with cords that are frayed or have wires exposed.
- Grounded plugs. Use grounded plugs or 3-prong adapters for medical equipment.
- Use of extension cords properly. Keep cords out of pathways to avoid excessive wear and prevent tripping. Do not overload outlets.

MEDICAL EQUIPMENT SAFETY - OXYGEN

- No smoking while oxygen is in use or in a room where oxygen is stored.
- Do not permit oil, grease, or other combustible materials to come in contact with oxygen equipment.
- Transport cylinders in proper carrier, and secure cylinders to prevent falling.
- Keep cylinders/concentrator in well-ventilated areas (no closets)-avoid extreme heat.
- Avoid use of electrical appliances (razors, hair dryers, etc.) while oxygen is in use.
- Any electrical equipment in use near an oxygen system must be properly grounded with three pronged plugs.
- Make sure you properly assemble and test oxygen equipment before use.
- Your nurse will set the flow meter to the prescribed rate per physician's orders.
- Make sure you have an adequate back-up supply of oxygen in case of emergency and/or evacuation.

MEDICAL EQUIPMENT SAFETY - DURABLE MEDICAL EQUIPMENT

- Follow manufacturer/supplier instructions.
- Call us at 818-774-3040 if you are having any problems.

MEDICATION SAFETY

- Medications should be removed from storage only at administration times and kept out of the reach of children, pets, and/or confused individuals.
- Store refrigerated drugs in a covered box, if available, inside the refrigerator, out of casual reach.
- Drugs labeled “For external use only” are to be kept separate from internal drugs.
- Store each individual family member’s drugs separately to avoid mix-ups.
- Do not take prescription drugs prescribed for another person.
- Do not keep drugs on windowsills or other surfaces where there is extreme exposure to light or heat.
- Re-fill prescription medications several days before you use the last dose in the container. Your nurse will help you refill the drugs supplied by Hospice.
- Check medication expiration dates and discard any that have expired by putting them in a plastic bag with liquid soap and placing them in your garbage can.
- Do not “catch-up” doses if you miss taking a dose of your medicine. Ask your nurse what you should do.
- Dispose of contaminated/soiled materials by placing them in a plastic bag and sealing the bag before throwing it away.

PROPER BODY MECHANICS—BASIC PRINCIPLES

Practice Good Body Mechanics

- Carry any objects close to your body; stay well balanced, and avoid stretching or leaning.
- Work at comfortable height.
- Lift with legs/hips, not your back.
- Keep back straight; do not twist or turn. (If possible, better to roll, drag, push or pull).
- Stand with one foot forward for a wider base of support and stability.
- Bend your knees, squat and use your thigh muscles.

PROPER TECHNIQUES WITH A WALKER

Using Your Walker

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

Standing with Your Walker

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

Walking With Your Walker

- Pick up the walker and place it one foot ahead of you. If your walker has wheels, push it about one foot in front of you.
- Place your affected (weaker) leg ahead of your unaffected (or stronger) leg.
- Push down with your hands and bring forward your unaffected (or stronger) leg.
- Keep repeating sequence.
- Always walk with the assistance of another person if you feel weak or unsteady. If you suddenly

feel as if you might fall, have the person assisting you gently lower you to the floor. Call us if there are any problems with your walker or if you need help learning how to use your walker.

SAFETY TIPS FOR HOSPITAL BEDS AND WHEELCHAIRS

Electric Hospital Beds

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

Wheelchairs

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

Please call us if there are any problems with your Hospital Bed or Wheelchair.

MOVING THE PATIENT FROM BED TO WHEELCHAIR OR COMMODE

STEP 1: Move the patient toward the edge of the bed

- Move the patient's head and shoulders. Remember to use good body mechanics.
- Move the patient's legs.
- Slide your arms well under the patient's hips.
- Keep your back and abdominal muscles tightened and in good alignment, move back as one unit, moving the patient's hips toward the edge of the bed.

STEP 2: Help the patient to sit up in bed

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

STEP 3: Help the patient to stand, then sit

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

FIRE PREVENTION AND RESPONSE

- Smoke detectors are recommended in each bedroom, hallway, and in the kitchen. Check them regularly.

- Mount or store a Fire Extinguisher (ABC type) in a central and accessible area. Make sure it functions well and that your know how to use it.
- DO NOT SMOKE IN BED or while sleepy.
- Keep space heaters/portable heaters away from furniture, cords, curtains, or other items that could ignite.
- Keep heaters away from walkways where they can be bumped and cause burns.
- Make sure you have a screen in front of your fireplace.
- Fire response—make sure you and all caring for you know how to use 911 for emergencies.
- Notify the Fire Department of any disabled persons at your residence

HAVE AN EVACUATION PLAN--

1. Establish specific exit routes for safe evacuation and make sure they are free of clutter.
2. Plan how to get someone who is ill out of an apartment that is not on the first floor.
3. Know the location of all doors and windows.

EARTHQUAKE PREPAREDNESS:

Before:

1. Keep a 1-2 week supply of food and water on hand and consider any special dietary needs or formulas you may be using. Place in a waterproof container.
2. Store a 1-2 week supply of medications and/or medical supplies that you will need (insulin, syringes, dressings.)
3. Know the procedure to follow if you are using medical equipment that runs on electricity and there is a power failure (oxygen concentrators, IV pumps, feeding pumps).
4. Keep a flashlight and portable radio handy. These are helpful if the lights go out or for an emergency.
5. Check the condition and charge on batteries, especially for special medical equipment.
6. Block or lock wheels of items such as hospital beds, commodes, and refrigerators.
7. Persons who live alone should appoint an official "buddy" who will check on them after an earthquake or disaster.
8. Anchor tall furniture to the wall and remove heavy items from the top shelves.

During:

1. If inside, stay inside and take cover under a heavy desk or table away from windows or objects which may fall.
2. Drag a bed bound patient (or transfer them to a wheelchair) to move to a safe area.
3. Lock the wheels on a wheelchair after moving to a safe area.
4. If outside, stand away from trees, electrical lines, and buildings.
5. Follow your evacuation plan.

After:

1. Skirball patients should go to the nearest emergency room if you run out of medications, solutions or supplies and are unable to contact the Agency. We will try to contact patients as soon as possible after an earthquake.
2. Turn off gas at the meter if you smell gas or hear hissing near gas appliances. DO NOT LIGHT ANY MATCHES IF A GAS LEAK IS SUSPECTED.
3. Assess for injuries and be prepared to administer First Aid.
4. Turn on a portable radio to listen for instructions from Public Safety Agencies.

****Also refer to the front section of your phone book for complete earthquake information.**

INFECTION PRECAUTIONS FOR THOSE GIVING DIRECT CARE TO PEOPLE IN THE HOME

General: People caring for persons in the home should use precautions designed to prevent blood and other body secretions from entering their body through any body opening, including cuts or open areas on the skin.

Hand washing is essential! Washing hands before giving direct care protects the patient who is susceptible to infection. Washing hands after direct care protects the caregiver. If a patient has a suspected or known infection or open wound or sore or has bleeding or discharge, gloves should be worn when attending to the patient.

Avoid

- Direct skin contact with blood.
- Surfaces which have been visibly soiled with blood, fecal material or other body secretions require disinfection. Household chlorine bleach is the best disinfectant because it is effective against organisms not killed by other household disinfectants.
- Use plastic bags to dispose of soiled tissues, dressings, bandages and soiled gloves. Close and secure the bag tightly when discarding. Dispose of the bag in the garbage, as you would other solid waste. Needles are considered infectious waste and should be placed immediately after use, intact, point downward and not capped, into the red puncture resistant container which we provide. Tell us when this container is full so that we can remove it and replace it with a clean one.
- At the end of any physical care, ALWAYS WASH YOUR HANDS.
- Hand Sanitizers may be used in lieu of hand washing with soap and water unless there is visible soil present. Keep the sanitizers close to the patient’s bedside and use often.

PAIN MANAGEMENT

As a patient of Skirball Hospice, you can expect that:

- your pain level will be assessed
- your reports of pain will be believed
- you will receive information about your pain and pain relief measures
- a concerned staff member will be committed to pain prevention and management
- you can receive effective pain management

As a patient of Skirball Hospice, we will expect you to:

- Take your medications as ordered
- Ask your nurse what to expect regarding pain and pain management and discuss your pain relief options with your nurse
- Work with your nurse to develop a plan. Ask for pain relief when pain first begins and help your nurse assess your pain
- Tell your nurse if your pain is not relieved
- Tell your nurse about any worries you have

You will be asked about your pain on admission and a full assessment of that pain will be completed by the nurse. You will also be asked during every visit if you are having pain, have experienced pain since your last visit and to rate the pain and describe it. It is our intention that your pain will be controlled to the level you are most comfortable with. You are the best judge of your pain and how much you can tolerate. Some people think they should be able to “tough it out”, but pain is exhausting. It makes doing the things you want to do more difficult. The best plan is to be tough on pain and to get control of it. Sometimes people assume we can tell they are having pain, but this is not always true. Only you know when you are in pain, how bad it is, and what it feels like. When you tell us about your pain, you help us do a better job. You are not bothering us, you are not distracting us from other important treatments, and you are not a complainer. You are our partner in your care.

SOME GENERAL INFORMATION ABOUT PAIN

Pain is a sensation or feeling that hurts enough to make you uncomfortable. You may feel mild or severe discomfort. Pain can only be described by the person who is feeling it. Pain can be caused by:

- pressure
- tumor growth
- infection or inflammation
- poor blood circulation
- blockage of an organ or tube in the body
- bone fractures caused by cancer cells that have spread to the bone
- after-effects of surgery or radiation
- stiffness from not being active
- side effects from medication (i.e., constipation, mouth sores)

What to look for:

- What is causing the pain? (i.e., anxiety, movement, fear of taking medications, physical and emotional changes due to the disease process or illness)
- What makes the pain go away?
- When does the pain come back?

- What medication makes the pain go away?
- How often does the medication need to be given?
- When do you notice the pain?

What to do:

- Comfort measures include: relaxation techniques, assistance with care, massages, repositioning.
- Spend time talking about what is causing the discomfort.
- Take medication as directed by hospice.
- As the pain is controlled with medications, increase activity gradually as tolerated.
- Understand that physical and emotional changes are due to the illness.
- Seek emotional support.
- Manipulate environment to provide periods of rest, such as:
    - o Making room dark
    - o Quiet time
    - o Time alone
    - o Position for comfort
- Provide periods of uninterrupted sleep.

What Not to do:

- Do not keep your main focus on the pain.
- Do not suddenly stop taking pain medications or other medications.
- Do not ignore or overlook the pain or discomfort.

When to call the Hospice Nurse:

- If any new or severe pain occurs.
- If pain or discomfort is not controlled by your present medication schedule.
- If you have any questions about the medications.

SOME MYTHS ABOUT PAIN MEDICATIONS:

Occasionally, people are afraid to ask questions about pain or pain medicines or they have beliefs about medications that may not be true. Look over the following information. Have any of these worries stopped you from talking about your pain?

Q: "I'm afraid I'll get addicted to the medicine."

When people have pain and use strong medicines, will they become addicts? The World Health Organization reports studies showing that addiction rarely occurs in patients who have no record of drug abuse. Drug addicts want and need drugs to get "high". They will do almost anything to get drugs. This is nothing like using pain medicines for pain. When your doctor gives you medicines for pain and you use them as directed, you are using them correctly and legally.

Q: "I'm afraid to use pain medicine now. What if the pain gets worse later and drugs won't work anymore? Shouldn't I save it?"

No. There are many things that we can do to control your pain:

- Sometimes a simple increase in dose will help. Some medicines can be increased as much as necessary - they have no upper limit. Medications can be increased gradually by your doctor.
- Sometimes changing medicines helps.
- Sometimes different drugs work well when taken together.
- There also may be other methods you can use to help control your pain, such as: relaxation, distraction, imagery, massage, etc. Talk to your hospice nurse to see if these or other methods may be incorporated into your pain control regime.

It is important to talk with your hospice nurse; do not make any changes yourself.

Q: "They want me to take strong pain medicine. Does that mean they've given up on me?"
Absolutely not! Strong pain medicine does not mean anyone's given up on you. Comfort is one of your main treatments. We continue all other treatments as well. When you do not hurt, you might find that you can move better and breathe more deeply. You will be able to enjoy your family and friends more. So, being comfortable is key to you feeling better.

Q: "I want to take pain medicine but I'm worried about side effects. What if I get constipated?"
Many pain medicines do have side effects. Constipation is a common side effect of many medicines. When we start you on pain medication, we will also start you on a routine bowel regimen to prevent constipation. It is important that you follow the directions to prevent constipation.

Q: "Will I get drowsy if I take pain medicines?"
Some pain medicines can make you feel drowsy at first. Often this will go away after a few days. If your pain has made you lose sleep, your may sleep a lot the first few days that you are comfortable. Check with your nurse if the drowsiness lasts more than a few days or makes it difficult to awaken you.

Q: "Won't my stomach get upset?"
Sometimes pain medicines can upset your stomach. This is another problem which may last just a few days. If it does not go away, check with your nurse about ways to decrease the nausea or dis comfort without giving up pain control.

Q: "I don't want to be confused."
Mental confusion may mean the dose (the amount of pain medication) needs adjusting. Call your nurse about problems with confusion.

Q: "If I talk about my pain, everyone will think I'm a pest. I don't want to complain. It's best to "tough it out."
Some people think it's a sign of strength to keep pain a secret and to refuse to take pain medicines. They use words like "sissy" or "wimp" and say they don't want to be a bother.

Good pain control can be a key to strength. It allows you to do the most you possibly can, to feel more rested and more in control of your life. It also helps your family and friends worry less. They can usually tell when you are in pain, even if no one talks about it. The best plan is to be tough on pain, to get control of it, so you can fell more like yourself again.

Just as it takes a while for diabetics to adjust to insulin, it will take a while to adjust to your pain medication(s). You should not sacrifice comfort because you are worried about side effects. Remember, side effects usually can be controlled or prevented. It is important to let your nurse know if you are having problems so you can work together to help you feel comfortable.

BOWEL PROGRAM

Most Hospice patients have some difficulty with their bowel movements (B.M.). There are several reasons why you may be constipated. Changes in your diet, decreased fluid intake or decreased activity may contribute to constipation. The use of pain medication is often a major cause of constipation. Untreated constipation can lead to a more serious condition (impaction or bowel obstruction) and a daily bowel program can help to prevent such problems. The overall goal is to have a bowel movement regularly. The following guidelines should help you maintain normal bowel function:

1. Drink plenty of liquids. Tea, hot lemon water and juices such as prune juice may be effective.
2. Try to have a B.M. at the same time of the day. Be sure to allow adequate time on the toilet or bedpan.
3. Keep a record of your bowel movements and note whether they are hard or soft.
4. Take your stool softener/laxative pill as prescribed. The dose can range from 2-8 pills per day or more if needed. Examples of such preparations are Colace and Senna S.
5. Other laxative preparations can be added if the stool softener/laxative pill alone does not work. Examples of these are Dulcolax, Milk of Magnesia or lactulose.
6. Call the nurse if you do not have a B.M. in 2-3 days. It might be necessary for you to have a rectal suppository, an enema, or be checked for a stool impaction.
7. Call the nurse if you have any of the following symptoms: abdominal distention or bloating, rectal pain with your bowel movement, the urge but inability to pass stool, oozing of liquid stool after no B.M. for several days or rectal fullness and pressure.

NUTRITION/HYDRATION

Eating is an important part of our lives. Many cultures place much importance on meal planning and social interactions centered around food. Often feeding and preparing a meal for a loved one is a way of communicating love, concern and caring in a non-verbal way. When a loved one is ill, we prepare wholesome food to help them recover.

Whenever anyone is ill, it is common for his or her appetite to decrease, whether the illness is the flu or related to the end of life. The body's need for calories and other nutrients is altered because of the change in activity and the change in metabolic rate, due to the disease process. Many hospice patients experience one or more of the following problems that interfere with nutritional intake: decrease in or loss of appetite, nausea, vomiting, chronic pain, diarrhea and constipation. This makes it difficult to find the right kind of foods that are well tolerated and accepted by the patient. Too often this challenge can turn into friction between the patient and the caregiver and interfere with open communication.

To keep communication open, it is best to allow the patient to eat what and when he/she desires. When a person is facing the end of life, priorities change and eating is no longer important. Furthermore, the disease process and medication can cause changes in taste as well as aversion to specific foods. The following are frequent eating problems and suggestions for overcoming them. Remember these are just suggestions and each person has individual needs and preferences. For increased nutritional needs such as added calories, protein, fluids, vitamins and/or minerals contact the hospice nurse who can consult with the dietitian.

WHEN IT IS DIFFICULT TO SWALLOW LIQUIDS OR SOLIDS

1. Thin liquids are usually the most difficult to swallow. Nectar consistency liquids and softer blended foods are sometimes easier to swallow. There is also commercial thickener available which we can provide.
2. If mucous is a problem cranberry, pineapple or citrus juice may be helpful in cutting or thinning the mucous. If milk is a problem, a milk free nutritional supplement can be used. Note: Ensure, Boost and the like are not made with milk. (For further information on swallowing difficulties or for special products contact the Hospice nurse who can consult with the dietitian).

WHEN THE PATIENT IS JUST NOT HUNGRY

1. Keep snacks handy and in sight for "nibbling."
2. Drinks such as milk shakes or frozen yogurt provide a large number of calories within a small

volume. Also supplemental drinks such as Carnation Instant Breakfast, Boost and Ensure provide additional nutrients.
3. Breakfast foods are often well tolerated. Give the patient whatever he or she likes whenever desired. Don't wait until "mealtime."
4. Try serving small meals with snacks in between (small meals may even be just one item).
5. Serve foods on a small plate so not to overwhelm the patient.

WHEN THE PATIENT EXPERIENCES NAUSEA/UPSET STOMACH

1. Provide frequent small meals.
2. Offer bland foods that are not greasy or too sweet, such as chicken noodle soup with saltine crackers, gelatin with fruit and apple juice.
3. Give liquids between meals rather than at meal times. Clear, cold beverages are usually better tolerated. Popsicles, flavored ice cubes are good choices.
4. Dry foods such as dry toast and crackers are usually well tolerated.
5. Position the patient in the sitting position as close to 90° as possible for eating and for at least two hours after eating.

WHEN THE PATIENT'S MOUTH OR THROAT IS SORE OR DRY

1. Give small bites of food and with a swallow of beverage with each bite.
2. Try cold foods such as popsicles, sherbet, and ice cream. Fruit ices, milk shakes and ice chips (sometimes if eaten first, ice cold foods may make eating other foods more tolerable).
3. Sometimes using a straw can make swallowing more comfortable.
4. Smooth foods such as whipped cream, pudding, cream pies, canned fruits or gelatins are usually less irritating to the mouth or throat.
5. Creamed soups and other creamed foods are often well tolerated. Keep temperatures warm rather than hot.
6. Offer soothing beverages such as apple juice, peach or pear nectar and milk (if tolerated). Carbonated beverages, liquids containing salt such as broth or vegetable juices and those containing acid such as citrus juices and highly spiced foods may irritate a sore mouth or throat.

WHEN THE PATIENT REFUSES TO EAT OR DRINK

Usually the difficulty swallowing or the refusal of food and fluids is a sign that death is near. The patient does not experience the pangs of hunger nor do they experience thirst. Research has shown that the only discomfort is that of dry mouth. At this point, comfort is provided by keeping the mouth clean and moist with drops of water or a moistened toothette. Use of lip moisturizers also provides comfort.

While it is tempting to want to provide food and fluids by artificial means, most often the burdens of the procedures outweigh any possible benefit. Fluids given intravenously do not diminish thirst. Patients may become bloated and experience swelling and even difficulty breathing due to inability of the body to use the artificial nutrients being given.This is often a very difficult time for loved ones and requires information and support in decision-making. We encourage you to talk about your concerns with members of the hospice team who will provide information or a listening ear.

PREPARING FOR APPROACHING DEATH

When a person enters the final stage of the dying process, two different dynamics are at work, which are closely inter-related and interdependent. On the physical plane, the body begins the final process of shutting down, which will end when all the physical systems cease to function. Usually this is an orderly and non-dramatic progressive series of physical changes which are not medical emergencies requiring invasive interventions. These physical changes are a normal, natural way in which the body prepares itself to stop and the most appropriate kinds of responses are comfort-enhancing measures.

The other dynamic of the dying process is at work on the emotional-spiritual-mental plane and is a different kind of process. The "spirit" of the dying person begins the final process of release from the body, its immediate environment and all attachments. This release also tends to follow its own priorities, which may include the resolution of whatever is unfinished of a practical nature and reception of permission to "let go" from family members. These "events" are the normal, natural way in which the spirit prepares to move from this existence into the next dimension of life. The most appropriate kinds of responses to the emotional-spiritual-mental changes are those which support and encourage this release and transition.

When a person's body is ready to cease functioning, but the person is still unresolved or unreconciled over some important issue or with some significant relationship, he/she may tend to linger even though uncomfortable or debilitated in order to finish whatever needs finishing. On the other hand, when a person is emotionally-spiritually-mentally resolved and ready for this release, but his/her body has not completed its final physical process, the person will continue to live until the physical "shut down" is completed.

The following signs and symptoms of impending death are to help you understand and know what to expect. Keep in mind that not all of these will occur with every person or in this particular sequence.

PHYSICAL SIGNS AND SYMPTOMS:

Coolness

The patient's hands and arms, feet and then legs may be increasingly cool to the touch, and at the same time the color of the skin may change. The underside of the body may become darker and the skin becomes mottled (bluish and blotchy). This is a normal indication that the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs. Keep the patient warm with a blanket, but do not use an electric one.

Sleeping

The patient may spend an increasing amount of time sleeping, and appear to be uncommunicative or unresponsive and at times be difficult to arouse. This normal change is due in part to changes in the metabolism of the body. An appropriate intervention would be to sit with the patient and hold their hand, speaking softly and naturally.

Disorientation

The patient may seem to be confused about the time, place and identity of people surrounding him/her, including close and familiar people. This is also due in part to the metabolism changes. Identify yourself by name before you speak, rather than ask the patient to guess who you are. Speak softly, clearly and truthfully when you need to communicate something important for the patient's comfort, such as, *"It's time to take your medication,"* and explain the reason for the communication, such as *"So you won't begin to hurt."*

Incontinence
The patient may lose control of urine and/or bowel as the muscles in that area begin to relax. Make every effort to keep the patient clean and comfortable.

Congestion
The patient may have gurgling sounds coming from his/her chest and these sounds may become very loud. This normal change is due to the decrease of fluid intake and inability to cough up normal secretions. Suctioning usually only increases the secretions and causes sharp discomfort. Gently turn the patient's head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. The sound of the congestion does not indicate the onset of severe or new pain. Hospice has medication to help dry up some of these secretions and reduce the gurgling sound.

Restlessness
The patient may make restless and repetitive motions, such as pulling at bed linen or clothing. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolism changes. Do not interfere with or try to restrain such motions. To have a calming effect speak in a quiet, natural way; lightly massage the forehead; read to the patient; or play some soothing music. If the patient becomes increasingly agitated, there are medications to help calm the restlessness.

Fluid and Food Decrease
The patient may have a decrease in appetite and thirst wanting little or no food or fluid. The body will naturally begin to conserve energy, which is expended on these tasks. Do not try to force food or drink into the patient. To do this only makes the patient much more uncomfortable. Small chips of ice, frozen Gatorade or juice may be refreshing in the mouth. Moistened swabs may keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also increase physical comfort.

Urine Decrease
The patient's urine output normally decreases and may become tea colored—referred to as concentrated urine. This is due to the decreased fluid intake as well as decrease in circulation through the kidneys.

Breathing Pattern Change
The patient's regular breathing pattern may change with the onset of a different breathing pace. A particular pattern consists of breathing irregularly (i.e. shallow breaths with periods of no breathing of 5 to 30 seconds and up to a full minute). This is called Cheyne-Stokes breathing. The patient may also experience periods of rapid, shallow pant-like breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Elevating the head, and/or turning the patient on his/her side may bring comfort. Hold his/her hand and speak gently.

EMOTIONAL, SPIRITUAL, MENTAL SIGNS AND SYMPTOMS

Withdrawal
The patient may seem unresponsive, withdrawn, or in a comatose-like state. This indicates preparation for release, a detaching from surroundings and relationships and a beginning of letting go. Since hearing remains intact all the way to the end, speak to the patient in your normal tone of voice and identify yourself by name when you speak.

Vision-Like Experiences
The patient may speak or claim to have spoken to persons, who have already died, or to see or have seen places not presently accessible or visible to you. This does not indicate a hallucination or a drug reaction. The patient is beginning to detach from this life and is being prepared for the transition so it

will not be frightening. Do not contradict, explain away, belittle, or argue about what the patient claims to have seen or heard. Just because you cannot see or hear it does not mean it is not real to the patient. Affirm his or her experiences. They are normal and common. If they frighten the patient, explain to him/her that they are normal. If they become severe, notify your nurse.

Decreased Socialization

The patient may only want to be with a very few people or even just one person. This is a sign of preparation for release and an affirmation of who the support is most needed from in order to make the appropriate transition. Help family members to understand that if they are not part of this inner circle at the end, it does not mean they are not loved or are unimportant but that they have already fulfilled their tasks and it is time to say good-bye.

Unusual Communication

The patient may make a seemingly out of character or illogical statement, gesture or request. This indicates that he/she is ready to say good-bye and is testing to see if the family is ready to let him/her go.

Giving Permission

A dying person will normally try to hold on, even though it brings prolonged discomfort in order to be sure that those who are going to be left behind will be all right. Giving permission and assuring the patient that everyone will miss them but will be OK may allow the patient to let go.

Saying Good-bye

When the patient is ready to die and the family is able to let go, then it is time to say goodbye. Saying good-bye is the final gift of love for it achieves closure and makes the final release possible. Tears are a normal and natural part of saying good-bye. You may lay in bed with the patient and hold him/her, or take their hand and say what they need to say. It may be as simple as saying “I love you” or it may include recounting favorite memories, places and activities they shared. It may include saying “I’m sorry.”

It is our goal that every death will be accompanied by comfort, dignity and compassion. It is our job to support the patient and the family in making the death experience exactly what they wish it to be. Death is not easy for most people to accept, at least initially, but we find that almost all patients reach acceptance before they die. It is always more difficult for the loved ones that are left behind. It is our other job to be there for the bereaved, before, during and after the death of their loved one. We thank you for the privilege of being allowed to attend to your loved one and to know you under these circumstances.

In the rising of the sun and its going down, we remember them.
In the glowing of the wind and the chill of Winter, we remember them.
In the opening of buds and the rebirth of Spring, we remember them.
In the blueness of the sky and the warmth of Summer, we remember them.
In the rustling of leaves and in the beauty of Autumn, we remember them.
In the beginning of the year and when it ends, we remember them.
When we are weary and in need of strength, we remember them.
When we have joys we yearn to share, we remember them.
So long as we live, they too shall live, for they are now a part of us,
We remember them.

Gates Of Prayer, Gittleson, R.B., (1975)

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