Patient & Caregiver GUIDE

We are all just walking each other home.

Ram Dass

Much of the care you will receive as an Avow patient or family member has been funded by people in the community who want the best for you. Their gifts allow us to offer you services that make you feel cherished, safe, and loved.

The Joint Commission — National Quality Approval

We Honor Veterans

Your Primary Physician: _____

Your Team Members: _____

_____

_____

_____

Interdisciplinary Team Communication Tool

	Initials	Date
Advance Directives: Living Will _____ Health Care Surrogate _____ DPOA: _____ DNRO: _____ Other: _____	_____ _____ _____ _____ _____	_____ _____ _____ _____ _____
Veteran Information:		
Religious Preference: _____ Church Affiliation: _____	_____ _____	_____ _____
Need for Language Services:		
Volunteer Needs:		
Complementary Therapy Services:		
Caregiver Needs:		
Communication Preferences:		

Emergency Contact:		
Funeral Arrangements:		

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Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

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When viewing the electronic version of this Guide:
Place your cursor over the chapter heading above and press the Control key to be taken directly to that chapter/page in the Guide

If you have a safety concern please:

- Call Avow (239)261-4404 (24/7)
- Tell an Avow Team Member
- Tell us on your Patient Survey
- Tell us on a customer feedback form

A Message from our Avow Team

Dear Family:

Thank you for choosing Avow as your partner in care. Our goal is to help each patient live as fully as possible, in their own familiar, comfortable surroundings, and in the company of family and friends.

To help you better understand our policies, procedures and practices, our professional staff, with the advice of hospice patients and families, have compiled this guide as a resource for you. This guide also provides specific information on symptom management for the caregiver.

You will read in this book that hospice care is a team effort and that our organization operates as an interdisciplinary team. The most important members of that team are the patient and family. We are here to assist you and to work with you throughout the course of your illness so that you can achieve comfort, peace, and dignity.

You may have a lot of questions as you learn about hospice care. We encourage you to ask your nurse, social services coordinator, chaplain, or any of our staff to respond to your questions or concerns. We realize that peace of mind often results from knowing and understanding the situation you face. So, please do not hesitate to call on us. We're here to help you.

The mission and vision of our organization, as well as the values we embrace, are provided on the next page. We hope you will take a moment to read them. They will give you a sense of what we believe and hold dear as an organization and the principles that guide everything we do.

We hope you find this book to be useful and helpful. Please share any ideas or thoughts you have to improve it with us or other members of your team.

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

We are privileged to be of service to you and your family.

Feel free to visit our website at www.avowcares.org. It provides a comprehensive review of our services.

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If you are unable to reach us at any time, please call us at (239) 280-2271.

Our Mission, Vision, Values

The Avow Mission Statement

We create peace of mind by providing compassionate care and support to those who need us. SM

Our Vision

To be our community's choice for support through life's transitions. SM

Our Values

We embrace the following values that guide everything we do and will make it possible for us to achieve our mission and make our vision a reality.

- **Innovation**: we embrace change and are always looking for creative ways to solve problems and serve new populations.
- **Integrity**: we are honest, hardworking professionals driven solely by the well-being of our patients, their loved ones, and the communities we serve.
- **Collaboration**: we know that we cannot achieve everything we want without working hand-in-hand with each other and with the community.
- **Celebration**: we believe in the importance of celebrating life and relationships.
- **Education**: we are teachers who believe it is important to guide those we serve and to educate our community. We are also responsible for continuously learning and developing our expertise.

Hospice Service's Mission

We believe by changing the way people die, we change the way people live.sm

Characteristics of the Hospice Program

The Hospice Goal

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
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To affirm life and focus on living in the face of a life-limiting illness.

The Hospice Program

Dedicated to caring for the physical, emotional, social, and spiritual needs of patients and their families.

Primary Unit of Care

The patient and the caregiving family/significant other(s) are embraced as the unit of care.

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Symptom Control

- **Physical** – pain, nausea, vomiting, breathing difficulties and other symptoms are controlled as effectively as medically possible.
- **Emotional** – the patient and family are helped to cope with emotional distress connected with the illness and impending death.
- **Spiritual** – the patient and family are assisted in finding meaning in life and experiencing peace, even in the face of death.

Physician-Directed Interdisciplinary Care

All health care is provided under the direction of a qualified physician and coordinated by our health care team of nurse practitioners, nurses, social workers, and chaplains. In addition our hospice aides, complementary therapists and trained volunteers provide services.

Services Available On Call

Hospice services are available 7 days a week, 24 hours a day.

Bereavement Follow-Up

Grief support services are extended to the family during the period of bereavement.

Hospice Services Based on Need

Hospice services are provided based on need rather than ability to pay. Approximately 12 percent of the care we provide is un-reimbursed. We depend on the generous support of the community to make up the deficit.

Communicating with Avow

Call Avow: 24/7 Telephone Access to Help

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

The Avow number, (239) 261-4404, is answered by someone who can direct you to the care or resources you need.

If you have questions or need help – any time day or night, simply call us at (239) 261-4404.

We'll send someone to your home, arrange for needed supplies or guide you on how to resolve minor issues safely on your own. Please call us any time you need us.

Non-discrimination Notice

Avow complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, gender, gender orientation or sexual orientation. Avow does not exclude people or treat them differently because of race, color, national origin, age, disability, gender, gender orientation or sexual orientation.
If you believe that Avow has discriminated in another way on the basis of race, color, national origin, age, disability, gender, gender orientation or sexual orientation you can file a grievance with the Chief Compliance Officer by mail at Avow Hospice 1095 Whippoorwill Lane, Naples FL. 34105; by telephone number at (855) 348-4998; or via the website using NAVEX Global at www.avow.ethicspoint.com. If you need help filing a grievance, contact any member of your care team, who are available to help you, or contact Avow Hospice at (239) 261-4404.

Access to Language Services

Avow provides free aid and services to people with disabilities to communicate effectively with us, such as: qualified sign language interpreters and written information in other formats (large print, audio, accessible electronic formats, other

formats). It also provides free language services to people whose primary language is not English, such as: qualified interpreters and information written in other languages.

If you need these services, contact Avow Hospice at (239) 261-4404 to request these services. If you believe that Avow has failed to provide these services, you can file a grievance with the Chief Compliance Officer by mail at Avow Hospice 1095 Whippoorwill Lane, Naples FL. 34105; by telephone at (855) 348-4998; or via the website using NAVEX Global at www.avow.ethicspoint.com. If you need help filing a grievance, contact any member of your care team, who are available to help you, or contact Avow Hospice at (239) 261-4404.

You can also file a civil rights complaint with the U.S. Department of Health and Human Services, Office for Civil Rights.
You may file a complaint electronically through the Office for Civil Rights Complaint Portal, available at https://ocrportal.hhs.gov/ocr/portal/lobby.jsf;
By mail at: U.S. Department of Health and Human Services 200 Independence Avenue, SW Room 509F, HHH Building Washington, D.C. 20201; or
By phone at: 1-(800) 368-1019, (800) 537-7697 (TDD).
Complaint forms are available at http://www.hhs.gov/ocr/office/file/index.html.

SPANISH
ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-(888) 484-2869.

FRENCH CREOLE (HAITIAN)
ATANSYON: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele 1-1-(888) 484-2869.

VIETNAMESE
CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-(888) 484-2869

PORTUGUESE (EUROPEAN)
ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 1-(888) 484-2869.

CHINESE
注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電1-(888)484-2869。

FRENCH
ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-(888) 484-2869.

TAGALOG
PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-(888) 484-2869.

RUSSIAN
ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-(888) 484-2869.

ARABIC
مقر) 1-(888) 484-2869- ةظوحلم إذا تنكلثدحتتركلا ةغلال إنفتامدخ ةدعاسملاةيغللارفوتتكلنا جمالبلصتمقربب
1.(1-(888) 484-2869- فتهم صمالمكلوا: 1

ITALIAN

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 1-(888) 484-2869.

GERMAN

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-(888) 484-2869.

KOREAN

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-(888) 484-2869 번으로 전화해 주십시오.

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

POLISH
UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 1-(888) 484-2869.

GUJARATI
સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 1-888-484-2869.

THAI
เรียน: ถ้าคุณพูดภาษาไทยคุณสามารถใช้บริการช่วยเหลือทางภาษาได้ฟรี โทร 1-(888) 484-2869.

The Team Approach to Care

No single person can provide for all the needs of hospice patients and their families. Therefore, hospice care is provided by a team of clinicians, with different specialties, working together. This provides a comprehensive and responsive form of care, benefiting both the patient and family. The team consists of the following members, all of whom (excluding volunteers) are paid professionals:

Attending Physician: The patient's primary physician, also known as the attending physician, is a key member of the hospice team. The attending physician assumes responsibility for medical management of the patient's treatment throughout his or her stay in the hospice program. An Advanced Practice Registered Nurse (APRN)/ nurse practitioner, can also assume the role of attending physician in hospice as the patient wishes. The hospice patient chooses whether a hospice physician or nurse practitioner or a community based provider will be their attending physician.

Clinical Medical Director: The Clinical Medical Director is a physician with special education, interest and expertise in care of the terminally ill. He/she is employed full time by Avow and is available to serve as attending physician for any patient who

receives hospice services. The Clinical Medical Director or a member of the medical team visits patients in the home, nursing home, or hospital; visits can also be requested by the patient, family, nursing staff or other physicians.

Nursing Staff: A Registered Nurse Case Manager is assigned to each patient/family and they act as the lead coordinator of the patient and family's hospice care. Avow nurses visit the patient at home, in assisted living or skilled nursing facilities or in the hospital. The visit schedule depends on patient and family needs. Avow nurses are experts in assessing and managing symptoms. They keep the primary physician informed about the patient's condition and support and teach the family about the patient's condition, what to expect and how to care for the patient.

Social Workers: A social worker is assigned to each patient and family in Avow's hospice services program. With any life-limiting illness, it is normal to experience grief, anger, frustration and depression. A very important role of the Avow social worker is to help family and friends express and understand the many challenging issues that may arise when a loved one has a terminal illness.
They can assist with end of life planning such as Advance Directives and funeral plans. The Avow social worker can act as liaison or advocate when other community agencies are needed. They are trained to respond in unique situations and will work with the patient and family to enhance the quality of life.

Hospice Aides: The hospice aide is available to assist patients with personal hygiene such as showers, baths, shampoos and linen changes. The frequency of visits is based on the patient's medical needs. They are specially trained and supervised under the direction of the nursing staff.

Hospice Chaplains: Spiritual care is offered as an optional service to each patient and family by Avow clergy. Avow's spiritual care is provided by clinically trained chaplains who can relate to the diverse needs of each patient and family.
Avow chaplains also work cooperatively with a family's local clergy to supplement the spiritual care requested.

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

Complementary Therapists: In keeping with our promise to help patients reach their goals of physical, emotional and spiritual comfort, we offer professional complementary therapies. These therapists have special education, credentials and expertise in their professions and in the care of hospice patients and families. Our massage therapists, art therapists, music therapists and Reiki practitioners visit patients in their homes, nursing facilities and Avow's Frances Georgeson Hospice House.

Volunteers: Avow has trained volunteers who provide respite and companionship to patients and their families. If you're interested in having one of our volunteers pay a visit, call us at (239) 261-4404 and ask for the Volunteer Department. If possible, please call at least 48 hours before you would like the volunteer to visit.

After Hours Advice and Assistance

The administrative offices at Avow are open five (5) days a week, from 8:30 a.m. to 5:00 p.m. to assist you or answer your questions.

In addition, a hospice team (a physician, nurse, family support, and administrator) is available twenty-four hours a day/seven days a week (24/7). If an unexpected change in the patient's condition occurs, or new problems arise, you may contact us at (239) 261-4404. **Give the staff member your name, the patient's name and phone number.** The staff member will notify the on-call nurse (if you haven't reached the on-call nurse directly) who will return the call within 15 minutes. **If you have not received a call within this time frame, please call again.**

In the event that you are unable to get an answer through our main number, you may use this alternate number (239) 280-2271.

If the county is in an Emergency Management Mode, for example a hurricane warning, and you cannot reach us on any of the above numbers, please dial (239) 263-4194 or (239) 263-4237.

Volunteer Program Guidelines

Avow Volunteers are a dedicated group of individuals who share their time, talents, and compassion with the patients and families served by Avow. Like Avow staff, volunteers are required to uphold the organization's code of professional conduct that ensures all patient/family contacts are documented, recorded, and are in accordance with the patient's plan of care.

Volunteers Do

Provide companionship
Prepare snacks, light meals
Assist with clerical tasks
Read to patients
Write letters for patients
Transport patients (if appropriate)
Provide haircuts in homes and facilities (licensed hairdresser volunteers)
Bring their trained pets to visit patients
Provide hand aromatherapy (gentle hand treatment combined with essential oils)

Volunteers Don't

Administer medications or vitamins
Lift or move patients
Provide hands-on physical care

Patient and Family Responsibilities

- Volunteer requests may be made by notifying a member of the patient care team who will make a volunteer referral to the Volunteer Services Department.
- Volunteer requests should be made at least 48 hours prior to the date of the desired service.
- The request should be specific in nature and include an estimated time duration.

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

- If you (the family member) find that you will be unavoidably detained from returning by the designated departure time of the volunteer, please call the volunteer to notify them of the delay.
- If you find that scheduled volunteer services are in fact not needed, please notify the Volunteer Services Department as soon as possible. If you are unable to reach Volunteer Services, please contact Avow (239) 261-4404 to cancel the volunteer request.
- Because volunteers are providing a service on behalf of Avow, they are not permitted to accept money, gifts, or social invitations. We ask that you respect our policy and refrain from making any such offers or requests to our volunteers.

Hand Aromatherapy

Hand Aromatherapy utilizes a therapeutic combination of aromatherapy and light, soothing touch to the patient's hands. Through a series of gentle, gliding, repetitive movements, pure essential oils are introduced through direct application to the skin. Hand Aromatherapy, provided by trained volunteers, is designed to naturally promote a more relaxed physical and emotional state.

Respite Volunteers

Avow can arrange for trained volunteers to visit your home for short periods of time to provide caregivers a break to enjoy a hobby, run errands, etc. You can arrange for a volunteer to visit on a regular or as-needed basis by contacting the Avow Volunteer Department at (239) 261-4404.

*Note: Volunteers **may not** administer medications, lift or move patients or provide hands-on medical care at any time.*

Complementary Therapies

In addition to prescriptive medical services provided by Avow, patients may take advantage of a variety of professional complementary therapies that further enhance comfort. Complementary therapies are offered free of charge, services are funded through the generosity of community philanthropy. Offerings include:

Art Therapy

At Avow, a registered art therapist facilitates and guides the use of art materials in a supportive and non-judgmental manner. The focus is on the process of making art rather than the resulting product or outcome. This process of creating and talking about art with an art therapist can help one increase awareness of self, cope with symptoms, reduce stress and communicate thoughts and feelings when words might fail. Additional benefits include improved quality of life and a greater sense of physical, emotional and spiritual well-being. Art creations can become a visible, tangible record of one's inner experience and a lasting legacy.

Massage Therapy

Massage therapy in hospice care is the use of gentle, nurturing touch to complement the traditional means of coping with the multidimensional pain associated with terminal illness. Our licensed massage therapists manipulate the soft tissue structures of the body through various techniques, with the goal of alleviating pain, discomfort, muscle spasms, stress and anxiety, and improving one's overall sense of well-being. In addition, massage is used to relieve edema (swelling), insomnia, restlessness, constipation and nausea. The massage therapist assesses the patient's needs at each visit and then determines the most appropriate combination of techniques to successfully address those needs.

Music Therapy

Music plays a significant role in the human experience and can become even more meaningful at the end of life. People find meaning and a sense of connection when experiencing music, regardless of age, culture, personality, intellect, emotional or physical state. Our music therapists are board certified clinicians who facilitate this connection using a variety of individualized interventions. Music therapy may include the singing or playing of live music for and with a patient, songwriting, music with

imagery for relaxation, song lyric interpretation and life review with music. These interventions are designed to reduce isolation, depression, anxiety and pain; provide opportunities for non-verbal or verbal expression of feelings; and improve coping ability and emotional well-being, all within the context of a supportive, therapeutic relationship.

Reiki (pronounced "ray-key")

Reiki is a Japanese word meaning "universal life energy." The belief of many ancient cultures, also supported by current research, is that energy extends throughout and beyond the physical body. It is believed that disruptions to or imbalances of the energy flow within the body correlate to illness and distress. The purpose of Reiki is to align the universal energy with one's individual energy. The art of delivering Reiki addresses both chronic and acute conditions by promoting balance among all the body systems. By gently placing the hands upon different areas of the patient's body for several minutes at a time, the Reiki practitioner serves as a channel of energy flow from the universal life energy to the individual. Reiki provides a deep relaxation experience, a heightened sense of well-being, release of muscle tension and relief from anxiety and depression. In addition, Reiki is effective in reducing pain.

Specialty Consults

Physical Therapy, Occupational Therapy, Speech Therapy, and Dietary Counseling

For some patients, a short course of physical therapy, speech therapy, occupational therapy, or dietary counseling improves quality of life and brings comfort.

Therapy services ordered by the attending physician, if determined to be appropriate by the Avow Medical Director, are arranged and paid for by Avow. The services are provided through licensed, contracted professionals.

Durable Medical Equipment (DME)

DME refers to rented assistive devices and equipment that are medically necessary to help the patient and family with meeting their hospice goals of care. DME can include items such as commodes, wheelchairs, hospital beds, over-bed tables, walkers, canes and shower chairs. They must be ordered by a member of the medical team.

Avow Hospice provides durable medical equipment (DME) necessary to assist patients in achieving therapeutic benefits and to enhance activities of daily living, through a licensed contracted vendor. For these purposes Avow has secured the services of an equipment company, SHEC/CAPSTONE HME which will provide equipment rental on a temporary basis to meet the patient's and family's needs while the patient is receiving hospice services with Avow.

DME rental costs are covered by the Hospice Medicare Benefit when the DME is medically necessary, ordered by the physician and included in the hospice plan of care. If the patient has a different type of health insurance, Avow's billing department can assist with identifying appropriate coverage.

SHEC/CAPSTONE HME will provide and maintain the equipment for the duration of the patient's stay at Avow, and the equipment must be returned to the equipment company when Avow hospice services are discontinued.

To promote safe, effective, and responsible use of DME, Avow patients and their representatives must comply with the instructions for use, intended use and purpose of the equipment provided for the duration of services and must respond to SHEC/CAPSTONE's request to coordinate pick-up of the equipment when services are discontinued.

Please note these important notices regarding any DME provided by SHEC/CAPSTONE HME:

1. DME provided to a patient either upon admission to Avow or while the patient is receiving hospice services from Avow Hospice Inc. is the property of and is owned by SHEC/CAPSTONE HME.

2. DME provided to the patient while receiving hospice services at Avow is only intended to be kept and used for the duration of the patient's stay with Avow and must be returned to its proper owner, SHEC/CAPSTONE HME, upon discontinuation of hospice services.

3. Patients/representatives are responsible for responding to SHEC/CAPSTONE HME's request for communications to coordinate pick up of the equipment and to ensure that the equipment is returned.

Admission, Discharge and Care Locations

Hospice care is provided through an agreement between the Avow staff, the patient, the person or persons providing the day-to-day care (caregivers) and the patient's physician.

Admission to Avow hospice services is voluntary. During an admission interview, patients sign an informed consent to participate. Avow then develops the plan of care with the patient and family.

Sometimes patients leave the Avow program. This may occur if the patient's disease goes into remission and the patient is no longer considered to have a life-limiting illness; if a patient moves out of our service area; or if the patient elects to be discharged from Avow's program. When a patient moves, Avow can make a referral to another hospice program in the patient's new home city, if one is available.

Avow delivers care anywhere, including private homes, nursing homes, assisted living facilities, our inpatient facility and hospitals within our service area of Collier County.

Hospice Care at Home

Home… a familiar and loving place where we feel secure, well cared for, and at peace. Home includes a home residence, a nursing home or an assisted living facility. Most people would prefer to spend their last days at home, surrounded by people and things they love. Avow is dedicated to making this goal a reality.

In this setting, the Avow team of nurses, physicians, social workers, chaplains, hospice aides and bereavement staff provide education and support to patients and their families. Avow's professional staff and volunteers, if requested, visit regularly to give care and comfort, answer questions, and make each day as full of life as possible. Complementary Therapies such as art therapy, music therapy, or therapeutic massage and Reiki, are also offered to patients living at home.

Patients may reside in an assisted living or skilled nursing facility for a variety of reasons, and Avow does provide hospice services to these individuals. The Avow team that provides care in this setting works closely with facility personnel to coordinate all aspects of care.

Inpatient Hospice Care

Inpatient services are available for those that meet the Medicare requirements for a General Inpatient Level of Care. These settings are designed to be home-like; there are no specific visiting hours so family members and friends can come and go as they please. Members of the medical team and nurses care for the patient around the clock. Additional services include social work, chaplains, aides, bereavement counselors, complementary therapies and volunteers.

Avow offers inpatient services in Collier County at our Frances Georgeson Hospice House. General inpatient care is ordered by our medical director for short term

symptom management and in times of symptom crisis. Our hospice house is located on Avow's main campus at 1095 Whippoorwill Lane, Naples, FL 34105. When entering the property, drive straight back past the administration buildings and past the lake on your left. The hospice house is located at the rear of the property.

Typically, patients come to a hospice house for a limited stay to obtain 24-hour skilled nursing care. (See inpatient admission agreement criteria.) Avow patients covered by Medicare or Medicaid (or selected commercial insurers) may be admitted to Georgeson Hospice House for short-term care for pain control or symptom management. This level of care is a short-term solution to a crisis. Patients receive intensive nursing, social work support and medical care to alleviate the situation that prompted the admission. Once a crisis has resolved and the patient no longer meets the General Inpatient criteria there is the potential of room and board charges that could be the patient's responsibility. This information is provided by the Social Worker and a member of the Patient Billing Department will contact you to discuss arrangements.

Some reasons for inpatient admission are:

Increased Pain requiring:

- complicated technical delivery of medication administration
- frequent evaluation by a nurse
- frequent medication adjustments

Symptom changes:

- requiring intensive nursing intervention
- respiratory distress that cannot be relieved at home
- complex wound care requiring intense, frequent and complicated dressing and treatment care

The length of the stay (number of inpatient days) is governed by medical necessity for each patient and Medicare/Medicaid/commercial insurer guidelines.

Inpatient Respite Care

Patients being treated under the Medicare Hospice or Medicaid Hospice Benefit have the option of being in an approved skilled nursing facility for up to five days to provide caregivers a break from care. You just need to ask a member of your Avow team to arrange this option for you and your loved ones.

Patients admitted for a respite stay will receive around the clock care by skilled nursing staff. When the stay is complete, the patient returns home and continues to receive care from their original Avow home care team. The respite benefit may be used as many times as needed, but for a maximum of five days each time.

Hospital Admission

One of the goals of Avow is to enable patients to remain at home, surrounded by their loved ones. If the patient's condition changes or a medical emergency arises, please call Avow at (239) 261-4404 anytime, day or night. A nurse will evaluate the patient's condition and contact the physician to determine the best course of action.
Please do not call 9-1-1.

For Medicare and Medicaid patients, Avow must pre-certify all medical care provided in order to be responsible for payment. If the physician determines that the patient needs to be hospitalized, Avow must be notified and this needs to be included in the plan of care. Be sure to tell the receptionist during the hospital admission process that the patient is an Avow hospice patient.

Four Levels of Hospice Care

Medicare (CMS – Centers for Medicare and Medicaid Services of the Federal government) defines and regulates how hospice services are provided in the USA.

The physician determines which level of care is needed and when, based on the patient's condition and type of care that must be provided.

Routine Hospice Care is the most common level of hospice care. With this type of care, an individual has elected to receive hospice care at their residence, which can include a private residence, assisted living facility or nursing facility. It is provided on an intermittent basis through clinician visits scheduled throughout the week based on needs and the plan of care.

General Inpatient Care is provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. General Inpatient Care begins when other efforts to manage symptoms have been ineffective. General Inpatient Care can be provided in a Medicare certified hospital, hospice inpatient facility, or nursing facility that has a registered nurse available 24 hours a day to provide skilled, direct patient care.

Continuous Home Care is shift care provided for between 8 and 24 hours a day to manage pain and other acute medical symptoms. Continuous home care services must be predominantly skilled nursing care, supplemented with caregiver and hospice aide services and are intended to maintain the terminally ill patient at home during a pain or symptom crisis. The Medical Director determines when this shift care should be provided to manage intermittent episodes of acute symptom management.

Inpatient Respite Care is available to provide temporary relief to the patient's primary caregiver. Respite care can be provided in a hospital, hospice facility, or a long term care facility that has sufficient 24 hour nursing personnel present on all shifts to guarantee that patient's needs are met. Respite care is provided for a maximum of 5 consecutive days.

Note: Patients who do not have Medicare as their insurer may not be eligible for coverage of all four levels of care. The Avow billing department can assist with this discussion with the patient's insurer or payer source.

Survey Feedback

Avow Hospice is committed to providing high quality care and service. We know you have entrusted us with the sacred task of caring for your loved one at an intensely meaningful time of life. Our goal is that your time with us meets all of your expectations for skilled and compassionate care.

The Centers for Medicare and Medicaid Services (CMS) works to ensure that hospice patients and their family members and friends receive high quality care. One of the ways CMS does this is to survey family members and friends for their feedback about the hospice care they experienced.

Following your loved one's stay in our program, you may receive a Consumer Assessment of Healthcare Providers and Systems survey (called a "CAHPS survey" for short). This survey was designed to measure and assess the experiences of patients who died while receiving hospice care, as well as the experiences of their family primary caregivers. This CAHPS survey helps hospices meet national priorities for improving care for patients and families.

We encourage you to fill out and return the survey. Your feedback is very important to our continuous improvement efforts at Avow.

If you'd like more information on the survey, visit either of these websites:
http://www.hospicecahpssurvey.org/

https://www.cms.gov/Research-Statistics-Data-and-Systems/Research/CAHPS/hospice_survey.html

You may also receive other surveys that Avow participates in such as the 'HGSS' – hospice grief support survey – to obtain your feedback on the grief support services we provide and help us to improve the quality and safety of care to individuals.

Thank you in advance for your participation in helping us better meet our community's end-of-life needs.

Patient Bill of Rights and Responsibilities

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

1. Receive complete information, verbally and in writing, of your rights and responsibilities before your hospice care is provided in a language and manner that can be understood.
2. Exercise your rights as a patient of the hospice. Consistent with state law, the patient's legal representative or person appointed by law to act on its behalf, may exercise the patient's rights when patient is unable to do so.
3. Receive a timely response from Avow Hospice, Inc. regarding your request for services.
4. Elect and revoke hospice care according to Medicare hospice regulations.
5. Receive information about the scope of services that the hospice will provide including the availability of spiritual counseling services, and any limitations on those services; and information on outcomes of care, treatment and services; including unanticipated outcomes.
6. Receive professional quality services without discrimination due to race, creed, religion, gender, national origin, sexual orientation, disability, age, diagnosis, availability of a caregiver, or ability to pay.
7. Receive information regarding Avow Hospice, Inc. policies and procedures, such as: Advance Directives, and Tracking and Disposal of Controlled Drugs.
8. Receive information about the procedure to follow for resolving ethical issues prone to conflict; and to be involved in resolving ethical issues and conflicts about care or service decisions.
9. Receive information about the Customer Complaint process, and have complaints heard, reviewed, and if possible, resolved; and suggest changes in service or staff without fear of reprisal or discrimination.
10. Receive information regarding Avow Hospice, Inc. charges, eligibility for third party reimbursement, and services covered under the Hospice Benefit.
11. Receive information regarding the identity and role of staff persons providing care, treatment and services.

12. Have communications needs met and receive information in a manner that you can understand.
13. Personal privacy and security including privacy of personal information.
14. Receive appropriate assessment and management of pain and symptom control for conditions related to the terminal illness.
15. Choose whether or not to participate in research, investigational or experimental studies, or clinical trials. Avow Hospice, Inc. does not conduct research, investigational or experimental studies, or clinical trials, but it allows patients to participate in studies/trials sponsored by another organization, as long as the patient continues to meet admission criteria.

16. Refuse care, treatment and services to the extent permitted by law and regulation, and receive information about the consequences of such action.
17. Choose your attending physician.
18. Have your end of life wishes and decisions respected and addressed.
19. Be treated with dignity and respect by:
    - having an honest relationship with the hospice organization according to ethical standards of conduct.
    - being told the truth about your diagnosis or prognosis.
    - being treated with courtesy and respect for person and property.
    - considering cultural and personal values, beliefs, and preferences, including accommodations for religious and other spiritual services
20. Be involved in decision making and make informed decisions regarding care, treatment, and services from admission to discharge including the right to:
    - receive written information about the nature and goals of the proposed care, treatment and services, including contracted services, prior to providing informed consent and initiating care.
    - give or withhold informed consent. Informed consent shall comply with applicable Medicare regulation and State of Florida Statute.
    - participate in care planning and in the development of your plan of care, and to discuss related problems or changes, including transfers, discharges and revocation of hospice care.
    - receive reasonable notice regarding termination of services or the

anticipated transfer of your care to another provider.

21. Privacy and confidentiality of information regarding the services Avow Hospice provides.
22. Give or withhold informed consent to produce or use recordings, films or other images for purposes other than identification, diagnosis or treatment.
23. Have a confidential clinical record, and to request access, release, amendment and accounting of disclosures of the clinical record according to policies and procedures for private health information (See page 24 for more specific information regarding privacy practices).
24. Be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of your property.
25. Report abusive, neglectful or exploitive practices. **(To report abuse, neglect or exploitation please call 1-(800) 96-ABUSE.)**
26. Voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone who is furnishing services on behalf of the hospice.

If you are residing in a facility, you have the following rights:

- To unlimited contact with visitors, including small children, at any hour, as specified by the facility, or to restrict visitors if so desired.
- To keep and use personal clothing and possessions, unless it infringes on others' rights or is medically contraindicated.
- To an environment that preserves dignity and contributes to a positive self-image.

In the exercise of patient's rights, the hospice must:

1. Ensure that all alleged violations of mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property by anyone furnishing services on behalf of the hospice, are immediately reported to the hospice administrator, investigated and actions taken to prevent further potential violations until the investigation is completed.
2. Take appropriate corrective action when a violation has been verified.

3. Report violations to the state and local authorities.

Patient's and families' responsibilities. Patients and families are partners in the healthcare process and are expected to fulfill their responsibilities and to have reasonable and responsible behavior.

As a patient, you have the *responsibility* to:

1. Provide Avow Hospice, Inc. with accurate (to the best of your knowledge) information about present complaints, past illnesses, hospitalizations, medications and other matters related to your health.
2. Provide accurate financial information to Avow Hospice, Inc. when requested to do so and meet financial commitments agreed to with the organization.
3. Share information about expectations and satisfaction with the organization and voice any concerns or problems.
4. Ask questions concerning anything not fully understood about care, treatment and services or what you are expected to do.
5. Provide and maintain a safe home environment in which your care can be provided.
6. Follow instructions for care, treatment and services and express concerns about your ability to follow instructions, and to accept responsibility for outcomes when instructions are not followed.
7. Participate in developing and implementing your plan of care and updating it as your condition or needs change.
8. Follow organizational policies and procedures.
9. Show respect and consideration for Avow Hospice, Inc. personnel, volunteers and others, and their property. Avow Hospice, Inc. is an equal opportunity employer. We do not discriminate based on race, creed, religion, gender, national origin, sexual orientation, disability or age in our hiring of employees and volunteers.

Patient Specific Policies

1. Confidentiality Policy

The patient shall have the right to confidentiality. All employees and volunteers are required to sign the written Statement of Confidentiality upon initial employment. Failure to comply with the confidentiality policies could result in dismissal. In addition, all Hospice contracts shall provide for patient confidentiality of the contracted service.

2. **Ethics Policy on Referrals**
   Avow Hospice, Inc. does not/shall not receive any financial benefit when referring a patient to another organization, service, or individual.

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.

OUR RESPONSIBILITY

Avow Hospice takes the privacy of your health information seriously. Avow Hospice is required by law to maintain that privacy, to provide you (or your representative) with this Notice of Privacy Practices, and to notify you (or your representative) following a breach of your health information. This Notice is to inform you about our duties and practices with respect to your health information. Avow Hospice is required to abide by the terms of this Notice, as amended from time to time.

USE AND DISCLOSURE OF YOUR HEALTH INFORMATION

THE FOLLOWING IS A SUMMARY OF THE CIRCUMSTANCES UNDER WHICH AND PURPOSES FOR WHICH AVOW HOSPICE MAY USE OR DISCLOSE YOUR HEALTH INFORMATION. Each category presented below provides an explanation, and in some cases examples, of different ways that Avow Hospice may use and disclose your health information. Not every use or disclosure has been listed in these categories.

However, all permitted uses and disclosures of your health information will fall into one of these categories.

Treatment. Avow Hospice may use and disclose your health information to treat you and coordinate your care. For example, your attending physician or members of the Avow Hospice interdisciplinary team may use information about your symptoms in order to prescribe appropriate medications. Avow Hospice also may disclose your health information to individuals outside of Avow Hospice involved in your care including family members, other relatives, close personal friends, pharmacists, suppliers of medical equipment, or other health care professionals.

Payment. Avow Hospice may use or disclose your health information in order to bill or collect payment for the services or items you receive from Avow Hospice. For example, Avow Hospice may be required by your health insurer to provide information regarding your health care status, your need for care, and the care that Avow Hospice intends to provide to you so that the insurer will reimburse you or Avow Hospice. Avow Hospice also may need to obtain prior approval from your insurer and may need to explain to the insurer your need for hospice care and the services that will be provided to you.

Health Care Operations. Avow Hospice may use or disclose health information for our own operations to facilitate the functioning of Avow Hospice and as necessary to provide quality care to all of Avow Hospice's patients. For example, Avow Hospice may use your health information to evaluate our performance, combine your health information with other Avow Hospice patients to evaluate how to more effectively serve all Avow Hospice patients, disclose your health information to members of Avow Hospice staff for training purposes, or use your health information to contact you or your family as part of general community informational mailings. Avow Hospice also may disclose your health information to a health oversight agency performing activities authorized by law, such as investigations or audits. These agencies include governmental agencies that oversee the health care system, government benefit programs, and organizations subject to government regulation and civil rights laws. In addition, Avow Hospice may disclose your health information

to another health care provider, as long as the provider has or has had a relationship with you and the health information is for that provider's health care operations.

Facility Directory. Unless you request otherwise, if you are receiving care in an Avow Hospice facility, Avow Hospice may disclose certain information about you that is contained in our facility directory (*e.g.,* your name, your general health status and your religious affiliation), to anyone who asks for you by name.

Fundraising Activities. Avow Hospice engages in fundraising activities, the money from which is used to help support the mission of the organization. Avow Hospice may use certain information about you (*e.g.,* demographic information, dates of health care provided, attending physician, outcome information and health insurance status), in order to contact you or your family to raise money for Avow Hospice. Avow Hospice also may release this information to an organizationally-related foundation for the same purpose. You may choose to "opt-out" of receiving these fundraising communications by notifying our Development Office at (239) 649-3683 that you do not wish to be contacted.

Appointment Reminders. Avow Hospice may use or disclose your health information to contact you to remind you about an appointment.

To Inform You About Information that May be of Interest to You. Avow Hospice may use or disclose your health information to tell you about or recommend possible options or alternatives for your care, or to inform you of other information related to your health that may be of interest to you.

Release of Information to Family/Friends. Unless you specifically request in writing that Avow Hospice not communicate with such person(s), Avow Hospice may release your health information to a family member or friend who is involved in your treatment or who is helping to pay for your care.

Business Associates. Avow Hospice may disclose your health information to our business associates that perform functions or provide services on our behalf if the

information is necessary for them to perform such functions or services. Avow Hospice requires our business associates to agree in writing to protect to privacy of your health information and to use and disclose your health information only as specified in that written agreement.

THE FOLLOWING CATEGORIES DESCRIBE ADDITIONAL CIRCUMSTANCES UNDER WHICH AND PURPOSES FOR WHICH AVOW HOSPICE MAY USE OR DISCLOSE YOUR HEALTH INFORMATION.

As Required by Law. Avow Hospice will disclose your health information to the extent we are required to do so by any Federal, State or local law.

Public Health Risks. Avow Hospice may disclose your health information for public health activities and purposes in order to:

- Prevent or control disease, injury or disability, report disease, injury, vital events such as death, and the conduct of public health surveillance, investigations and interventions.
- Report adverse events, product defects, to track products or enable product recalls, repairs and replacements and to conduct post-marketing surveillance and compliance with requirements of the Food and Drug Administration.
- 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 an Avow Hospice staff member in certain limited situations, as authorized by law.

Abuse, Neglect or Domestic Violence. Avow Hospice is allowed to notify government authorities if Avow Hospice reasonably believes a patient is the victim of abuse, neglect or domestic violence. Avow Hospice will make this disclosure only when specifically required or authorized by law or when you authorize the disclosure.

Health Oversight Activities. Avow Hospice may disclose your health information to a health oversight agency or other organization for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. If you are the subject of a health oversight agency investigation, Avow Hospice may disclose your health information only if it is directly related to your receipt of health care or public benefits.

Judicial And Administrative Proceedings. Avow Hospice 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. In certain circumstances, Avow Hospice also may disclose your health information in the course of a judicial or administrative proceeding in response to a subpoena, discovery request or other lawful process.

Law Enforcement Purposes. As permitted or required by State law, Avow 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 a court order, warrant, subpoena, 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 Avow Hospice has a suspicion that your death was the result of criminal conduct.
- To a law enforcement official if Avow Hospice believes the information constitutes evidence of criminal conduct that occurred at Avow Hospice.
- In an emergency in order to report a crime.

Coroners And Medical Examiners. Avow Hospice 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.

Funeral Directors. Consistent with applicable law and, if necessary, to carry out their duties with respect to your funeral arrangements, Avow Hospice may disclose your health information to funeral directors prior to and in reasonable anticipation of, or following, your death.

Organ, Eye Or Tissue Donation. Avow 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.

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

Limited Data Set. Avow Hospice may use or disclose a limited data set of your health information, that is, a subset of your health information for which all identifying information has been removed, for purposes of research, public health, or health care operations. Prior to our release, any recipient of that limited data set must agree in writing to appropriately safeguard your health information.

Serious Threat To Health Or Safety. Avow Hospice may, consistent with applicable law and ethical standards of conduct, disclose your health information if Avow 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.

Specified Government Functions. In certain circumstances, the Federal privacy regulations authorize Avow 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.

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

OTHER USES OR DISCLOSURES OF YOUR HEALTH INFORMATION

Uses and disclosures of your health information for purposes other than those referred to in this Notice of Privacy Practices will be made only with your written authorization. If you (or your representative) sign an authorization to use or disclose your health information, you (or your representative) may revoke (*i.e.*, take back) that authorization at any time. Your revocation must be in writing. If you (or your representative) revoke your authorization, Avow Hospice will no longer use or disclose health information about you for the reasons covered by your written authorization. However, your revocation will not stop Avow Hospice from any uses or disclosures that Avow Hospice made before you (or your representative) revoked your authorization.

Your authorization (or the authorization of your representative) is specifically required before Avow Hospice: (i) uses or discloses your psychotherapy notes; (ii) uses your health information to make a marketing communication to you for which it receives financial remuneration from a third party, unless such communication is face-to-face or in other limited circumstances; or (iii) discloses your health information in a manner which constitutes the sale of such information under the Health Insurance Portability and Accountability Act of 1996 ("HIPAA"). Also, some types of health information are particularly sensitive, and the law, with limited exceptions, may require that Avow Hospice obtain your authorization to use or disclose that information. Sensitive information may include information dealing with genetics, HIV/AIDS, mental health, developmental disabilities, and alcohol or substance abuse. If required by law, Avow Hospice will ask that you (or your representative) sign an authorization before we use or disclose such sensitive information.

YOUR RIGHTS REGARDING YOUR HEALTH INFORMATION

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

- **Right to receive confidential communications.** You (or your representative) have the right to request that Avow Hospice communicate with you about your health and related issues in a particular manner or at a certain location. Such requests shall specify the requested method of contact or the location where you wish to be contacted. For instance, you may ask that Avow Hospice only conduct communications pertaining to your health information with you privately with no other family members present. All requests for confidential communications must be made in writing using the appropriate Avow Hospice form. This form can be requested by contacting Avow Hospice's *Privacy Officer at (239) 261-4404*. Avow Hospice will accommodate reasonable requests. You (or your representative) do not need to give a reason for your request.
- **Right to request restrictions.** You (or your representative) have the right to request restrictions on certain uses and disclosures of your health information. For example, you have the right to request a limit on Avow Hospice's disclosure of your health information to someone who is involved in your care or the payment of your care. All requests for restrictions must be made in writing using the appropriate Avow Hospice form. This form can be requested by contacting Avow Hospice's *Privacy Officer at (239) 261-4404*. Avow Hospice is not required to agree to your request; however, if Avow Hospice does agree, it is bound by that agreement except where otherwise required by law or in emergencies. Except as otherwise required by law, Avow Hospice must agree to a restriction request if: (i) the disclosure is to a health plan for purposes of carrying out payment or health care operations (and not for the purpose of carrying out treatment); and (ii) the health information pertains solely to a health care item or service for which Avow Hospice has been paid out of pocket in full by you or someone else on your behalf (not the health plan). If you self-pay and request a restriction, it will only apply to those health records created on the date that you received the item or service for which you, or another person (other than the health plan) on your behalf, paid in full, and which document the item or service provided on such date.

- **Right to inspect and obtain copies of your health information.** You (or your representative) have the right to inspect and copy your health information, including billing records. All requests to inspect and copy records must be made in writing using the appropriate Avow Hospice form. This form can be requested by contacting Avow Hospice's *Privacy Officer at (239) 261-4404*. If you (or your representative) request a copy of your health information, Avow Hospice will provide you (or your representative) copies of your health information in the format you request unless we cannot practicably do so. Avow Hospice may charge a reasonable fee for copying and assembling costs associated with your request. Avow Hospice may deny your request to inspect and/or copy your health information in certain limited circumstances. If Avow Hospice denies your request, you (or your representative) may request that we provide you with a review of our denial. Review will be conducted by a licensed health care professional who Avow Hospice has designated as a reviewing official, and who did not participate in the original decision to deny the request.
- **Right to amend health care information.** You (or your representative) have the right to request that Avow Hospice amend your records, if you (or your representative) believe that your health information is incorrect or incomplete. The request may be made so long as Avow Hospice still maintains your records. Also, the request must include a reason for the amendment. All requests for amendments must be made in writing using the appropriate Avow Hospice form. This form can be requested by contacting Avow Hospice's *Privacy Officer at (239) 261-4404*. Avow 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 the requested amendment pertains to health information that was not created by Avow Hospice, if the records you are requesting to amend are not part of Avow 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 Avow 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 Avow Hospice for certain reasons, including reasons related to public health purposes authorized by law and certain research. All requests for an accounting must be made in writing using the appropriate Avow Hospice form. This form can be requested by contacting Avow Hospice's *Privacy Officer at (239) 261-4404*. The request should specify the time period for the accounting, which may not be in excess of six years. Avow Hospice will 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 (in either paper or electronic format). To obtain a separate paper copy, please contact Avow Hospice's *Privacy Officer at (239) 261-4404.* You (or your representative) also may obtain a copy of the current version of Avow Hospice Notice of Privacy Practices at our website, *www.avowcares.org.*
- **Right to breach notification.** You (or your representative) have the right to be notified of a breach of your unsecured health information. Notification of a breach may be delayed or not provided if so required by a law enforcement official. If you are deceased and there is a breach of your health information, the notice will be provided to your next of kin or personal representative if Avow Hospice knows the identity and address of such individual.

CHANGES TO THIS NOTICE

Avow Hospice has the right to change this Notice at any time. Revisions to this Notice will be effective for all of your health information that Avow Hospice created or maintained in the past, and for any of your health information Avow Hospice may create or maintain in the future. We will post a copy of the current Notice in a clear and prominent location in our facility. You may request a copy of the current notice

in person or by calling Avow Hospice's *Privacy Officer at (239) 261-4404*. You may also view it on our web site at www.avowcares.org.

QUESTIONS OR CONCERNS REGARDING THIS NOTICE

Avow Hospice encourages you to call Avow Hospice's *Privacy Officer at (239) 261-4404* if you have any questions or concerns about the privacy of your health information.

COMPLAINTS

If you believe that Avow Hospice may have violated your privacy rights or you disagree with any action Avow Hospice has taken with regard to your health information, you may file a complaint with Avow Hospice or the Office of Civil Rights of the Department of Health and Human Services. Avow Hospice will provide you with the necessary assistance and paperwork. You will not be retaliated against in any way for filing a complaint.

To express a complaint to Avow Hospice, please contact Avow Hospice's *Privacy Officer at (239) 261-4404*. Alternatively, you may contact Avow Hospice in writing at the following address:

Avow - Privacy Official
1095 Whippoorwill Lane
Naples, FL 34105

EFFECTIVE DATE This Notice is effective September 20, 2013.

Privacy of Personal Information

Avow Hospice, Inc. recognizes the importance of protecting and preserving an individual's personal identifying information and will take steps to prevent, detect and respond to identity theft and suspicious activities.

All individual personal information is considered private and will be used for the intended purpose for which it was obtained; minimally necessary personal information will be used and disclosed. Disclosure of information for personal gain or fraudulent activities will not be tolerated.

Reports of suspicious activities and identity theft will be investigated and appropriate actions taken according to policies, procedures, law and regulation.

Gift Giving Policy

Avow staff members are professionals who are providing a health care service. They are not permitted to accept money, gifts, or social invitations of any kind or value, and have been instructed not to accept these offers. We ask that you respect this policy and refrain from offering gifts to Avow staff.

If you wish to express your appreciation to Avow, a kind word of gratitude to your care team or a letter of appreciation to the management will let us know that you value our services and the professionalism with which care was delivered.

Contributions to our mission may be made in honor of a staff person or in memory of your loved one. To make a gift please visit avowcares.org/donate or contact Avow foundation at foundation@avowcares.org or (239) 649-3683.

Donations of clothing, books, furniture, or household items may be arranged with the Treasures Thrift Stores by calling (239) 249-0201.

What is of greatest value to us is your satisfaction with our services and your assistance in spreading the word about the important mission of Avow.

Here are a few ways you can help us with our education efforts:

- Please tell your friends about what quality end-of-life care means to you and your family.
- Write a letter to your doctor about your hospice experience.
- Invite us to speak at a meeting of a group you belong to.

These are the greatest gifts you can give us.

Advance Directives or Living Wills

The following is related to Florida law regarding advance directives or living wills. Under Florida law (see note below), every adult has the right to make certain decisions concerning his or her medical treatment. The law also allows for the individual's rights and personal wishes to be respected even if he or she is too sick to make decisions.

Note: The legal basis for these rights can be found in the Florida Statutes: Life-Prolonging Procedure Act, Chapter 765; Health Care Surrogate Act, Chapter 745; Durable Power of Attorney, Section 709.08; and court decision on the Constitutional Right of Privacy, Guardianship of Estelle Browning, 1990.

Living Will*

You have the right, under certain conditions, to decide whether to accept or reject medical treatment, including whether to continue medical treatment and other procedures that would prolong your life artificially. These rights may be spelled out by you in a living will containing your personal directions about life-prolonging treatment in the case of serious illness that could cause death.

Healthcare Surrogate*

You may also designate another person, or surrogate to make decisions for you if you become mentally or physically unable to do so. This surrogate may function on your behalf for a brief time or longer, for a life-threatening or a non-life-threatening illness.

Any limits to the power of the surrogate in making decisions for you should be clearly expressed.

** Ask a hospice team member for living will or healthcare surrogate forms.*

Avow Policy

It is the policy of Avow, to inquire about the existence of previously executed advance directives and to offer all patients the opportunity to sign the Living Will and/or Health Care Surrogate form available through Avow. Copies of properly executed advance directives will be made a part of the patient's medical record.

Avow Hospice, Inc., acknowledges that documentation of advance directives by a patient is not a pre-condition for admission to the hospice program, nor does Avow Hospice, Inc. discriminate against a patient based on whether or not advance directives have been documented.

Resolution of Conflict/Ethical Issues

If a hospice patient or family member feels conflicted about an aspect of hospice care or an ethical issue and/or moral value related to hospice care, they may ask the Avow Ethics Committee for a consult.

When a consultation is requested, a trained committee gathers to listen, talk and help clarify values that are in conflict. The consultation process is well-defined in bioethics literature and is conducted according to established standards. The Ethics Committee recommends a course of action, but final decision-making always remains with the patient and family.

When should an ethics consult be used?

There are times when a patient or family has a difficult choice to make related to the following:

- Informed consent
- Treatment decisions
- Withholding/withdrawing treatment
- Surrogate decision making
- DNR orders
- Nutrition/hydration
- Truth telling

- Advance directives

Some examples of when a consult may be called include:

- When a patient/family is having difficulty making a decision following a conversation with a physician and care team.
- When there is a difference of opinion between the health care team and the patient or decision-maker.
- When there is a difference of opinion among the health care team members.
- When there is a difference of opinion among family members.
- When there is a decision to be made about withdrawing or withholding treatment, nutrition, or hydration.

To make a referral to the Ethics Committee ask a primary member of the hospice team to refer your request to the Ethics Committee or call Avow at (239) 261-4404.

Pre-Hospital Do Not Resuscitate Orders

Statement of Policy Regarding Pre-Hospital Do Not Resuscitate Order:
The following relates to Florida State law regarding health care advance directive Do Not Resuscitate Order (DNRO) specific to Emergency Medical Services (EMS).

One component of the health care advance directives legislation authorizes EMS personnel to honor a pre-hospital DNRO. The order must be written on a form adopted by rule of the Florida Department of Health and Rehabilitative Services (HRS) and **must be presented to EMS personnel when they respond to a call for assistance.**

You have the right to communicate your wishes (to not be resuscitated) to your physician and together you determine the need to sign the DNRO form. You also have the right to revoke this decision at any time.

This DNRO is the only form EMS is authorized to honor. A living will is a helpful guide to a physician in trying to plan a course of treatment for an incapacitated patient and may form the basis for the issuance of the DNRO. EMS personnel in the field are without the guidance of the patient's attending physician and need the medical authorization provided by the DNRO to withhold life-prolonging procedures.

Avow Hospice, Inc., acknowledges that documentation of a DNRO by a patient is not a pre-condition for admission to the Hospice program, nor does Avow Hospice, Inc. discriminate against a patient based on whether or not a DNRO has been signed.

Note: The legal basis for these rights can be found in Florida Statues, Chapter 765 and 401, F.S., Health Care Surrogate, 765.101(9) F.S., Revocation, 765.104; F.S.

Making a Decision Concerning DNROs

When is CPR (Cardiopulmonary Resuscitation) **most important?**

- When the heart or lungs stop working **unexpectedly**.
- When there is a possibility that the cause for the heart or lung failure can be fixed.

What is involved in the procedure?

- The procedure involves applying pressure to the chest using one's hands and electric stimulation to the chest in an attempt to restart the heart.
- Medications may be administered and a tube placed in the throat to assist breathing.
- The procedure may last from 15 to 30 minutes.

What happens if CPR is not administered?

- After loss of consciousness death will occur within 5 to 10 minutes.

What are the benefits of CPR?

- For a patient dying of a terminal / life-limiting illness **there is no benefit**.
- For patients with good overall health and administered within 5 minutes of heart or lung failure, it may permit prolonged life.

What are the burdens of CPR?

- The pressure to the chest could result in soreness, broken ribs, or a collapsed lung.
- Most people who receive CPR will need to be in the intensive care unit on a machine to assist breathing for a period of time.
- Less than 10% of all hospitalized patients survive CPR and return to their previous state. Most of these people were in the coronary care unit when CPR was performed. Most patients live for a short period afterwards but still die in the hospital.
- Only 1% to 4 % of patients with multiple chronic illnesses survive to leave the

hospital.

- Of the patients who received CPR, survived, and did leave the hospital, many continue to live in a weaker state, or with brain damage. Half the people who survive CPR become chronically dependent.

Adapted From: Physician Orders for Life Sustaining Treatment

Customer Concerns Processing Procedures

If You Have a Concern

Avow stands by the quality of its care. If you have a concern about our services, here are steps you can take:

- Notify any Avow staff member of your complaint. You may submit the complaint in writing, or ask the staff member to report your complaint.
- The staff member you report your complaint to will try to resolve your complaint immediately. Your complaint will also be reviewed by the Compliance Officer.
- To report a complaint regarding services you receive, you may call the State toll-free number at 1-(888) 419-3456 if your complaint has not been resolved to your satisfaction by Avow, or you may write to:

  Agency for Health Care Administration
  Regional Services Center
  2295 Victoria Avenue, Rm #340
  Fort Myers, FL 33901
- You may also contact the Joint Commission at (630) 792-5000. This agency certifies the quality of our care.

Avow does not tolerate abusive, neglectful, or exploitative practices

If you experience treatment that you feel is abusive, neglectful, or exploitative, please call and report abuse, neglect, and exploitation at the following toll-free abuse hotline telephone numbers:

- 1-(800) 96ABUSE or 1-(800) 962-2873
- Telephone Device for the Deaf 1-(800) 955-8771

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

Report Medicaid Fraud

To report suspected Medicaid fraud, please call the statewide toll-free telephone number for the central Medicaid fraud hotline. The number is 1-(888) 419-3456.

Medicaid fraud means an intentional deception or misrepresentation made by a person with the knowledge that the deception could result in some unauthorized benefit to him or herself or some other person. It includes any act that constitutes fraud under applicable federal or state law as it relates to Medicaid. The office of the Inspector General at the Agency for Health Care Administration accepts complaints regarding suspected fraud and abuse in the Florida Medicaid system by phone at 1-(888) 419-3456 or on the Agency web site at:

http://ahca.myflorida.com/Executive/Inspector_General/medicaid.shtml

EMERGENCY PREPAREDNESS and RESPONSE

Avow Hospice has established a comprehensive emergency management plan to prepare and respond to natural disasters and other emergencies that may impact patient and employee safety, and the organization's ability to provide care, treatment, and services.

While Avow plans to continue providing care, treatment, and services during an emergency, at times those services may be disrupted by mandatory closures and evacuation orders, or the organization's inability to provide services in a manner that preserves the safety of our employees. Avow has developed procedures to continue to provide care as it prepares and responds to emergencies and will assist you in preparing individual plans to prepare and respond to emergencies when services may be interrupted and evacuations may be necessary.

Avow Emergency Preparedness and Response:

Avow prepares for a variety of procedures involving severe weather, fire, and other threats to the organization and the community. Preparing for severe weather annually during hurricane season beginning on June 1st, is a priority.

1. At the time of admission, Avow employees will provide patients and caregivers with emergency planning information and request information regarding the patient's/caregivers emergency plans including possible evacuation. Assistance will be provided in completing a Disaster Preparedness Plan and the Special Needs Shelter registration form.
2. In response to an imminent emergency or impending threat, the leadership at Avow Hospice will activate the organization's emergency management plan and operate in emergency mode.
3. Emergency response and recovery procedures are initiated and directed in coordination with Collier County's emergency response.

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

4. Patients and caregivers will be notified when the organization's emergency plan has been activated and the organization operates in emergency mode.
5. During emergency operations, all current patients will continue to receive hospice services for as long as such services can be safely provided including patients who choose to evacuate to the special needs shelter.
6. To contact Avow, patients and families may continue to use the main number (239) 261-4404 as long as it remains functional. The following numbers will be used when Collier County is operating in emergency mode and the main number cannot be reached (239) 263-4194 and (239) 263-4237.
7. Anticipated disruptions in services will be communicated. Instructions for continuing the plan of care and plans to restore services will be communicated.

8. Families of patients receiving services at the inpatient facility will be contacted to communicate patient status, possible evacuation to another facility or return to inpatient, and plans to restore normal operations and inpatient services.
9. Attempts to communicate unexpected interruptions will be made through direct methods of communications such as phones as long as they are in operation. If direct methods are out of order, alternate methods such as public broadcasting will be used.
10. After the emergency, patient contact will be initiated to assess patient/caregiver status and needs. Plans to resume services will be communicated when hospice operations are resumed and permission from authorities has been granted.

Patient/Caregiver Emergency Plans:

1. At the time of admission, the Avow Hospice admission team assists patients and their caregivers in planning for a possible emergency. The plans will be documented and additional information may be requested from time to time to update the plan.
2. Hurricane preparedness documents are distributed to patients/families upon admission. These include: Evacuation/Special Health Needs Program Information; Special Needs Registration forms; Information for Hospice Patients Registered with the Special Needs Shelter (SNS); Hurricane Preparedness

Information Sheet; Additional Information Regarding the Special Needs Shelter; Pet Shelter Information (if available and as needed).

3. Disaster Preparedness and Special Needs Registration forms are completed on admission.
4. The patient/caregiver must notify Avow of changes in their disaster/evacuation plans and if they will be evacuating to a location other than the shelter.
5. An updated list of medications and a list of supplies and equipment will be provided to the patient/caregiver at the time of the emergency and upon evacuation.
6. During an interruption of services, Avow will provide a two (2) week supply of medications. A portable tank with enough oxygen to last through an evacuation will be provided. The patient/caregiver is responsible for securing additional supplies of medication and oxygen until Avow and their vendors can resume operations.
7. The patient must secure a caregiver that will assist the patient with necessary care and emergency preparations. The caregiver must be available to provide care which would normally be provided by the hospice staff. If not, arrangements for alternative caregiver services will be initiated.
8. The patient and caregiver have plans for evacuation and transportation when necessary or as mandated.
    a. For patients/caregivers not registering for the Special Needs Shelter (SNS), an alternative evacuation plan is developed.
    b. Patients/caregivers registered with the Collier County Special Needs Shelter (SNS) at Palmetto Ridge High School SNS are notified that services at the shelter may not be equal to those provided by the hospice program and conditions in the shelter may be stressful and/or inadequate to meet the patient's needs. The shelter is an option of last resort.
    c. The items listed on the Information for Hospice Patients Registered with the Special Needs Shelter are reviewed with the patient/caregiver.
    d. The following documents must be kept with the patient at all times when evacuating: advance directives including DNRO, an up to date medication sheet, the Hospice Patient and Caregiver Guide, Face Sheet.

e. The Caregiver must arrange for transportation to the shelter or other evacuation site. Collier County Emergency Management provides transportation services to the SNS.
f. At the shelter the patient/caregiver will be responsible for administering medications and maintaining their own supply and equipment list.
g. As long as Avow remains in operation, it will provide the same type and quantity of services at the SNS until it can no longer be provided. After the emergency, Avow will initiate contact to resume care of the patient at the SNS during recovery operations.

Handling a Death in the Home during an Emergency

While preparing for an emergency, Avow staff will assess and communicate the patient's status and possible imminent death to the family/caregiver. If the family/caregiver does not wish to relocate the patient, the following procedures will assist the family in handling a death until Avow is able to assist.

The family/caregiver should keep in mind that during an emergency it may not be possible for staff to contact or reach patients. However, attempts will be made to contact/reach patients as soon as possible after the emergency if communications are available. Visits will resume when roads are safe.

1. Prepare to remain at home without visits for a minimum of one (1) week.

2. If the phones are in working order, contact Avow Hospice to communicate the patient's death. Handle the patient's body as follows:
   a. Wash the body removing any body fluids.
   b. Wrap the body in clean sheet.
   c. Place the body in a separate room if possible and then close the door, keeping windows in that room closed. If odor becomes a problem, seal off the room by placing towels under the door. Another option is to wrap the body in plastic sheeting, plastic trash bags, or tarps.
   d. Lower the temperature of the air conditioning, if possible.

3. Stay calm as hospice will be there to help out soon.

Compassion Fatigue

The Stress of Caring So Much

Compassion fatigue is a state of emotional, physical and mental exhaustion in which one feels depleted, chronically tired, helpless, hopeless and bad, even cynical, about oneself, work, life and the state of the world. Those who constantly and conscientiously care for others, in whatever capacity, are the most vulnerable. Even though these activities are voluntary, emotional strains can develop and the once-satisfying relationship can become increasingly stressful. Over time, the clash between expectations and reality, can lead to despair.

Avoiding Compassion Fatigue

Incorporating the following ideas into your caregiving can help you adjust and avoid the pitfalls of compassion fatigue.

1. **Be realistic.** Do your best to understand the demands associated with caring for your loved one. Try not to project unrealistic expectations on yourself or the person for whom you are caring. Don't be afraid to ask for help.
2. **Know your limits and be honest about them**. If you are too tired to do errands, make alternative arrangements. This can decrease resentment.
3. **Share the care by accepting offers of help from friends, family or Avow volunteers.** If they ask if they can help, give them a specific task or a list of tasks they can choose from.
4. **Make time for fun by breaking the routine.** Remember to enjoy activities that lighten the atmosphere for both you and the person for whom you are caring. Go for a ride, play cards, share a movie—whatever is meaningful for you both. Remember to take time for yourself as well.
5. **Seek support if you need it.** If you are exhibiting multiple symptoms of compassion fatigue, don't be afraid to seek support. Joining a caregivers' support group or venting frustrations and emotions to another person can be beneficial interventions.

Symptoms of Compassion Fatigue

- Increased impatience
- Increased irritability
- Loss of purpose/meaning in life
- Decrease in confidence
- Increase in perfectionism or irresponsibility
- Apathy, low motivation
- Exhaustion/emotional numbness
- Increased use of alcohol, tobacco or other substances
- Anxiety
- "Survivor guilt"

Symptoms of Compassion Fatigue continued:

- Increased preoccupation with death/death imagery
- Sleep disturbances
- Loss of concentration
- Resentment of demands that "go with the territory"
- Increased conflict in personal or co-worker relationships
- Cynicism/negative attitude
- Somatic (physical) complaints
- Hyper-vigilance (extremely sensitive to your surroundings)
- Pervasive hopelessness
- Avoidance of certain tasks or previously enjoyable activities

Symptoms may show up quickly or may take several months to appear. Each caregiving situation is unique. Though it may be easier to run away or avoid situations, it only prolongs working through the experience and the stress.

Ask a member of your Avow care team for suggestions and resources related to caregiving and compassion fatigue including options for respite care.

Caregiver Training Videos

For additional information about Compassionate Fatigue and other important topics, including what symptoms to expect and how to care for your loved one, please visit our website https://avowcares.org/caregiver-videos/ , or use the QR code below, to view the "Avow Video Library." We have created these videos to educate, inform, and inspire you. *Simply take a picture of this with your phone camera to access it*.

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

Family Pet Support

"Avow's mission is to create peace of mind, and for our hospice patients who are pet parents, that means knowing their beloved cat or dog will be cared for and loved," said Jaysen Roa, President and CEO of Avow companies. Avow helps hospice patients complete their lives without worrying about their pet's current or future needs.

Avow provides pet support services in partnership with the national Pet Peace of Mind Program https://petpeaceofmind.org/ and locally with the Humane Society Naples and community veterinarian, Dr. Lesli Reiff, DVM. Family pet support services are provided to our patients free of charge, funded by in-kind and monetary donations.

Pet Peace of Mind Volunteers

Avow can arrange for our trained volunteers to provide scheduled routine cat and dog care, such as walking and playing and waste cleanup (2-3 times/week maximum); transportation of pets to grooming and vet appointments; temporary boarding of pets when patients are on a 5-day respite care stay in a facility or hospice house; and rehoming help for pets prior to and after their owner's death. Ask your hospice care team to make a Pet Peace of Mind Program referral.

When the patient and family have determined they need to plan a transition for their pet, Avow then works with our community partner, the Humane Society Naples, to find temporary or permanent homes for our patient's pets. Services include:

Foster Care

The Avow team will assist patients with placing their pets in foster care. If a patient can no longer care for a pet, the Humane Society will place the pet in foster care, on a "space limited*" basis, until a permanent home can be secured or until the pet can return to its own home. Pets needing foster care should have proof of current vaccinations.

Adoption

Avow assists patients with finding a permanent home for pets when the time comes.

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

For more information on the programs and services of the Humane Society, contact

The Humane Society Naples
370 Airport-Pulling Road North
Naples, FL 34104
Clinic: (239) 643-2143 Shelter: (239) 643-1555
www.hsnaples.org

* If there is no space available for your pet, please ask for references to other nonprofit rescue groups in the area.

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Children's Responses

Things You Can Do As a Parent

Adapted from *"How to understand and support your child when someone special is very sick,"* by James Boulden.

1. Tell Your Children the Truth

Being honest can be painful. Nevertheless, dishonesty, even with the honorable goal of protecting the children, *may be the single biggest mistake you as a parent can now make.* There is nothing more important in their lives than that they continue to trust the people they love most – the parent who is sick and the parent who will continue to care for them.

Tell them 3 things:

- Tell them you are seriously ill.
- Tell them the name of your disease.
- Tell them your best understanding of what may happen.

Remember: a child can imagine much worse things than the truth.

Three common worries children might have:

1. That they somehow caused the disease
2. That the disease is contagious and they'll get it
   Simple answers work best:
   "Nothing you ever did made me get it."
   "You can't get it from me. No one else can catch this. This is something that's going to affect just me."
3. Who will take care of them?
   Work this one out before you share it with the child. Remember that, especially for younger children, **routine equals security.**

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Think about how you'll maintain their routine: who will baby-sit when one parent takes the other to the doctors; who will get the children to band practice, soccer games, etc.

2. Set Aside Special Times to Be with Your Child

Realize that children grieve differently from adults. They are more likely to grieve in small chunks of time with stretches of good and normal time in between. Be sure to provide them with opportunities to "just be kids" and share fun times with you.

3. Allow All Feelings

Your child will respond and be sensitive to the "emotional climate" in your home. It is natural for your child to feel some of the stress that is happening to your family at this time. Although you may not want to hear them, all your child's feelings are valid and need to be expressed. You don't have to agree; just let your child know that you hear them, and accept their feelings even if you don't agree with or understand them. There are no "wrong feelings," but there is unacceptable behavior. Continue to enforce consequences for inappropriate behavior.

4. Relate to the Child on Their Level

Use words and concepts that are right for the age and development of your child. The child's concept of death may be very different from yours (e.g., younger children are not able to fully comprehend the "permanent" or "universal" nature of death). Older children are more interested in the bodily changes that occur with illness and death. Most children are worried about "what will change" in their daily life. Be sensitive to this and try to prepare them ahead of time for any major changes in their routine.

5. Explain That Illness and Death Are Not a Punishment

Neither the child nor the ill person is being punished for anything they have done. Children often feel that somehow they are to blame when bad things happen in their family. Reassure children that they are not the cause of what is happening to their loved one.

6. Let Your Child Be a Part of the Family Support and Grieving Process

Don't try to "protect" the child by hiding the fact of grave illness or physical death. Children need to feel that they are helping to take care of their family member (e.g., bringing a glass of water, making sure tissues are near the bedside, etc.).

Attendance at a memorial service when a family member has died is an important experience of closure. Children need to say their good-byes. Arrange ahead of time to have a friend available to leave with younger children should they become "antsy" or irritable.

7. Provide Security

Children feel more secure when they know what is happening and what is expected of them. It is important to remain consistent with family rules and expectations. This is not the time to become "lax" with discipline. Keep routines as predictable as possible. School is a wonderfully "structured" routine; make sure they are going.

8. Provide Reassurance

Children often worry that another special person will also become ill or will die. Reassure the child that you (the caregiver) are healthy and plan to live a very long time. The child should know that there will always be someone to care for them (name family members and friends if the child wants specifics). Younger children may need a "transitional object" to hold on to when you need to be away (e.g., a photo of you or something you tell them to take care of until you return).

9. Allow Time For Healing

It takes time to process all the changes that are occurring at this time. Each child will do that in his/her own way and time. Seek support for yourself. Research shows that children do best when their parent is receiving the support they need.

Note: Talk with a member of your Avow care team if you would like more information regarding children's reactions or ways to support your child including "what to expect from children at various age levels" and other recommended readings.

Bereavement Support

Avow is dedicated to providing guidance and support to families, relatives, friends and professional caregivers experiencing the loss through death of a significant relationship. Avow maintains a connection with the family/significant other(s) for 13 months to provide grief and bereavement support following the passing of the patient.

Avow understands that each person's grief is uniquely their own. It is neither predictable nor orderly and working through it does not always happen on a

predictable schedule. Avow offers individual counseling and support groups as a community service for anyone who has lost a loved one.

Bereavement support groups meet at various times and days throughout the county. For current meeting times and locations call Avow at (239) 261-4404 or check Avow's web site, www.avowcares.org for schedules.

When children suffer losses, Avow provides specialized support through our Avow Kids program. These services are provided at the children's schools, in their homes or in a home like atmosphere at Aunt Janet's House, our children's bereavement center on our main campus.

Although a loss is never forgotten, Avow offers opportunities to ease the pain and renew the spirit. Avow helps meet these special needs through the following, all of which are provided free of charge:

- Individual support
- Support groups
- Children's and teen's grief workshops
- Seasonal bereavement workshops
- Educational programs on bereavement (and other topics)
- Resource materials and referrals

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

Ways to Remember

Remembering℠ Ceremonies

Avow supports family and friends long after their loved one has died. An example of this commitment to those who are grieving is our series of Remembering community memorial services.

Family members whose loved one died with us within the past five to six months receive an invitation to join us for a Remembering service. The services are also open to the public and all are welcome to attend.

Remembering celebrates and respects the uniqueness of each person and their spiritual orientation. The ceremonies include inspirational music, poems and passages and a reading of names of those who have passed.

Royal Palm Memorial Courtyard

The Royal Palm Memorial Courtyard is located on the Avow campus. The courtyard offers visitors a place to meditate and remember their loved ones in an environment filled with foliage, benches, and quiet sitting areas. The courtyard grounds are filled with engraved memorial bricks donated by Avow families and friends.

Additional memorial tributes are featured throughout the Avow campus including personalized benches and dedicated trees with commemorative plaques. Tribute dedication ceremonies are held in the courtyard periodically throughout the year. The ceremonies recognize individuals commemorated by a recent brick, bench or tree tribute amid a gathering of family, and friends are invited to attend.

Butterfly Release

The butterfly is the international symbol for hospice. In its metamorphosis from the common, colorless caterpillar to the exquisite winged creature of delicate beauty, the butterfly has become a metaphor for transformation and hope across cultures.

Annually, usually in early spring, Avow holds a Butterfly Release outdoors at Cambier Park in downtown Naples. Family and friends of loved ones can purchase a butterfly to be released and their loved one's name to be read during this loving and peaceful ceremony. Hundreds of loved ones come from the area and all over the country annually to remember. Music, poetry and meditations are shared during the ceremony which ends with the release of hundreds of beautiful butterflies from the large butterfly tent, in honor and memory of those we have loved. Anyone can participate, it is open to the public and those we remember do not need to have been an Avow patient.

Caring for your loved one

Moving and Lifting

The hospice nurse or hospice aide can teach the family and/or caregiver how to move or lift a patient. It is easier to help another person move when the helper remembers to follow some simple guidelines:

- Do not attempt to lift anyone if there are any doubts of the ability to do so safely.
- Whenever possible, use push and/or roll techniques rather than direct lifting practices.
- A second flat sheet, folded lengthwise and placed directly under the patient, can be used for repositioning (turning or lifting).
- If a hospital bed is being used, always raise the height of the bed when giving care to help prevent back strain.
- Try to always stand close to the bed or chair and keep your knees slightly bent and your back straight and perpendicular to the floor.

Activity and Rest

Most patients like to be active and involved with family life as long as they can. If strength permits, patients should dress for the day, join the family for meals and other activities, and go for short outings.

When someone is ill and strength is limited, activities should be moderate. Conserving energy is more productive than trying to do too much. To conserve the patient's energy, alternate activities with rest.

Assistive Equipment

Equipment such as a wheelchair, bedside commode, and shower chair can be used to help the patient maintain independence and safety while still conserving energy.

An electric hospital bed is helpful when the patient is too ill to get out of bed. It allows the patient to change his/her position with the controls and lets the caregiver adjust the height of the bed when giving care. The bedrails provide safety and can help the patient turn him/herself in bed by giving him/her something to hold onto when moving from side to side. In addition, the head of the bed can be raised to help with breathing and for meals.

The hospice nurse will assist in determining what equipment will be most helpful and how to obtain it.

Skin Care

A person who sits or lies down for long periods of time must pay attention to the health of his or her skin. Two common skin problems patients develop are pressure sores and chafed skin; both of which can be prevented or made less severe by proper skin care.

Pressure Sores

Pressure sores are caused when an area of skin loses its blood supply for an extended period of time. The area begins to break down and the skin cells may eventually die as a result. Parts of the body where this often happens are the

tailbone, back of the head, ears, hips, spine, elbows, heels, ankles, and shoulder blades. If redness appears and does not go away from these areas a short time after pressure is removed, the skin may not be receiving enough blood flow. *Please report this to the Hospice nurse.*

The following suggestions may help prevent pressure sores:

- Change the patient's position frequently (at least every 4 hours while awake).
- Special equipment such as an alternating pressure mattress or a sheepskin pad may be helpful.
- Disposable bed pads and incontinence briefs can help keep skin dry and clean between baths.
- Hospital gowns or gowns and pajamas split up the back help keep clothing from bunching up under the patient. They are also easier to change.

Chafed Skin

Chafed or irritated skin is caused by a combination of heat, moisture, and friction. This occurs most often in areas of the body where skin folds are prevalent. Common areas include the groin, under the breasts, or in the abdominal area. For chafed skin problems, it is especially important to keep the area clean and dry.

Even with the most attentive care, a patient may develop pressure sores because of his/her declining condition. Special dressings can be placed over beginning sores to help prevent further breakdown and make the area more comfortable. The Hospice nurse will provide individualized instruction in such cases.

(*Note*: If there are any difficulties with skin care, please call the Hospice office at (239) 261-4404 for further professional guidance.)

Nutrition

Food and Water: A Hospice Perspective

"She never feels like eating. I try to give her food so that she can keep up her strength. I can't let her starve. What can I do?"

Hospice nurses and social workers hear these questions asked by almost every family with which they work. Terminally ill patients experience loss of appetite and subsequent weight loss as their illness progresses. The patient's family sees food not only as necessary for survival, but also as a source of caring, nurturing and comfort. While the family members focus on the need for food and insist that the patient eat even when he/she says "no," the patient rarely becomes concerned about his or her own loss of appetite. This conflict can be emotionally painful to everyone concerned and may lead to friction within the family, adding more stress to the family system as the disease progresses.

In the hospice program, nutrition is an issue that is discussed at almost every visit. As with other aspects of hospice care, nutrition includes: physical, psychological, and spiritual issues. Hospice team members work with the patient and the family to prepare them for the changes that will occur as the disease progresses. The hospice team will explain why these changes occur, what options for care are available, what outcomes can be expected of the intervention, and then supports the patient and family in their decisions.

Concerns related to hydration and nutrition are emotionally charged. Patients and families need to understand that weight loss and loss of appetite are part of the natural disease progression and the dying process. While medical treatments are available to reduce many of the problems experienced by hospice patients, there is little to offer in reversing this weight loss. Family members need to know that the human body has many ways of adapting during the dying process. Reduced interest in food and water is one of nature's strategies which allows the patient to die more comfortably and peacefully.

It is important that both the patient and their caregivers understand the effects of food and water from the early to the final stages of the terminal illness.

In the early stage, it is appropriate to offer the patient his or her favorite foods in small quantities throughout the day. During this time, the patient should be encouraged to eat and drink. It is helpful for families to know what amount of food they can realistically expect for the patient to eat or drink.

The following are some practical suggestions regarding nutrition:

- Offer small, frequent meals.
- Softer foods are easier to swallow.
- Avoid foods with high acid or fat content.
- Cooler foods are more easily tolerated.
- Try to serve the foods that are being tolerated well.
- Provide mouth care as directed.

When the patient's level of activity decreases, the metabolic rate slows down and the amount of calories he or she needs will decrease. As the disease progresses, the family needs to understand that continuing to encourage the patient to eat and drink does not work. Forcing food and liquids may cause not only physical discomfort, but emotional discomfort as well. An increase in the amount of food ingested will not significantly increase the patient's life expectancy.

The hospice nurse will assess the patient for causes of decreased appetite -- such as nausea and vomiting, constipation, pain, or mouth sores--and will recommend treatment as needed.

Feel free to discuss nutrition issues with a member of the Avow Team.

Bathing

A bath or shower is always refreshing. However, there are times when a bath or shower is not convenient or possible. In such instances, bed bathing may be a desirable alternative for the patient. Avow has hospice aides who can assist caregivers in bathing patients. Please consult with the hospice nurse to arrange for a hospice aide, if needed.

If the caregiver chooses to bathe the patient in bed, he or she may find the following suggestions helpful:

- Gather all the necessary items for the bath, and place them near the patient.
- Be certain the water being used is warm.
- Change the water frequently, if necessary, to maintain freshness and temperature.
- Be certain the patient remains warm throughout the entire process. This might entail covering the parts of the patient's body which are not being washed with a sheet or light blanket.
- Use soap sparingly and only on those areas of the body which perspire or are in need of extra cleansing due to odor or drainage. Use latex gloves if there is body drainage.
- Soaps can cause dryness and irritation. Plain, warm water is usually sufficient.
- If the skin is dry, a capful of baby oil or body lotion in the water can be helpful. Should the skin remain dry, the use of skin moisturizers may be helpful.

An alternative to a bed bath is a bath while sitting on a chair or commode either next to the sink or, if the patient is able, while sitting in the shower.

***Note*: If the patient is receiving radiation, do not use any soaps or lotions on the radiated area.**

If there are any questions or need for specific instructions, call Avow at (239) 261-4404 for further professional guidance.

Mouth Care

Mouth care is important when little food or drink is being taken in. The normal release of saliva, which is the body's own way of cleansing the mouth, does not occur when a person is not eating. In addition, the patient may experience a dry mouth due to:

- Breathing through the mouth.
- Increased or continuous use of oxygen.
- Certain medications.

Regular mouth care helps prevent sores and may improve the patient's appetite. If the patient is unable to do his/her own mouth care, it will be necessary to do it for him/her.

Note: When providing mouth care, make sure the head of the bed is elevated or the patient is in a sitting position.

One or more of the following may be used to ensure proper mouth care:

- Soft bristle toothbrush
- Piece of gauze moistened with water
- Soft wash cloth moistened with water
- Toothettes - little sponges on a stick that can be moistened with water or a non-drying mouthwash

The teeth, gums and tongue should be gently swabbed using any of the above. This can be done several times a day.

In addition, dentures should be removed and cleaned daily and after meals. If they are loose, they should be left out.

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Further suggestions for maintaining a clean, moist mouth include:

- Moisten lips with Chapstick, KY Jelly, or other moisturizer. Do NOT use Vaseline/petroleum based products when the patient is on oxygen or oxygen tanks are present.
- Avoid the use of mouthwashes with alcohol, as they can be drying.
- Dry mouth can be relieved by sucking on ice chips or hard candies or by frequent sips of water.

Note: If there is any difficulty with mouth care, call Avow at (239) 261-4404 for further professional guidance.

Gastrostomy Tube Care

Preliminary steps:

Wash your hands with soap and water. Gather supplies: gloves, a funnel, a large syringe, warm water, tablespoon, measuring cup, and prepared feeding or medication.

Checking tube position and residual:

Look for a mark on the tube where it should exit the body. If you can't see the mark, or if you see more tube below the mark than usual, contact the Hospice nurse before trying to administer feedings or medicine through the tube. Once you're sure the tube is positioned correctly, put on gloves, remove the plug from the end of the tube, insert tip of syringe into end of the tube and unclamp the tube. To assess how much gastric fluid is in the stomach, pull back the plunger of the syringe, measure the amount and record. Put gastric fluid back into the stomach. If there is over 100ml do not give feeding. If the patient complains of feeling too full after feedings or experiences regurgitation, hold feeding and report to your Hospice Nurse.

Preparing your medicine:

If liquid medication is not available, you will need to crush pills or tablets so they can go through the tube (extended-release or time-release pills cannot be crushed If the patient is on time-released medication, discuss this with your Hospice nurse as medications may need to be changed or given rectally). Most pills can be crushed with a mortar and pestle or a pill crusher (available from your Hospice Nurse). Crush them into a powder, and dissolve the powder in warm water. Contact your hospice Nurse with any questions regarding your medications.

Clearing the tube and giving the feeding or medication:

Raise the head of the bed. Measure the feeding using a measuring cup. Unplug and insert the funnel or syringe into the opening of the tube (if you are using a syringe, remove the plunger or bulb). Pour 2 tablespoons of water into the funnel

or syringe. Unclamp tube, let the water flow into the stomach by gravity. If the water flows easily, slowly begin pouring small amounts of feeding or medication into the tube. Continue until all the feeding or medication is given. Once completed, pour 2 ounces (60ml) of water into the funnel or syringe as a final flush to clear the tube. Re-clamp the tube and remove the funnel or syringe. Replace the plug on the end of the tube. The head of bed should remain elevated for at least one hour. Wash the funnel or syringe thoroughly. Remove gloves and wash your hands.

Urinary Catheter Care

In some conditions, patients may have difficulty emptying their bladder and a catheter (a tube from the bladder to a collection bag) may need to be inserted. The nurse inserting the catheter will provide instruction regarding its care.

Some common problems with catheters that need to be reported to the Hospice nurse include:

- Burning or pain
- Sudden decrease in urine through the catheter
- Leaking of urine around the catheter
- Blood or mucus in or around the catheter

Some useful actions if the catheter does not seem to be draining properly include:

- Checking the catheter to make sure it is not twisted, pulled too tight, kinked, or under the patient
- Making sure the catheter collection bag is hanging below the level of the patient's body

- Irrigating the catheter as ordered by the physician and instructed by the nurse

It is also important to clean the area where the catheter enters the body at least once a day and after each bowel movement. Use soap and water and rinse and dry well.

Note: If there is difficulty with the catheter, call the Hospice office for further professional guidance.

Standard Precautions for the Caregiver

The Centers for Disease Control and Prevention, a division of the U.S. Public Health Service, has published guidelines for health care workers handling human blood and other potentially infectious body fluids. These are called **Standard Precautions** and, while intended for health care workers, are applicable to any person caring for another.

As these guidelines are implemented by Avow, human blood and all other human body fluids (e.g., wound drainage, urine, feces, vomitus) are considered potentially infectious, and appropriate precautions should be taken as follows:

Hand-washing

- Hands should be washed before and after patient contact, and immediately, if hands become soiled with blood or other body fluids.
- Hands should also be washed after removing gloves.
- **Washing hands before and after contact is the single most important means of preventing the spread of infection.**
- **Hands should be washed using soap and warm running water for at least 20 seconds.**

Gloves

- Gloves should be worn whenever there is the possibility of contact with any body fluids.
- Gloves should always be worn if there are any cuts or sores present on the caregiver's hands.

Gowns/Masks/Eye Protection

- These are not usually needed, however their use should be considered when splashing of blood or other body fluids is likely.

Syringes/Needles

- Sharp objects represent the greatest risk to infectious exposure. Immediately after use, dispose of in puncture-resistant container.
- **Do not bend, break, recap or remove needle from syringe.**
- Keep the disposal container in an upright position, in the room where the needles and syringes are used, but well out of reach of children or visitors.

Spills of Blood/Body Fluids

- Wearing gloves, wipe up excess material with disposable towels.
- Clean spill with soap and water.
- Disinfect contaminated area with 1:100 solution of household bleach and water (1 tablespoon of bleach to 1 quart of water).

Laundry

- Wear gloves to handle clothing and bed linens soiled with blood or body fluids.
- If body fluid stains are present, put linens through cold wash cycle first. Then wash in hot water with 1 cup of bleach added to the wash cycle.

Infectious Waste

- Flush all liquid waste down the toilet. Tissues or other flushable items containing body fluids may also be flushed.
- Non-flushable materials containing body fluids (e.g., wound dressings, diapers, paper towels) should be placed in a plastic bag. This should be closed securely.

Disposal Tips

- Recommendations by the Florida Department of Environmental Protection following the guideline provided by the United States Environmental Protection Agency include the following:

For Sharps		**For Non-Sharps**

Place needles, syringes, lancets, and other sharp objects into hard plastic or metal container with a screw-on or tightly secured lid. Before discarding, be sure to reinforce the lid with heavy-duty tape. Do not put sharp objects in any container you plan to recycle, and do not use clear plastic or glass containers.		Place soiled bandages, disposable sheets, medical gloves, and other contaminated non-sharp material into a plastic bag. Secure the top of the bag. Place the bag into a garbage can with your other trash.

Safety in the Home

Please review the following tips to help prevent accidents and injuries.

Fall Prevention

- Remove and prevent clutter in pathways.
- Remove scatter rugs and only use rugs that are secured to the floor.
- Keep floors free of standing water.
- Do not walk on floors until they are completely dry.
- Keep all cords (telephone, electrical and oxygen tubing) out of the way.
- Use ladders and step stools only for out of reach objects. Never stand on furniture.
- Do not grab furniture with wheels to maintain your balance while rising or ambulating.
- Provide good lighting, use night lights or keep lights on at night.
- In the bathroom:
    - Use grab bars.
    - Use nonskid mats.
    - Keep floors dry.
    - Use night lights.

Fire Safety

- Do not use extension cords.
- Do not use appliances or equipment with frayed electrical cords.
- Do not use electrical equipment near water.
- Remove clutter.
- Keep all exits clear.
- Check smoke detectors monthly and replace batteries annually.
- Keep fire extinguisher in a neutral location that is easy to access.

- If you have Oxygen in the home:
    - Never use equipment until you have been given instructions on the proper usage and maintenance.
    - Do not use petroleum based products like Vaseline; use only water based products like KY jelly.
    - Post signs that oxygen is in use.
    - Never allow smoking in the home.
    - Do not light a flame such as a candle or ignite gas appliances while oxygen is on.
    - Oxygen tanks should be stored upright and never in an enclosed place such as a closet.
    - Oxygen concentrators should not be stored in an enclosed area.
    - Concentrator filters should be checked and cleaned weekly.

Medication Safety

- Store medications in an area where children, pets or confused family members cannot access them.
- Keep medications in their original containers unless you are filling a medication box.
- Keep each family member's medications in separate locations to avoid taking the wrong dose.
- Medications that sound similar or look alike should be kept in separate locations to avoid mistakes.
- Never take someone else's medication.
- Discard all expired medication.
- Discard all medications that are no longer used.
- Do not chew, crush or break any medication unless instructed to do so.
- Do not keep tubes of ointments or creams near your toothpaste.
- Keep a list or journal of all prescribed and over the counter medications and share this list with all healthcare providers.
- For instructions on medication disposal, please call (239) 261-4404 and speak with your nurse.

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Managing Controlled Substances in the Home

(Summary of Avow's Policy)

POLICY

Avow Inc. will manage controlled drugs in compliance with federal and state regulations governing the procurement, dispensing, and disposal of controlled substances. Adequate records, control, and accountability of ordered, dispensed, and disposed controlled drugs will be maintained to comply with requirements of the Federal Comprehensive Drug Abuse Prevention and Control Act of 1970, commonly referred to as the Controlled Drug Act.

Avow will not accept any unused, expired, or returned medications including controlled drugs from home hospice patients or community patient families.

Avow educates patients and caregivers/family members in the safe use and disposal of controlled substances in accordance with State and Federal regulations.

Licensed nursing personnel may assist with disposal of patient's medications including controlled drugs at the time of death.

PURPOSE

The processes to manage controlled substances from ordering through disposal are subject to regulatory requirements. Established processes promote control and accountability to prevent or minimize diversion and possession by unauthorized individuals for medications prescribed in home care. Processes for managing controlled substances include: ordering, procuring and receiving, storage, dispensing, administering, recording, disposing/returning, and filing records.

ASSUMPTION

Drugs in schedules II through V identified in the Controlled Drug Act are subject to special handling, storage, disposal, and recordkeeping. These schedules are based on the drugs' potential for abuse, acceptance for medical use in the U.S., and safety.

Controlled Drug Act Schedules

Schedule I – contains drugs with high abuse potential, no accepted medical purpose, and lack of accepted safety for use. For example, heroin.

Schedule II – contains drugs with high abuse potential, accepted restricted medical purpose, and abuse may lead to dependence. For example, morphine, meperidine, methadone, hydromorphone, fentanyl, cocaine, amphetamines, secobarbital, hydrocodone, and hydrocodone combinations.

Schedule III – contains drugs with a potential for abuse lower than schedule I and II, accepted medical purpose, and moderate to low dependence. For example, Tylenol with Codeine, marinol, and anabolic steroids.

Schedule IV – contains drugs with a potential for abuse lower than schedule III, accepted medical purpose, and limited dependence relative to schedule III. For example, propoxyphene, meprobamate, chloral hydrate, lorazepam, diazepam, chlordiazepoxide, depo-testosterone, and tramadol.

Schedule V – contains drugs with a low potential for abuse relative to schedule IV, accepted medical purpose, and limited dependence relative to schedule IV. For example, Codeine containing cough syrups, Lomotil, and pregabalin (Lyrica)

PROCEDURE

Responsibilities to Ensure Proper Management of Controlled Drugs

1. ONLY licensed nursing, physicians, and pharmacy personnel may access controlled drugs.

2. Licensed physician and nursing personnel ensure proper handling and implement procedures for monitoring and disposal of controlled drugs for infusion and non-infusion medications.
3. Clinical managers and supervisors oversee the implementation of policies and procedures for managing controlled substances.
4. Avow Hospice employees and volunteers are prohibited from taking any medications out of the patient's home or out of any facility including unlabeled medications to be re-labeled by the pharmacy. Controlled substances must not be removed from the home, inpatient, or residential facility at any time or for any reason.

Monitoring Controlled Drugs and Disposal of Medications in Home Care and Non-Hospice Facilities

(Summary of Avow's Procedure)

1. When controlled substances are first ordered for a patient in the home, the nurse educates the patient/caregiver in the proper management and disposal of controlled substances. The nurse will:
    a. Include a copy of the summary of Avow Hospice's policy on management and disposal of controlled medications in the patient's caregiver guide for the patient/caregiver to review as needed.
    b. Review and discuss the written policy and related procedures with the patient/caregiver in a language and manner that they understand to ensure proper education regarding the safe use and disposal of controlled drugs.

c. Document in the electronic medical record (EMR) that the policy was provided and reviewed/discussed and that controlled substance education was provided.

2. At the time of death or when controlled substances are no longer needed, information and education is provided to patients and/or caregivers/family members regarding safe and effective methods for disposing of controlled substances. Disposal options such as drug take-back events, mail back programs, and collection receptacles for drug disposal are discussed. Education with patient/family is documented in the EMR.

3. Licensed nursing personnel will monitor controlled drugs and report any discrepancies.
   a. To monitor non-infusion medications, compare the amount of medication dispensed to the amount of medication remaining to verify that the patient is taking the medication as prescribed.
   b. To monitor infusion medications, review the pump settings and document on the Parenteral Therapy Record form #MM0012 and in the EMR.

4. The patient/family receives notification when medications are no longer needed by the patient, at the time of death or upon completion of therapy. At this time, licensed nursing personnel will educate the patient/family on the policy for managing and disposing of controlled drugs and review/discuss proper disposal and options.

5. Processes are in place to assist patients/families with disposal of controlled drugs maintained in the patient' home when these medications are no longer needed by the patient, e.g. at the time of death, when medications have expired, or upon completion of infusion therapy. At the time of death licensed nursing personnel may physically assist by disposing of the medication if the family member requests it or agrees to it.

6. After a patient's death, licensed nursing personnel attending the death may assist a family member with the proper disposal of unused medications according to organizational policies and procedures and requirements described in *Process to Provide Physical Assistance with Medication Disposal* (page 64). If patient /family requests and agrees to the disposal, the nurse will physically dispose of the patient's medications following *Guidelines for Disposal of Unused/Expired Medications* (page

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65) and record required documentation listed in *Process to Provide Physical Assistance with Medication Disposal* (page 64).

7. If patient/family wishes to dispose at a different time or in a different manner, inform them of known take-back events, mail-back programs, or collection receptacles by authorized registrants. Refer to *Medication Disposal Options* (page 65).

8. Refusal by family members to dispose of controlled drugs or desire to delay disposal/use other methods for disposal is documented in the EMR.

9. For disposal of medications in non-hospice facilities, the facility will assume responsibility for disposal of patient's medication and documentation. When a death occurs in any nursing facility, Avow staff shall not dispose of medications, but will allow the facility to dispose of the medications and will document disposal on the EMR.

REFERENCES

1. Tags: 694, 695, 696, 697
2. The Joint Commission Edition. July 1, 2021.Medication Management Standards: MM.01.01.03, 03.01.01,, 05.01.11, 05.01.19.
3. CMS. Medicare Conditions of Participation 418.106(e)(2) – Disposing of drugs and biologicals.
4. Hospice Rule. FAC 58A-2.005(7) Administrative policies and practices – Drug control policies including disposal of class II drugs.
5. Controlled Substances Act of 1970, US Department of Justice, Drug Enforcement Administration.
6. Title 21 CFR 1300 – Definitions, 1305 – Orders for Schedule I and II Controlled Substances.
7. Florida Statutes. F.S. 893.03 – Drug Abuse Prevention and Control, Standards and schedules; 893.07-Records

DEFINITIONS

1. **compounded stock medications -** refers to medications that are specially compounded that must be ordered through the pharmacy distributor utilizing the "multi-use" order form and signed by a physician.
2. **controlled drugs** - drugs or other materials that, because of their potential for abuse, are closely regulated by the Federal government and are classified according to Schedules I-V; drugs subject to the Controlled Substances Act of 1970.
3. **drug diversion** - illegal distribution or abuse of prescription drugs or their use for unintended purposes.
4. **drugs no longer needed** - those drugs that have been discontinued by the physician or are remaining at the time of death.
5. **patient's family** - the person or those persons designated by the patient as having primary responsibility for care, or persons who are closely linked with the patient and are involved in the health and supportive care of the patient.
6. **patient and family unit** - the patient and the patient's family.
7. **order-** refers to an order for medication that is dispensed for immediate administration to the ultimate user (for example, an order to dispense a drug to an inpatient for immediate administration is not a prescription).
8. **prescription:** refers to an order for medication that is dispensed to or for an ultimate user (for example, the physician will write a prescription for the patient to take home upon discharge from Georgeson House (GH), or to be filled by the pharmacy and dispensed to the patient to take home upon discharge from GH**.**
9. **schedule II drugs** - certain narcotic, stimulant, and depressant drugs that have a high abuse potential with severe psychological or physical dependence. The drug or other substance has a currently accepted medical use or treatment in the U.S. with severe restrictions.
10. **stock medications -** refers to controlled and non-controlled medication that are ordered in unit of use, or individual injectable vials that are provided in original manufacturer's packaging.
11. **ultimate user** - is a person who has lawfully obtained, and who possesses, a controlled substance for his/her own use or the use of a member of his/her household.

Process to Provide Physical Assistance with Medication Disposal

1. Licensed nursing personnel performing a visit, (including attending a death) may provide physical assistance with proper disposal of unused medications to a family member if the following conditions apply:
    a. The patient is/was residing in a personal residence.
    b. An adult family member (person designated by the patient as having primary responsibility for care or closely linked with the patient and involved in the health and supportive care of the patient) requests assistance or gives their permission for physical assistance with medication disposal.
    c. The family member requesting or permitting the demonstration or assistance is physically present for the duration and for the documentation of the assistance.

2. The licensed nursing personnel disposing of the medications will obtain permission to dispose of the medications and dispose according to organizational policies and procedures. The permission granted by the family member and the disposal are fully and contemporaneously documented on the Medication Disposal Acknowledgement form, #MM0028, in the patient's EMR. The documentation includes:
    a. Date and time of disposal
    b. Participants
    c. Method of rendering the medications irretrievable/unusable
    d. Method of disposal
    e. Name, type, and amount of medication
    f. Acknowledgement (with a physical signature by the adult family member)
    g. of the accuracy of the inventory and process

Guidelines for Medication Disposal (US FDA CONSUMER UPDATES, 2020)

How to Dispose of Medicines at Home

When a take-back option is not readily available, there are two ways to dispose of prescription and over-the counter (OTC) medicine, depending on the drug.

Flushing medicines

Because some medicines could be especially harmful to others, they have specific directions to immediately flush them down the sink or toilet when they are no longer needed, and a take-back option is not readily available.

How will you know? Check the label or the patient information leaflet with your medicine. Or consult the U.S. Food and Drug Administration's list of medicines recommended for disposal by flushing when a take-back option is not readily available.

Disposing medicines in household trash

Almost all medicines, except those on the FDA flush list, can be thrown into your household trash. These include prescription and over-the-counter (OTC) drugs in pills, liquids, drops, patches, and creams.

Follow these steps:

1. Remove the drugs from their original containers and mix them with something undesirable, such as used coffee grounds, dirt, or cat litter. This makes the medicine less appealing to children and pets and unrecognizable to someone who might intentionally go through the trash looking for drugs.
2. Put the mixture in something you can close (a re-sealable zipper storage bag, empty can, or other container) to prevent the drug from leaking or spilling out.
3. Throw the container in the garbage.
4. Scratch out all your personal information on the empty medicine packaging to protect your identity and privacy. Throw the packaging away.

If you have a question about your medicine, ask your health care provider or pharmacist.

Disposing of Fentanyl Patches

Some prescription drugs — such as powerful narcotic pain medicines and other controlled substances — have instructions for flushing to reduce the danger of overdose from unintentional or illegal use.

One example is the fentanyl patch. This adhesive patch delivers a strong pain medicine through the skin. Even after a patch is used, a lot of the medicine remains. That's why the drug comes with instructions to flush used or leftover patches.

Disposing of Inhaler Products

One environmental concern involves inhalers used by people who have asthma or other breathing problems, such as chronic obstructive pulmonary disease. Read handling instructions on the labeling of inhalers and aerosol products. These products could be dangerous if punctured or thrown into a fire or incinerator. To properly dispose of these products and follow local regulations and laws, contact your trash and recycling facility.

Medication Disposal Options

Mail Back Programs through Retailers

Mail-back medications through the US Postal Service to Sharp's Compliance Corp. licensed facility for safe disposal.

A Sharps Compliance Take Away Medication Recovery System is available for approximately $4.79 at select CVS pharmacies. Contact pharmacy for more information.

Pain Management

Definition of Pain: Pain is what the patient says it is--discomfort, aching, restlessness, anxiety, cramping, gnawing, sharp or stabbing sensation.
Pain causes not only physical discomfort, but also emotional discomfort.

When pain is relieved, life becomes more enjoyable and of better quality. The Team will perform an individualized pain screening and assessment to evaluate the best treatment options to manage a patient's pain. The goal of treatment is to effectively

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manage a patient's pain within 48 hours of admission and maintain a level of pain control consistent with patient's desired level of comfort and reasonable expectations based on the patient's condition.

The criteria used for screening and assessment is consistent with the patient's age, condition, and ability to understand. This includes: the use of age-specific tools; scales based on the patient's condition and disease processes; and assessing factors interfering with a patient's ability to understand. Treatment alternatives are evaluated and may include opioids, non-opioid alternatives, or a combination of both.

The patient/caregiver are involved in developing treatment planning goals for pain management based on reasonable, realistic expectations considering that there might be clinical situations for which a complete elimination of pain may not be a reasonable expectation or goal. Objectives for pain are established to evaluate treatment progress.

When opioids are necessary to manage a patient's pain, patients and caregivers must abide by Avow's policies, practices, and special considerations for safe and responsible use, storage, and disposal of opioid medications described in this Guide or provided by the clinical team.

When pain medications such as narcotics (e.g., Morphine) are used to relieve pain, patients do not become addicted to them. Hospice uses only enough medication to relieve pain and recommends that it be taken on a regular, around-the-clock basis to prevent pain from coming back. Some medications may be used in combination with others, which can be more effective than either drug alone.

Side effects of pain medication and ways to manage them may include:

- **Sedation**: Feelings of drowsiness are usually short-lived--up to 48 hours. Pain zaps a person's energy. When pain is relieved, a person can rest comfortably.
- **Nausea**: This can usually be controlled by an anti-nausea medication.
- **Constipation**: A mild laxative with a stool softener taken on a regular basis can
- control constipation.

- **Dry Mouth**: Sucking on ice chips or hard candy can help relieve dry mouth.

Alternatives: The following measures other than medication may also help relieve pain and suffering:

- Relaxation exercises to decrease tension
- Gentle oil or lotion massage of painful areas
- Therapeutic touch, or moving hands over tender areas without touching them
- Heating pads or ice packs applied to areas of local pain or tenderness
  Note: Heating pads should be used only with careful supervision
- Deep heating local rubs to soothe nerve or muscle pain
- Changes in position
- Elevation of sore or swollen limbs on pillows
- Diversions such as quiet music, visitors, humor, reading aloud, or television to help focus attention away from suffering (although they are rarely enough in themselves to alter awareness of pain).

Please access this link to view "Alternatives to Opioids for Pain Management", an informational pamphlet produced by the Florida Board of Medicine:

https://flboardofmedicine.gov/pdfs/HB451_pamphlet_6-28-19.pdf

For additional information about Pain Management and other important topics, please visit our website https://avowcares.org/caregiver-videos/, or use QR code, to view the "Avow Video Library." We have created these videos to educate, inform, and inspire you. It's our pleasure to provide them to you.

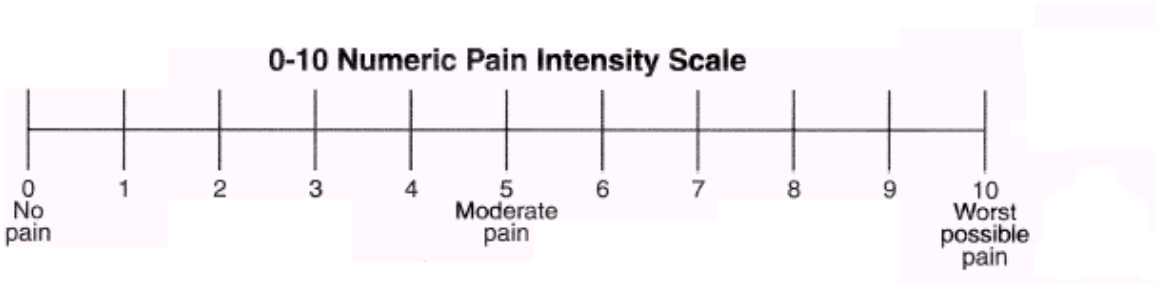
Comfort Assessment

The hospice nurse will assist in monitoring the patient's pain using the Pain Management Record (see pg. 83).

Note: If pain is not relieved with the medication as directed, call the Hospice office at (239) 261-4404 for further professional guidance.

Controlling your pain is an important part of your care. Tell your doctor or nurse if you have pain, if your pain is getting worse, or if you are taking pain medicine and it is not working. They can help you get relief from your pain.
You should not wait until your pain is severe to take your medicine. Pain is easier to control when it is mild than when it is severe. You should take your pain medicine regularly and as your doctor and nurse tell you. This may mean taking it on a regular schedule and around-the-clock.

In order to help us assess your pain, we have developed a Pain Assessment Guide for you. Our goal is to keep your pain and comfort level as close to '0'(zero) on the pain scale as possible. This means that you are not experiencing any pain.



If your pain or discomfort reaches a level 3 or above, please let your nurse know right away. Your medications can be adjusted to make you more comfortable.

It is important to remember that pain is whatever you say it is. Some of the other questions a nurse or doctor may ask you are:

- Location - is it the same as previously or is it new pain or discomfort?
- How frequently are you experiencing pain or discomfort?
- What makes it better?
- What makes it worse?
- How often are you taking your medication?
- What is your level of pain 1 hour after you take your medication?
- Is there any pattern to your pain or discomfort?

If you are the caregiver and the patient cannot tell you what his/her pain is, there are other cues that may be used to assess pain or discomfort. These include:

- resistance to being moved
- holding/guarding a specific area
- facial grimacing, frowning
- vocalization, moaning, whimpering
- restlessness/combativeness
- any change in behavior.

If any of these occur, please call Avow right away.

Starting Morphine Treatment

What is morphine and how does it work?

Morphine, and morphine-like drugs, are the mainstay of treatment for severe pain. Morphine is simple to administer, is widely available and, when properly used, provides good pain relief in most patients.

Does this mean I am at the end of the road?

Morphine is used to control pain which no longer responds to other pain medication. It is used at many different stages of the illness, and not just at the

end of the road. Many need it for weeks, months or years because of continuing pain. Others need it for just a few days or weeks.

Will morphine make me die sooner?

There is no evidence that this is so. You may find you can sleep comfortably through the night because you are free of pain.

Will I get drowsy on Morphine?

Drowsiness may occur during the first few days, possibly up to a week. You should persevere in the knowledge that the drowsiness will lessen after a few days.

The principle that will be followed is to increase the dose in steps until you are pain-free but still alert. Drowsiness is a feature of advanced disease. It is part of your illness. Your energy may go up and down when you are ill, and some days you need more rest than others.

Will I go on feeling drowsy?

It is important to distinguish between persistent drowsiness and weakness. You may drop off to sleep if sitting quietly. This can be an advantage if you have limited stamina due to the progression of your disease and require more rest and sleep.

Where can I get more information about Morphine?

Talk with your nurse. Your nurse can answer your questions or bring you more information.

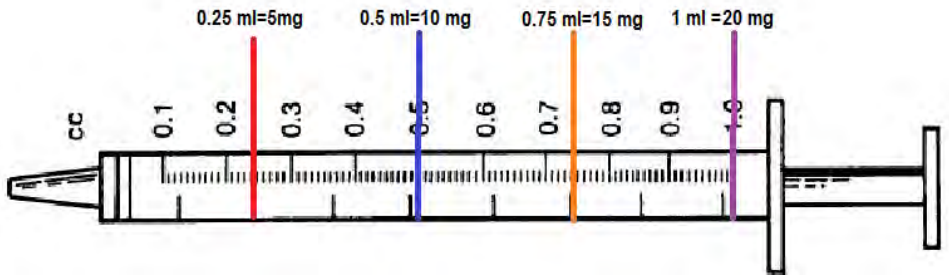
Liquid Morphine Patient Education

Liquid morphine is supplied in a highly concentrated liquid form where in each 1 milliliter there is 20 mg of morphine. The physician will order a certain dose for you. It can ONLY be measured out with a 1ml syringe that hospice will provide for you.

These syringes can be washed and reused until the marking's wear off. Ask your nurse to bring you more when this happens.

Please use this picture to assist you in measuring out the correct dose. Your nurse will assist you in learning this.

Your nurse will also inform you when there is a change in the dose.
If you need assistance, please call us at Avow (239) 261-4404 and ask for a nurse.



Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

Anxiety/Confusion

Adapted from Roxane Form # RX-1924

Many patients may experience anxiety or confusion during the course of their illness. Changes in metabolism and disease processes affecting the brain or liver are some of the physiological reasons this may occur. When a person becomes confused, he or she may be aware of the confusion and become anxious about this loss of control.

The following suggestions may be helpful in caring for a patient who is anxious or confused:

- Be aware of safety issues. Confused patients may try to get out of bed when it is not safe to do so.
- Have a clock and calendar within sight to help keep the patient oriented.
- Remember, changing routines or environment may cause confusion. Keep the patient in a quiet, well-lit, familiar room with familiar people.
- Do not treat the patient as if he or she doesn't know what is happening.
- Remain calm and reassuring to the patient. A caregiver's anxiety will only increase a patient's anxiety.
- Helping the patient to remain calm and relaxed counteracts the effects of anxiety.
- Certain medications can help clear confusion and reduce anxiety. Ask the Hospice nurse about those medications.

Note: If anxiety and confusion problems continue, call Avow at (239) 261-4404 for further professional guidance.

For additional information about Anxiety and other important topics, please visit our website https://avowcares.org/caregiver-videos/, or use QR code, to view the "Avow Video Library." We have created these videos to educate, inform, and inspire you. It's our pleasure to provide them to you.

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Breathing Problems

For a patient who is very ill, the process of getting air in and out of the lungs can be difficult at times. Breathing difficulties are often referred to as "shortness of breath" or "air hunger." Being short of breath can be very frightening to a patient. It is important that the caregiver try to remain calm and not contribute his or her own anxiety to that of the patient.

Signs of low oxygen may include a restless or anxious feeling, as well as a faster breathing rate. If breathing problems do occur, the caregiver can do some things to help the patient breathe easier:

- Remain calm and reassuring.
- Raise the patient's head by raising the head of the bed or by placing pillows behind the patient's back, neck, and head.
- Place the patient in a position he or she identifies as most comfortable.
- Utilize air conditioners, fans, humidifiers, or vaporizers.
- Eliminate smoking from the patient's immediate area.
- Place a cool cloth on the patient's forehead.
- Give breathing medications to the patient, as ordered by the physician.

Oxygen Therapy

A patient may, at some point in his or her illness, require therapy to assist in breathing comfort. If oxygen therapy is needed, the Hospice nurse will assess the patient and contact the physician for instruction. The nurse will assist in contacting the medical supply company. The medical supply company will then deliver the oxygen to the home and instruct the patient and caregiver on its usage. The most common way to receive oxygen therapy is by nasal cannula (breathing tube that is placed in the patient's nose).

Things to remember about oxygen therapy:

- Do not smoke or light matches in a room where oxygen is in use.

- Do not use oxygen around a gas stove.
- The prongs of the nasal cannula must be in the patient's nose and kept clean with a soft, moist cloth.
- The nasal cannula and tubing should be replaced every month.
- Even though a patient may be mouth breathing, oxygen via the nasal cannula is still being inhaled.
- Do not use petroleum based products like Vaseline on or around the patient.

(*Note*: If breathing problems continue, call Avow at (239) 261-4404 for further professional guidance.)

Nebulized (Aerosol) Medication

Many hospice patients can at some point in their disease progression, suffer shortness of breath, cough and respiratory (lung) congestion. There are several frequently used medications that the doctor may prescribe to relieve these symptoms after assessment by your hospice nurse, some of which are nebulized medication.
A nebulizer is a breathing machine used intermittently that helps the patient breathe in medications that can be helpful to them.
At Avow Hospice, the following nebulized medications are commonly used:

Duoneb®- a combination of atrovent (ipratropium) and albuterol that is used to relax muscle spasms in the airways and thereby ease breathing, or opening up airways to allow mucous to clear better. It is generally well tolerated, though side effects may include jitters or tremors that may occur for about 15 minutes after your treatment. These will ease.

Lidocaine- an anesthetic or numbing agent that is used to stop coughing caused by a source of irritation or that has not been controlled with other medications. Safe and very effective when used as prescribed, lidocaine should never be used more frequently than prescribed or could cause problems with heart rhythm. Do not eat or drink for 30 minutes after taking this medication as your throat may be numb.

Saline- nebulized salt water is used to moisten airways and loosen thick, sticky phlegm so it can be coughed up more easily. Use only the saline provided for this purpose.

See medication package inserts for more information about actions, effects, side effects and usage of the above medications.

For additional information about Dyspnea/ Trouble Breathing and other important topics, please visit our website https://avowcares.org/caregiver-videos/, or use QR code, to view the "Avow Video Library." We have created these videos to educate, inform, and inspire you.

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Nausea/Vomiting

Nausea and/or vomiting is very uncomfortable and can be caused by many different factors, such as:

- Foods and smells that are poorly tolerated
- Certain medications
- Infection
- The disease process
- Poor oral hygiene

In most cases, nausea and vomiting can be controlled or stopped. Here are some practical suggestions:

- Give only clear liquids or saltine crackers to the patient until nausea subsides.
- Provide mouth care as directed.
- Use prescribed anti-nausea medications as directed.

Note: If nausea and/or vomiting continue, call Avow at (239) 261-4404 for further professional guidance.

Elimination

Elimination of urine and stool is the body's way of removing waste. Problems with elimination can cause the patient a great deal of anxiety, embarrassment, and discomfort. Bowel habits differ from person to person. Understanding a person's bowel history--before he or she becomes ill--is helpful.

Constipation

Constipation is a very common symptom for Hospice patients and one which can cause significant distress. Constipation is characterized by frequent or irregular hard bowel movements.

The use of pain medications, decreased activity, the disease process, and decreased intake of food and fluids all contribute to constipation. The best treatment for constipation is prevention. Patients are encouraged to:

- Increase activity, if able.
- Increase fluid and fiber in the diet if tolerated, such as water, juices, fruits, bran, whole grains, and vegetables.
- Drink prune juice or hot water with lemon.
- Take stool softeners and laxatives as instructed.
- Use the Daily Elimination Record to monitor bowel movements and to communicate with the hospice nurse.

Diarrhea

Diarrhea is less common, but no less distressing. Diarrhea is characterized by frequent (more than four times in 24 hours), unformed stools. The patient may also experience stomach cramping with diarrhea. If diarrhea occurs, the patient should:

- Stop all stool softeners and laxatives.
- Increase fluid intake.
- Eat small amounts, frequently, of foods that are mild e.g., rice cereal (dry), bananas, applesauce, dry toast, or plain baked potato.
- Avoid dairy products; avoid fried, spicy, or fatty foods.
- In severe cases, it may be necessary to take a prescribed medication. Ask the hospice nurse about such medication.
- If prescribed treatment has been followed for 24 hours without improvement, notify the hospice nurse.
- Severe constipation can actually cause liquid stools that leak around the

constipated stool. Any patient who develops diarrhea should seek evaluation by a nurse for this problem.

Note: Special attention to skin care will be needed for the patient who is bed-bound and having diarrhea. Keep the area clean and dry, and use a protective lotion or ointment as needed.

Urinary Problems

For various reasons, patients may find that they are unable to urinate. This may cause discomfort, or the patient may not even be aware of it. If a patient has not voided in 12-18 hours or is having lower abdominal pain when urinating, notify the Hospice nurse.

Note: If problems with elimination continue, call Avow at (239) 261-4404 for further professional guidance.

Oral Thrush

Oral thrush is a very common infection that occurs in many patients who are very ill. It is an infection of the mouth, tongue and throat caused by microscopic organisms known as yeast. The type of yeast that most commonly causes oral thrush is called Candida and is normally found in the mouth, skin and stomach of just about everyone.

The main symptom of oral thrush is the appearance of soft, white patches in the mouth or back of the throat.

Oral thrush is not contagious. When you are healthy and your immune system is strong, it poses no threat. In patients with cancer, the use of chemotherapy and steroids increases the chance of getting thrush. These therapies allow the yeast to grow while suppressing the ability of the immune system to do anything about it.

Because a patient's immune system is already weakened it is very important for you to carefully follow your doctor's instructions. Doctors treat thrush with drugs known as antifungals that help control the infecting yeast. These are prescribed in a tablet or liquid form.

If left untreated, thrush may be a bigger problem by becoming more severe and painful.

Several things can be done to help reduce the risk of developing oral thrush.

1. After eating, gently brush all surfaces of teeth, gums and tongue with a soft toothbrush.
2. Gently floss teeth daily with dental floss.
3. Rinse mouth before and after meals and at bedtime with plain water or a mouthwash made from one teaspoon of salt dissolved in one quart of water.

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

Note: Avoid the use of commercial mouthwashes.

4. If the patient wears dentures, remove and brush them thoroughly after meals and brush gums and tongue.
5. Dentures should also be soaked regularly in a cleaning solution.
6. If using Magic Mouthwash or Nystatin:
    a. Remove dentures before swishing and swallowing.
    b. This should be done 4 times a day for 1 week.
    c. The nurse will look at the mouth after 1 week of treatment and order something else if needed.

Fever

Fevers are often common in very ill patients. The goal is to keep the patient comfortable. It is not necessary to take a temperature reading routinely. Suggestions to help provide comfort to the patient include:

- Offer extra fluids as tolerated.
- Sponge with lukewarm water.
- Cover loosely with a sheet or light blanket.

Note: Call the hospice nurse at (239) 261-4404 for medication to help decrease fever.

Recognizing Signs and Symptoms of Dying

As the final days and hours approach and death becomes imminent, you will begin noticing physical changes in the patient:

- Usually, he or she will refuse liquids and/or medications.
- There may be a change in responsiveness (more difficult to arouse).
- The extremities (arms and legs) may become cooler to touch and may take on a bluish tinge. This is due to slowing of circulation.
- Breathing may become more labored, noisy, and irregular.

Should any of these signs occur, please notify the Hospice nurse. The phone number is on the sticker on your phone. Should death come quickly, notify the nurse by calling the Hospice office. We are available at any time, 24 hours a day.

If you haven't already received it, ask your team for a copy of a helpful booklet called "When the Time Comes". It will help you and your loved ones understand what to expect.

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Note: Even though the patient may seem unresponsive, please remember that hearing is very acute. Speak to the patient assuming that he/she can still hear you.

For additional information about symptoms near the end of life, and other important topics, please visit our website https://avowcares.org/caregiver-videos/, or use QR code, to view the "Avow Video Library."

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In-Home Medication List

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In-Home Equipment List and Supplier

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
If you are unable to reach us at any time, please call us at (239) 280-2271.

Individual Skin Care Instructions

Avow is available 24 hours a day and 7 days a week. Call (239) 261-4404.
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DAILY ELIMINATION RECORD

Date/Time	Consistency (Hard, Soft, Loose)	Amount (Small, Medium, Large)	Comments (Unusual Color, Blood, Etc.)	Nursing Instructions

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PAIN MANAGEMENT RECORD

0 No Pain — 1 — 2 — 3 — 4 — 5 Moderate Pain — 6 — 7 — 8 — 9 — 10 Worst Possible

DATE	TIME	MEDICATION	DOSAGE	INTENSITY SCALE	DROWSINESS	INITIALS

*Drowsiness: 0 = None 1 = Mild 2 = Severe

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