

## Arden Hospice Informed Consent for Hospice Services

Consent is hereby given for such care and services through **Arden Hospice of \_\_\_\_\_ Mississippi** as ordered by my physician. In relation to this admission, I voluntarily acknowledge, consent, and agree to the following:

I understand that I have been diagnosed with (disease description)

\_\_\_\_\_ and that further attempts to achieve a cure or attain a significant remission are not likely to be successful. I understand that Arden Hospice will provide comfort care, without curative intent, to meet the physical, emotional, and spiritual needs of me and my family. The focus of care is aimed at maintaining my quality of life through the management of pain and other symptoms. I understand that choosing hospice care shifts the focus of care for the terminal illness from cure to comfort measures and waives the Medicare benefits for curative care. I understand that I am free to change my mind about this method of care and withdraw from hospice care at any time.

### Hospice Services and Levels of Care

(A) Routine Home Care: I understand that Arden's services are provided primarily in the home by an interdisciplinary team consisting of physicians, nurses, social workers, hospice aides, dietitians, spiritual counselors, physical, occupational and speech therapists, and/or volunteers. Services may include care by the interdisciplinary team as well as medical supplies, medical equipment, and/or medications related to the terminal illness. Intermittent visits will be provided by scheduled appointment and on-call assistance is available 24 hours per day, seven days per week for management of my care outside of scheduled visits.

(B) General Inpatient Care: I understand that inpatient hospice care may be provided when it is deemed necessary by the interdisciplinary team. I understand that general inpatient care is intended for short term admissions required for pain control or symptom management. My interdisciplinary team will continue to follow my care during these admissions.

(C) Respite Care: I understand that inpatient respite care may be provided for short periods, not to exceed 5 contiguous days when deemed necessary for my family or primary caregiver caring for me at home.

(D) Continuous Home Care: I understand that continuous care may be provided during periods of crisis in my home to manage pain and other acute symptoms and when it is deemed necessary by my physician and interdisciplinary team.

### Resuscitation/Advance Directive

I have received information on Arden's policy and state law for Advance Directives. I understand that Cardiopulmonary Resuscitation (CPR) is not routinely provided by Arden's staff and is not part of a palliative plan of care. I also understand that admission to Arden Hospice will not be denied if I desire CPR.

Check all that apply. I have a:

- ☐ Living Will    ☐ DNR    ☐ Health Care Power of Attorney
- ☐ I do not have an Advance Directive.

My agent is \_\_\_\_\_ My agent's phone number is \_\_\_\_\_  
(Please provide Arden Hospice with a copy of your Advance Directive so we may follow your wishes.)

### **Patient/Family Role**

My caregiver and I will have the opportunity to join the interdisciplinary team in making decisions about the type, frequency and intensity of services provided by Arden and may review my hospice plan of care at any time. My primary caregiver is \_\_\_\_\_ and he/she will be the person primarily responsible for coordinating care with Arden and meeting my needs at home. I understand that if I am to receive the full benefits of hospice care, it is important for me and/or my primary caregiver to make my needs and concerns known to the Arden staff. I (we) will actively participate in plans for my care.

### **Release of Information/Patient Records**

I authorize Arden Hospice to use and disclose protected health information (PHI) for the purposes of treatment, payment and health care operations. I understand that Arden uses an electronic health record and, as necessary for care or to process claims, may release PHI to, or receive PHI from, physicians, hospitals, other health care providers, assisted living facilities, skilled nursing facilities, third party payers, regulatory agencies, and/or family members involved in my plan of care.

### **Consent of Photograph**

I hereby consent to having my photograph taken along with any photographs of any skin or wound changes for the purpose of identification and/or for documenting my medical condition.

### **Telemedicine Consent**

I agree to receive hospice services as telemedicine services. I understand that the hospice practitioner is located in another location.

### **Infection Control/Safety Information (Pages 12-13)**

Arden follows accepted standards of practice to prevent the transmission of infections and communicable diseases. I have received information on the prevention of infection, including the use of standard precautions. Home safety tips and Arden's Emergency Preparedness/Disaster Plan has been explained to me.

### **Medications/Controlled Substances/Drug Disposal/Part D Coverage and Responsibilities (Page 11)**

I have received verbal and written information on Arden's policy for managing controlled drugs. I hereby consent and agree that, if allowable under state law, any pharmacist who dispenses any of my prescription drugs may select a drug product that is generically equivalent to the brand prescribed by my physician, unless I submit to Arden, a written request for a brand name product.

Regular and Controlled Medications. Unused, unneeded or expired medications will be taken from their original container and mixed with an undesirable substance, put into an impermeable container and put into the trash. **Hospice staff may not remove medications from the home.** If a family member refuses the destruction of medications, specifically controlled medications, the hospice nurse will perform a count with the family member, document the count and have the family sign in acknowledgement.

Federal regulations require that Medicare hospice providers conduct and document a patient specific comprehensive assessment in writing, which identifies the patient's need for hospice care and services, as well as any need for physical, psychosocial, emotional, and spiritual care. The written assessment of the patient includes all areas of hospice care related to the palliation and management of the terminal illness and related conditions. The comprehensive assessment must also include a drug profile with all of the patient's prescription and over-the-counter (OTC) drugs, herbal remedies, and other alternative treatments that could affect drug therapy. The hospice plan of care is based on the needs identified in the initial, comprehensive, and updated plan of care assessments. Therefore, the requirement is that hospices will have appropriate medication documentation for each hospice beneficiary upon completion of these assessments. Medication information obtained through the assessments, including whether the medications are related or unrelated to the terminal illness and related conditions, should be provided to the Part D sponsor proactively—meaning before a hospice beneficiary presents a prescription for fill—or, failing proactive provision of the information by the hospice, should be provided to the Part D sponsor, after the Part D sponsor contacts the hospice provider during the PA process.

Four Categories of drugs typically covered by the hospice:

1. Analgesics
2. Antinauseants
3. Laxatives
4. Antianxiety

#### Drugs in the Four Categories That Are a Beneficiary Liability

There may be some drugs that were for the treatment of the terminal illness and/or related conditions prior to the hospice election that will be discontinued upon hospice election, as it has been determined by the hospice interdisciplinary group, after discussions with the hospice patient and family, that those medications may no longer be effective in the intended treatment, and/or may be causing additional negative symptoms in the individual. These medications would not be covered under the Medicare hospice benefit, as they would not be reasonable and necessary for the palliation of pain and/or symptom management. If a beneficiary still chooses to have these medications filled through his or her pharmacy, the costs of these medications would then become a beneficiary liability for payment and not covered by Part D. These medications would not be covered by Part D because their further coverage is prohibited under Medicare. Similarly, if a beneficiary requests a drug for his or her terminal illness or related conditions that is not on the hospice formulary and the beneficiary refuses to try a formulary equivalent first; or the drug is determined by the hospice provider to be unreasonable or unnecessary for the palliation of pain and/or symptom management, the beneficiary may opt to assume financial responsibility for the drug. However, no payment for the drug will be available under Part D.

#### Language Translation

Arden Hospice will make all reasonable efforts to secure a professional, objective translator for hospice-patient communications, including those involving the notice of patient rights. We will provide written copies of the notice of rights available in the language(s) that are commonly spoken in the service area. Family members or friends as translators will be used as a last resort. Language assistance services are provided free of charge to you by calling 1-877-746-4674.

## **Hospice Patient Bill of Rights. Hospice Patients have the right to:**

- receive care of the highest quality;
- have relationships with hospice organizations that are based on ethical standards of conduct, honesty, dignity, and respect;
- in general, be admitted by a hospice organization only if it is assured that all necessary palliative and supportive services will be provided to promote the physical, psychological, social, and spiritual well-being of the dying patient. However, an organization with less than optimal resources may admit the patient if a more appropriate hospice organization is not available, but only after fully informing the client of its limitations and the lack of suitable alternative arrangements;
- be notified in writing of their rights and obligations before their hospice care begins. Consistent with state laws, the patient's family or guardian may exercise the patient's rights when the patient is unable to do so. Hospice organizations have an obligation to protect and promote the rights of their patients;
- be notified in writing of the care the hospice organization will furnish, the types of caregivers who will furnish the care, and the frequency of the services that are proposed to be furnished;
- be advised of any change in the plan of care before the change is made;
- participate in the planning of the care and in planning changes in the care, and to be advised that they have the right to do so;
- refuse services and to be advised of the consequences of refusing care;
- request a change in caregiver without fear of reprisal or discrimination;
- confidentiality with regard to information about their health, social, and financial circumstances and about what takes place in the home;
- expect the hospice organization to release information only as consistent with its internal policy, required by law, or authorized by the client;
- be informed of the extent to which payment may be expected from Medicare, Medicaid, or any other payor known to the hospice organization;
- be informed of any charges that will not be covered by Medicare, and the charges for which he or she may be liable;
- receive this information orally and in writing within 15 working days of the date the hospice organization becomes aware of any changes in charges;
- have access, on request, to all bills for service the patient has received regardless of whether they are paid out of pocket or by another party;
- be informed of the hospice's ownership status and its affiliation with any entities to whom the patient is referred;
- be informed of the procedure they can follow to lodge complaints with the hospice organization about the care that is, or fails to be, furnished, and regarding a lack of respect for property;
- know about the disposition of such complaints;
- voice grievances without fear of discrimination or reprisal for having done so; and
- be told what to do in the case of an emergency.

## Notice of HIPAA Privacy Practices, Rights and Choices

### Your Rights

You have the right to:

- Get a copy of your paper or electronic medical record
- Correct your paper or electronic medical record
- Request confidential communication
- Ask us to limit the information we share
- Get a list of those with whom we've shared your information
- Get a copy of this privacy notice
- Choose someone to act for you
- File a complaint if you believe your privacy rights have been violated

### Your Choices

You have some choices in the way that we use and share information as we:

- Tell family and friends about your condition
- Provide disaster relief
- Include you in a hospital directory
- Provide mental health care
- Market our services and sell your information
- Raise funds

### Our Uses and Disclosures

We may use and share your information as we:

- Treat you
- Run our organization
- Bill for your services
- Help with public health and safety issues
- Do research
- Comply with the law
- Respond to organ and tissue donation requests
- Work with a medical examiner or funeral director
- Address workers' compensation, law enforcement, and other government requests
- Respond to lawsuits and legal actions

### Your Rights

When it comes to your health information, you have certain rights. This section explains your rights and some of our responsibilities to help you.

Get an electronic or paper copy of your medical record

- You can ask to see or get an electronic or paper copy of your medical record and other health information we have about you. Ask us how to do this.
- We will provide a copy or a summary of your health information, usually within 30 days of your request. We may charge a reasonable, cost-based fee.

Ask us to correct your medical record

- You can ask us to correct health information about you that you think is incorrect or incomplete. Ask us how to do this.
- We may say "no" to your request, but we'll tell you why in writing within 60 days.

## Notice of HIPAA Privacy Practices, Rights and Choices (continued)

### Request confidential communications

- You can ask us to contact you in a specific way (for example, home or office phone) or to send mail to a different address.
- We will say “yes” to all reasonable requests.

### Ask us to limit what we use or share

- You can ask us not to use or share certain health information for treatment, payment, or our operations. We are not required to agree to your request, and we may say “no” if it would affect your care.
- If you pay for a service or health care item out-of-pocket in full, you can ask us not to share that information for the purpose of payment or our operations with your health insurer. We will say “yes” unless a law requires us to share that information.

### Get a list of those with whom we’ve shared information

- You can ask for a list (accounting) of the times we’ve shared your health information for six years prior to the date you ask, who we shared it with, and why.
- We will include all the disclosures except for those about treatment, payment, and health care operations, and certain other disclosures (such as any you asked us to make). We’ll provide one accounting a year for free but will charge a reasonable, cost-based fee if you ask for another one within 12 months.

### Get a copy of this privacy notice

You can ask for a paper copy of this notice at any time, even if you have agreed to receive the notice electronically. We will provide you with a paper copy promptly.

### Choose someone to act for you

- If you have given someone medical power of attorney or if someone is your legal guardian, that person can exercise your rights and make choices about your health information.
- We will make sure the person has this authority and can act for you before we take any action.

### File a complaint if you feel your rights are violated

- You can complain if you feel we have violated your rights by contacting us using the information on page 1.
- You can file a complaint with the U.S. Department of Health and Human Services Office for Civil Rights by sending a letter to 200 Independence Avenue, S.W., Washington, D.C. 20201, calling 1-877-696-6775, or visiting [www.hhs.gov/ocr/privacy/hipaa/complaints/](http://www.hhs.gov/ocr/privacy/hipaa/complaints/).
- We will not retaliate against you for filing a complaint.

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

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

### Help with public health and safety issues

We can share health information about you for certain situations such as:

- Preventing disease
- Helping with product recalls
- Reporting adverse reactions to medications
- Reporting suspected abuse, neglect, or domestic violence
- Preventing or reducing a serious threat to anyone’s health or safety



## Authorization for Payment

I hereby authorize payment for hospice services to be made on my behalf directly to Arden for health insurance benefits otherwise payable to me. I authorize the release of all records required to implement this authorization.

**Initials of Arden Team member providing education related to informed consent for Hospice:**

Int.	Document	Int	Document	Int	Document
	Hospice Philosophy		Arden Medication Disposal Policy		Arden Telephone Numbers
	Hospice Levels of Care		Hospice and Part D Medications		After hours procedure & numbers
	Services to be provided		Language Translation		Sensory Impaired Accommodations
	Advanced Directive		Patient Bill of Rights		Safety in the Home/Fall Risk
	Patient/Caregiver role in Care		Arden Transfer/Discharge Policy		Oxygen Safety
	Release of Information		Notice of HIPAA Privacy Practices		Medical Waste Disposal
	Consent to Photograph		Authorization for Payment		Last Phases of Illness Changes
	Telemedicine Consent		Complaint process/numbers		POLST Portable Medical Orders
	Infection Prevention		State Hotline Numbers		
	Controlled Substance & Drug Policy		Emergency Preparedness/Plan		

## To voice complaints and/or ask questions about local hospice agencies contact:

If you have a complaint concerning Arden hospice, you may report your concern to any Arden team member or you may call the hospice office and ask for a supervisor. A supervisor will contact you for more information and will investigate your concern. You will receive information regarding the resolution of your concern after investigation.

If you are unhappy with the resolution offered, or you have additional questions or concerns, you may

1. Call our Corporate office at 1-855-ARDEN4U
2. Call the Mississippi Department of Health at 1-800-227-7308

**Arden hospice services have been explained to me and I have been given the opportunity to ask questions about the hospice benefit and program. All questions have been answered to my satisfaction. I have been verbally informed of and certify that I have received copies the above list of documents prior to my consent.**

Signature of Patient: (or Patient representative)

Date:

Printed Name of Patient: (or Representative and Relationship to Patient)

Signature of Arden Representative:

Date:

Reason patient is unable to sign:

**Please call our office 24 hours 7 days a week at this number:**

<b>Table of Contents</b>	<b>Page</b>
Informed Consent for Hospice Services <ul style="list-style-type: none"> <li>• Focus of Hospice Care/Hospice Philosophy</li> <li>• Hospice Levels of Care and Services</li> <li>• Resuscitation/Advanced Directive</li> <li>• Patient/Family Role</li> <li>• Release of Information</li> <li>• Consent to Photograph</li> <li>• Telemedicine Consent</li> <li>• Infection Control/Safety Information</li> <li>• Medications/Controlled Substances/Drug Disposal/Part D Coverage and Responsibilities</li> <li>• Language Translation</li> <li>• Hospice Patients Bill of Rights</li> <li>• Notice of HIPAA Privacy Practices, Rights and Choices</li> <li>• Authorization for Payment</li> <li>• Voicing a Complaint</li> <li>• Hospice 24/7 Numbers</li> </ul>	1-9
Table of Contents	8
Auxiliary aids Policy and Sensory Impaired Checklist	9
Home Safety and Fall Risk	10
Oxygen Safety Tips	11
Medication Safety, Storage and Disposal	12
CONTROLLED MEDICATION MANAGEMENT AND DISPOSAL POLICY	12
Infection Control in the Home	13
Handwashing Guidelines	13
Medical Supplies and Disposal Guidelines	14
Nutrition and Hydration	14
Pain Management	14
Pressure Ulcer	15
Emergency and Disaster Preparedness	15
Agency Transfer and Discharge Policy	16
Arden Hospice Last Phases of Illness Resources	17-20



## **Limited English Proficiency or Impairment in Communication**

Hospice will provide for communication with person with impairments in communication, e.g., vision, cognitive, hearing or speech impaired or Limited English Proficient (LEP) persons, including current and prospective patients, family, interested person, employees and potential employees to ensure an equal beneficial services opportunity.

1. Hospice will facilitate the provision of interpretation (including translation services) as necessary. If a translator is needed the Director is responsible for contacting an interpreter. IN order to ensure competency of translators, family members or friends may be used as the translator only if specifically authorized by the patient or designated power of attorney for healthcare.
2. Hospice will facilitate communication by utilizing other special devices or communication aids.
3. When a significant portion of the Hospice caseload (25% or greater) understand one language that is not English, Hospice provides required written material in that language to patients.
4. The Sensory Impaired Checklist will be utilized as indicated by Nursing Assessment.

### **Sensory Impaired Checklist to help us serve you better**

1. Can you speak?
2. Can you lip read?
3. Can you write with paper and pencil?
4. Would you like to use a special amplifier to make the sound louder on your telephone?
5. Do you need Braille equipment?
6. Do you need a translator/interpreter?
7. Can you communicate with our office via your TTY/TDD?

## Home Safety and Falls Risk

Your home, the place where you feel the most comfortable, can also be dangerous in terms of accidents, falls and injuries. Here are some tips to help you stay safe in your home.

### THE HOME

- Secure loose carpet.
- Remove throw rugs.
- Keep phone accessible at all times. Consider using a telephone emergency alert system such as Lifeline.
- Check and install smoke detectors, if needed.
- Use extreme caution with space heaters and kerosene heaters.
- Know your fire escape route.
- Do not use frayed electrical cords.
- If on oxygen, do not smoke or allow smoking in your home.

### THE BEDROOM

- Keep the pathway to bathroom clear.
- Consider a bed that is adjustable such as a hospital bed to allow for ease in repositioning, comfort, and clinician/caregiver access.
- Use transfer and mobility aids such as patient lifts.
- If necessary, have a bedside commode or urinal available.
- Never sleep with a heating pad if it is turned on.
- Keep a flashlight at bedside.
- Do not smoke in bed.

### THE KITCHEN

- Do not overreach for items.
- Only use footstools that have handrails attached.
- Use a long-handled mop to clean spills (avoid bending over).
- Place commonly used items within easy reach.
- Keep the fire extinguisher in the kitchen.
- Keep small appliances unplugged when not in use.

### THE BATHROOM

- Have non-skid surface in shower/tub area.
- Equipment, such as elevated toilet seats, grab bars, shower chair, and shower head extender are available as needed.
- Set hot water heater below 100 degrees F.

### STAIRS AND HALLWAYS

- Ensure all hallways and stairwells have adequate lighting.
- Use handrails when negotiating stairs.
- Keep stairs clear of all objects.
- Tack down any loose carpet.

### Falls Risk

In addition to home safety, there are additional factors that can lead to falls for hospice patients. It is important that you and your caregiver be aware of these factors to decrease your risk of having a fall.

- Prior history of falls.
- Mobility problems due to muscle weakness or balance.
- The inability to make it to the bathroom or commode in a timely matter due to frequency or urgency.
- Visual impairment.
- Loss of sensation in feet.
- Medications, including changes in dosage or new medications.
- Not following medication equipment safety instructions.
- Improper use of assistive devices (walkers, cane, shoes, etc.)

## Oxygen Safety Tips

Oxygen is a drug and is effective and safe ONLY when used as prescribed by your physician. Never change your oxygen liter flow without first consulting your physician.

### WHAT ARE THE CAUSES OF OXYGEN FIRE?

- Oxygen is not flammable and will not explode. However, oxygen does support combustion. This means that oxygen makes things burn faster and ignite easier.
- Not avoiding open flames while using oxygen, including matches, fireplaces, barbeques, stoves, space heaters, candles, etc.
- Smoking while on oxygen therapy and allowing others to smoke near you.
- Using electrical appliances that produce sparks such as electrical heaters, electric razors, hair dryers, friction toys, remote toy cars, etc.
- Using and storing oxygen in a poorly ventilated area because oxygen accumulates around the user and immediate surroundings.
- Storing oxygen in a confined space such as a cabinet or closet.
- Using petroleum-based ointments or lotions around your nose, such as Vaseline, Vicks, Chapstick, etc. Oxygen can react violently with these oily substances and create burns.

### OXYGEN SAFETY

- Keep all oxygen equipment at least 15 feet from any type of open flame.
- Take care to avoid open flames while using oxygen.
- DO NOT SMOKE within 15 feet of oxygen set-up or oxygen patient.
- Keep all smoking materials (such as cigarettes, cigars, pipes, etc.) 15 feet from oxygen set-up or oxygen patient.
- Avoid using electrical appliances that produce sparks.
- Smoke detectors and fire extinguishers are highly recommended with oxygen in the home.
- Check smoke detectors regularly to make sure they are working.
- Use as store oxygen in well-ventilated areas.
- NEVER use or store oxygen in a confined space.
- DO NOT use petroleum-based ointments or lotions around your nose.
- Plan an evacuation route for you and your family in the event of a fire.

### STORAGE AND HANDLING:

- Oxygen tanks should be stored in a stand or cart to prevent tipping and falling. Store extra, unsecured tanks by placing them flat on the floor. Do not allow tanks to stand or lean in an upright position while secured.
- DO NOT store oxygen systems in unventilated areas such as closets or cabinets.
- NEVER drape clothing over oxygen systems.
- DO NOT store oxygen systems near heat or ignition sources OR in the trunk of your car.
- While transporting oxygen in a vehicle, ensure containers are secure.
- Oxygen should be transported in the passenger compartment of a vehicle with the window open slightly (2-3 inches) to permit adequate ventilation.

### CONCENTRATOR SAFETY:

- Concentrators are electrical devices that should only be plugged into a properly grounded outlet.
- DO NOT use extension cords or multi-outlet adaptors such as power strips.
- Avoid using power sources that create heat or sparks.
- Use a power supply or electrical circuit that meets or exceeds the amperage requirements of the concentrator.

### SMOKING WHILE USING OXYGEN IS EXTREMELY DANGEROUS

Not adhering to oxygen safety puts neighboring residences and buildings at risk for oxygen related fires.

## Medication Safety, Storage and Disposal Guidelines

### CONTROLLED SUBSTANCES

While under hospice care we will manage and provide medications related to your terminal illness. Your Hospice Nurse will provide written policies and procedures as well as educate you and your caregiver on the safe use and disposal of controlled substances.

### MEDICATION SAFETY

- Keep your nurse informed of medications you are taking. This includes over-the-counter drugs, vitamins and herbs.
- Take all medications exactly as prescribed by your physician. If you or your caregiver are not comfortable on how to administer medication, talk to your Nurse.
- Never guess the contents or dating of medication. If you have trouble with small print, ask for assistance.
- Take your medications in a well-lit room so you can clearly see that you are taking the correct pill.
- Store medications as indicated on the label and out of reach of children.
- Have your prescriptions refilled before you take the last dose to prevent running out of medication.

### CONTROLLED MEDICATION MANAGEMENT AND DISPOSAL POLICY

#### Purpose

To establish guidelines for appropriately storing and disposing of controlled substances in the home setting that are in compliance with state and federal requirements.

#### Definitions

Controlled substances are drugs that are regulated by state and federal laws that aim to control the danger of addiction, abuse, physical and mental harm, the trafficking by illegal means and the dangers from actions of those who have used the substances. Such drugs may be declared illegal for sale or use but may be dispensed under a physician's prescription.

#### Policy

The Agency staff will assist/educate family and patients in safe storage and usage of controlled substances in the home setting and provide education to assure appropriate disposal of controlled substances in compliance with state and federal requirements. Nurses and other staff will continue to instruct on medication storage safety in the home on an on-going basis. Medications should be stored away from direct light or heat and out of reach of children and pets.

#### Procedure

Skilled nursing staff will provide patients and families with information on safe storage, use, and disposal of medications at the time that controlled substances are first ordered in the home.

- The Registered Nurse (RN) will instruct the patient/family in a manner that they are able to correctly demonstrate the safe storage, use and disposal of controlled substances.
- The instruction and return demonstration will be documented in the patients' medical record.

The Agency Interdisciplinary Team (IDT) members will assess the home situation for risk factors for compliance, and the potential for diversion; and will take the appropriate steps to minimize these risks, for example use of a lock box. Consultation on this issue should include the Medical Director and the Attending Physician.

If the patient leaves the home temporarily, for example for caregiver respite or general inpatient (GIP) symptom management, the skilled nursing staff will advise the family regarding safe storage of the medications in the home.

If the patient dies, is discharged, or is permanently transferred to an inpatient/nursing home setting, or if a controlled medication is discontinued, skilled nursing staff will advise the family of safe disposal methods for the controlled medications. If the family/caregiver refuses to dispose of controlled medications, this will be documented in the medical record.

- It is preferred that medications are taken to a "take back" site or returned to the pharmacy of origin as available.
- If "take back" or returning to the pharmacy of origin is not available, staff will advise the family of other local options available such as mail in programs that meet the federal and state guidelines.
- In South Carolina, when a patient expires the Hospice nurse will dispose of controlled medications and have the family sign that the medications were disposed of. This will be documented on Form 106C.

In the inpatient and nursing home setting, the staff of the contracted facility will be responsible for the disposal of the controlled substances in accordance with the policies and procedures of the facility.

## **STORAGE GUIDELINES**

- Store tablets and liquids at room temperature. Store suppositories in the refrigerator.
- Medications stored in the refrigerator should be stored away from food items, with proper labeling.
- Follow specific guidelines for storage and handling given by the pharmacy.
- Consider using a lock box for controlled substances to prevent medication from being stolen or taken by anyone but you.

## **DISPOSAL GUIDELINES**

- Take unused, unneeded, or expired prescription drugs out of their original containers and throw them in the trash.
- Mixing prescription drugs with an undesirable substance, such as used coffee grounds or kitty litter, and putting them in impermeable, nondescript containers, such as empty cans or sealable bags, will further ensure the drugs are not diverted.
- Do not flush prescription drugs down the toilet unless the label or accompanying patient information specifically instructs doing so.
- Take advantage of community drug take-back programs that allow the public to bring unused drugs to a central location for proper disposal. Call your city or county government's household trash and recycling service (see blue pages in phone book) to see if a take-back program is available in your community.
- Before throwing out a medicine container, scratch out all identifying information on the prescription to make it unreadable. This will help protect your identity and the privacy of your personal health information.
- Do not give medication to friends. Doctors prescribe drugs based on a person's specific symptoms and medical history. A drug that works for you could be dangerous for someone else.
- When in doubt about proper disposal, talk to your Nurse or contact your local pharmacy.
- The same disposal methods for prescription drugs could apply to over-the-counter drugs as well.
- Depending on the type of product and where you live, inhalers and aerosol products may be throw into household trash or recyclables, or may be considered or thrown into a fire or incinerator. To ensure safe disposal, contact your local trash and recycling facility.

## **Infection Control in the Home**

### **COMMON SIGNS OF INFECTION**

- Pain/tenderness/swelling of skin
- Rash/sores
- Nausea/vomiting/diarrhea
- Fever/chills/headaches
- Coughing
- Fatigue/lethargy/confusion\
- Redness or yellow/green foul-smelling drainage from wound or body opening

**If you develop any of these symptoms, notify your Hospice Nurse.**

### **PREVENTION**

You can help control infection by following these guidelines:

- Cover your mouth and nose when coughing, sneezing or blowing.
- Practice good personal hygiene.
- Prepare and store food properly.
- Maintain a clean environment.

### **HAND WASHING GUIDELINES**

Washing your hands is the most effective way to prevent the spread of infection. Hands should be cleansed:

- Before and after contact with another person.
- Before and after all procedures and dressing changes.
- Following bathroom use.
- After coughing, sneezing or blowing.
- Whenever hands are soiled.

- After handling soiled equipment or dressings.
- After removal of gloves.
- Before and after handling or preparing food.
- Before and after eating.

#### **HAND WASHING PROCEDURES**

**Soap and Water Procedure:** Use when hands are visibly soiled, contaminated, or soiled with blood or other bodily fluids.

- Remove all jewelry.
- Use warm water and soap (preferably liquid soap).
- Wash full surface of hands for at least 20 seconds.
- Dry hands with a clean towel.

**Alcohol-Based Hand Rub:** Can be used if hands are not visibly soiled or contaminated for routine decontamination of hands. Follow directions for specific product use.

### **Medical Supplies and Disposal Guidelines**

**Medical Supplies:** Store disposable medical supplies in their original packages in a dry, clean place. If a package becomes contaminated or wet, dispose of it immediately. Wash hands with soap and water prior to touching cleaning supplies.

#### **Disposal Guidelines**

- Contaminated disposable items such as tissues, bandages, plastic equipment, urinary catheters, disposable diapers, paper cups, medical gloves, etc. should be disposed of in a securely fastened plastic bag prior to putting them in your household garbage container for regular trash pickup.
- Contaminated sharps such as needles, syringes, lancets or other sharp objects must be put into a rigid, puncture-resistant container such as metal or hard plastic with a reinforced lid that can be tightly secured. Do not use glass or clear plastic containers. Label container "do not recycle".

### **Nutrition and Hydration**

As your illness progresses, how much or how often you eat is not as important as how much you enjoy the experience of eating. Loss of appetite is a natural part of the process and is not like starvation. Foods stop tasting good, drinking liquids for some may cause discomfort such as nausea, vomiting or bloating. This may be hard for caregivers and family members to understand since food is one way we show our love and is such an important part of our culture. Your Hospice Nurse will provide nutrition and hydration, but there are ways you caregiver can improve your eating experience:

- Offer small portions of food and small sips of fluid.
- Provide ice chips, popsicles and flavored gelatins.
- If not on a restricted diet, provide variety of your favorite foods.
- Respect your wishes and not force you to eat or drink.

Dry mouth is often uncomfortable, so frequent mouth care is important. Your caregiver will be taught how to apply sponges or swabs to keep your mouth and lips moist.

### **Pain Management**

One of the primary goals of hospice care is to provide a pain management program that will enhance comfort and promote quality of life for you and your family members. Pain is unique to each person and can make it difficult to eat, sleep or participate in simple activities. It is important that you or your caregiver communicate with your Hospice Nurse about the pain you may be having. To help manage pain, follow these guidelines:

- Be as accurate as possible when describing your pain since your physician may prescribe different types of medications based on your symptoms.
- Let your Nurse know of side effects such as constipation, dry mouth, etc. so these side effects can be managed.
- Take your medication as prescribed by your physician including taking your pain medication on schedule. You should not suddenly stop taking any medication without talking to your physician.
- Keep track of your pain medication(s), how you feel and the effectiveness of your treatment.
- Ask if you have any questions about your medicines or side effects.

## Pressure Ulcer

### WHAT IS A PRESSURE ULCER

- A pressure ulcer is an injury to the skin or underlying tissue.
- It can be referred to as a bed sore or decubitus ulcer.
- It is usually caused by sitting or lying in one position too long.
- Pressure restricts blood supply to the affected area resulting in an ulcer.

### WHERE DO PRESSURE ULCERS OCCUR

- Tailbone or buttocks.
- Heels.
- Hips.
- Gluteal folds.
- Anywhere over a bony area.

### RISK FACTORS

- Recent surgery or hospitalization.
- Decrease in mobility.
- Unable to move without help.
- Low nutritional intake.
- Diabetes.
- Medications: steroids, anti-inflammatory and diabetic medications.
- Loss of bladder or bowel control.
- Memory impairment.

### HOW CAN PRESSURE ULCERS BE PREVENTED

- If you are in a chair for prolonged periods, shift your body position every 15-30 minutes.
- Avoid scooting while transferring. Use a draw sheet or a slide board for transfers. Your Hospice Aide or Nurse will teach your caregiver proper techniques for transfers.
- Turn and reposition frequently if in bed.
- Protect skin from moisture by using a moisture barrier cream that contains zinc or Vaseline.

### TAKE CARE OF YOUR SKIN

- Wash your skin in warm water. Avoid water that is too hot or too cold.
- Dry completely after bathing.
- Use a mild pH balanced soap.
- Apply alcohol-free moisturizers such as Aquaphor or Eucerin cream.
- Inspect the skin daily and notify your Nurse of any skin changes.

## Emergency and Disaster Preparedness

Our Clinical Team will help to assist you and your family in preparing a personal emergency/disaster plan. Emergencies can include:

### Natural Disasters

- Ice/Snow
- Flooding
- Earthquake
- Hurricane
- Tornado
- Volcano
- Tsunami
- Avalanche

### Man-Made Disasters

- Hazardous Material Spills
- Fire



- Pandemic/Infectious Disease
- Electrical Failure

Along with preparing a personal emergency/disaster plan, it is important to be prepared prior to a disaster occurring. General guidelines include:

**Keep an Emergency Contact List:**

You can use the Emergency contact list included in this handbook on page 2.

**Make a list which includes:**

- Medications
- Medical Information
- Allergies
- Copies of Health Insurance Cards

**Have on Hand:**

- A 7-day supply of essential medications.
- Cell Phone
- Flashlights and small battery-operated radio with extra batteries
- Emergency food and water. Manual can opener
- Assorted sizes of resealable plastic bags for storage, food, waste, etc.
- First Aid Kit

**Evacuation Plan:**

- Know where the shelter is that meets your special needs.
- Plan for alternative locations.
- Plan for transportation to shelter or other location.
- Arrange for assistance if you are unable to evacuate yourself.
- If you need assistance with transportation in the event of an evacuation, you may register in advance with Transportation Assistance Registry by dialing 2-1-1.

Dial 2-1-1 as soon as possible:

- If you have a disability or special health care need and require assistance to get out.
- If you cannot drive and cannot arrange transportation.
- If you do not have a vehicle and you have no one else to help you evacuate.

In the event of a disaster or emergency, the Hospice will utilize a patient priority system. This system is used to identify those patients at higher risk for injury or adverse effect if their care is interrupted. Each patient is assigned a priority level and updated as needed.

- **Priority Code 1-Emergent (Must have visit within 2 hours)** Life threatening (or) and requires ongoing medical treatment. When necessary, appropriate arrangements for evacuation to an acute care facility will be made. Any equipment dependent upon electricity should be listed with the power company. Oxygen dependent patients should request a back-i[ tank from the supplier. Proceed to the hospital (with supplies) if not able to manage your care.
- **Priority Code 2-Urgent (Must have visit same day)** Not life threatening but would suffer severe adverse effects from interruption of services (i.e., daily insulin, IV medications, sterile wound care of a wound with a large amount of drainage.) Proceed to the hospital (with supplies) if not able to handle your care.
- **Priority Code 3- (Needs visit within week)** Visits could be postponed without adverse effects (i.e., post op with no open wound, anticipated discharge within the next 10-14 days.

**Agency Transfer/Discharge Policy**

The agency will follow accrediting standards (if applicable), federal, state and local regulations related to patients transfer/discharge. The Agency may discharge a patient if:

1. The patient moves out of the Agency's service area including when patients:
  - Relocate;
  - Go on vacation outside the Agency's service area where a hospice travel agreement is not an option; or
  - Are admitted to a hospital or SNF that does not have a contractual arrangement with the Agency.
2. The patient is determined to be no longer terminally ill;

3. There is discharge for cause, when the patient's (or other persons in the patient's home) behavior is disruptive, abusive, or uncooperative, to the extent that delivery of care to the patient or the ability of the hospice to operate effectively is seriously impaired; or
4. The patient's payor source does not authorize continued services.

The Agency may transfer or discharge a patient without prior notice under the following conditions:

1. Per the patient's request;
2. If the patient's medical needs require transfer, such as a medical emergency;
3. In the event of a disaster when the patient's health and safety is at risk; or
4. If the patient fails to pay for services, except as prohibited by federal law.

## **Arden Hospice Last Phases of Illness Resource**

Arden Hospice's approach to pain and symptom management is individualized to optimally meet each patient's need and situation. Arden's hospice nurses and interdisciplinary teams are specially trained to identify, and alleviate, end of life pain and symptoms. They understand that symptoms have varying causes.

To determine which medications and/or treatments have the greatest likelihood of success, it is very important that the hospice team first discern the underlying cause of the symptom(s) that are to be treated. During the last phases of a terminal illness, pain and symptom identification and alleviation is the primary objective. This includes physical, social, spiritual and emotional pain and symptoms.

### **Physical Changes that may occur during the last weeks of life:**

1. **Pain:** During the last phases of the terminal illness, as the disease process advances, your loved one may experience increased pain. They may need increase dosages to maintain good pain control. Arden utilizes noninvasive modalities such as music, massage, or meditation as well as medications and treatments to manage pain. Because these medications and treatments intent is to address end of life pain and suffering, you as the caregiver should not fear that administering these needed medications and treatments will cause long-term side effects, increased sleep, decreased breathing, hasten death and/or addictive concerns. Our clinical staff will consult with, and obtain orders, from the Hospice Medical Director, Advanced Practice Registered Nurse and/or the designated attending physician (if any) for all medications and treatment prior to initiation.

**What you can do:** Ask your loved one frequently if they are in pain and contact your hospice nurse if you believe that any pain or symptoms are not being managed effectively.

Give medications at prescribed intervals. Do not skip dosages. Medications must be given at regular intervals to control symptoms. Pain crisis may be avoided with adherence to routine dosing and early identification and intervention.

Be on alert for these common signs of pain if your loved one is having difficulty communicating and speak to your hospice nurse if any symptoms are identified:

- Facial grimacing
- Clenching of fists or jaws
- Increased, rapid breathing "panting"
- Tremors or shaking
- Restlessness
- Agitation
- Poor sleep patterns

- Any change in usual behavior

Reposition your loved one at regular interval using pillows and other soft props to avoid pressure points: head, arms, legs, hands, or side to side.

Play soft music that is preferred by your loved one.

Avoid bright lighting in the primary room where your loved one spends most of their time. Lamps or dim lighting is recommended.

Coordinate visitors to allow your loved one to rest when pain medications are given. Understand that initially your loved one may experience increased sleepiness and be less alert. This is usually temporary as adjustments are made to new or changed medications.

- 2. Skin and Temperature Change:** Your loved one's hands, arms, feet and legs become increasingly cool to the touch, moist or sweaty to touch. The skin may appear bluish or flushed in appearance. Purple spotting on the skin will often occurs. This is an indication that the circulation of blood throughout the body is decreasing and is a normal part of the dying process.

**What you can do:** When cool, keep them warm with a light bedding. An electric blanket or multiple layers of clothing cause discomfort and is typically not recommended.

If warm, apply a cool washcloth on the forehead.

Change bed pads and linens as often as needed to keep skin clean and dry.

- 3. Confusion, Agitation and Restlessness:** Your loved one may become confused about things that are normally known: place, time, names of family or visitors. They may talk to family and friends who are deceased. They make aimless movements, pick at their sheets and clothing, become easily irritable, exhibit mood swings or have difficulty focusing. These changes normally occur due to decreased circulation of blood to the brain and other changes in the body and is a very normal part of the dying process and your loved one transitions between life and death.

**What you can do:** Communicate these changes to your hospice nurse as these symptoms are sometime associated with pain or other symptoms. Provide the medications as prescribed for agitation and restlessness, do not skip dosages.

Sit with them, hold their hand, and speak softly and naturally. Identify yourself by name before you speak. Communicate tasks clearly, for example "It is time to take your medication," and explain the reason for the communication such as "So you won't begin to hurt." Avoid arguing or trying to convince them that deceased loved ones are not there. This often leads to further agitation.

Read from their favorite book. Play their favorite genre of relaxing music.

Lower the amount of stimulation that your loved one is experiencing by dimming the lights, limiting visitors, and reducing the noise level.

The sense of hearing remains intact during the dying process, be mindful of topics of conversation in the presence of your loved one.

- 4. Changes in bowel and bladder functions:** Your loved one may experience changes in elimination due to diet, decrease activity, medication changes or decreased fluid intake. A decrease in the amount of urine output and

bowel movements is common. Urine may appear concentrated and cloudy. This is normal due to the decreased amount of intake and circulation.

**What you can do:** The inability to communicate the need for elimination may lead to soiled linens and clothing. Ensure that you have the correct supplies (beds pads, incontinent briefs, catheter) to maintain your loved ones dignity. Change the linens, clothing and incontinence supplies as often as necessary to maintain comfort.

When they can no longer safely walk to the bathroom, make use of a beside commode, urinal, disposable briefs, and bed pads.

Consider the use of a catheter if moving your loved one for toileting purposes is too tiring for them or causes pain.

5. **Breathing Changes:** Your loved one's breathing pattern may change and become irregular. They may exhibit shallow and quickened respirations, or slow, spaced respirations with periods of no breathing that become longer as your loved one approaches death. The ability to cough and swallow may be lost, which often causes secretions to pool in the back of the mouth. As air moves across these secretions, it creates a rattle type of noise. This is common and due to decreased activity, blood circulation and the shutting down of major organs. This condition does not typically indicate pain or discomfort. But can be distressing to caregivers and visitors because it sounds uncomfortable. Mechanical suctioning is generally not recommended in most situations, as this causes an increase in secretions. There are medications that can be used to control the secretions.

**What you can do:** Reposition your loved one's head by gently turning the head to the side allowing gravity to drain the secretions or turn the entire body to the side until comfort is achieved.

Consider elevating the head of the bed or adding an additional pillow.

Administer medications that may be prescribed for control of secretions as scheduled. Do not skip doses.

6. **Food and liquid intake changes:** As body systems enter the normal process of shut down, the desire for food and liquids is diminished. Your loved one may begin to eat less or refuse food. Caregivers should be mindful that this is a natural response by the body and avoid coercing their loved one to eat or drink. Excessive liquids or fluids, as the body functions slow, may cause discomfort by causing stress on the heart and lungs, making breathing more difficult or create congestion in the lungs.

The smell of food cooking near your loved one may worsen a symptom called nausea. Nausea, which may or may not be associated with vomiting, is usually associated with an aversion to food or liquids. Early identification of the cause and quick intervention is our goal.

**What you can do:** Dry Mouth is the main discomfort of not taking in liquids. Offer ice chips, small sips of water or swab the mouth with a moist sponge type device.

Have a variety of simply ingested foods and fluids available: Popsicles, broth, gelatin, ice cream or supplemental high calories shakes.

Be aware of signs that your loved one may not want to eat:

- Turning away from the offered food or liquid
- Verbally indicating the refusal
- Biting the utensil
- Pocketing the food in the cheek and not swallowing

- Clenching the mouth shut
- Spitting out or coughing up food or liquids

For nausea, Optimize good air circulation and minimize odors. Apply a cool damp washcloth to the forehead, neck, and wrist. Avoid the use of scented soaps and perfumes for personal care and for visitors. If vomiting does occur, provide mouth care after each episode. Contact your hospice nurse if the prescribed medications do not alleviate the nausea and vomiting.

## **Emotional, Spiritual and Social Changes.**

### **1. Withdrawal and Loss of Interest:**

You may observe that your loved one become quieter and less interested in physical surroundings, family, or visitors. They may become withdrawn and less sociable. This is typically indicative of energy conservation and/or realization of physical decline, dying or letting go.

**What you can do:** Reduce visitors and coordinate daily personal activities to allow sleep and quiet time. Consider increased visits from the hospice social worker or chaplain for support and coordination of end-of-life needs.

### **2. Emotional States**

Your loved one may be going through different emotional states such as guilt, anger, frustration, helplessness, or sadness. They may experience anticipatory grief for what is to come. Tears are a natural expression of one's feelings and may occur in both your loved one and family members. Your loved one may want to talk with you about letting and preparing for the future without them.

**What you can do:** Focus on being present for your loved one and let them speak. Allow them to express emotions without judgement or interruption. Your presence can provide a quiet strength for your loved one. Consider increased visits from the hospice social worker or chaplain for support.

### **3. Spirituality, Beliefs and Cultural Rituals. What Can You Do?**

Spirituality and cultural rituals are important and can vary greatly. Take action during the last phases of illness to help your loved one reconcile any feelings or anxieties relating to their personal values and beliefs. During this time a member of the clergy, chaplain or a spiritual adviser may provide support to your loved one.

# arden

**Hospice | Your Life Matters.**