Confident Caregiving: A resource for patients and families





Please forgive me.

I forgive you.

Thank you.

I love you.

Dr. Ira Byock, a palliative care physician and long-time public advocate for improving care through the end of life, says that these four sentences carry enormous power and in many ways, they contain the most powerful words in our language. He also says that these four phrases provide us with a clear path to emotional wellness, and they guide us through the thickets of interpersonal difficulties to a conscious way of living that is full of integrity and grace.



Your Care Team Members

Drimory Nurco		
Primary Nurse		
Hospice Aide/Certified Nurse Aide		
Social Worker		
Your Four Seasons Physician		
Your Primary Care Physician		
Music Therapist		
Chaplain		
Volunteer		
Others		
A nurse is available 24 hours a day, 7 days a week. Call 866-466-9734		

Contact Information

Please complete this sheet for all persons listed on Release of Information form, and show to Your Care Team.

Name:		Relationship To Patient:	
Address:			
Email Address:			
Home Phone:	Cell Phone:	Work Phone:	
Name:		Relationship To Patient:	
Address:			
Email Address:			
Home Phone:	Cell Phone:	Work Phone:	
Name:		Relationship To Patient:	
Address:			
Email Address:			
Home Phone:	Cell Phone:	Work Phone:	
Name:		Relationship To Patient:	
Address:			
Email Address:			
Home Phone:	Cell Phone:	Work Phone:	

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😸 FOUR·SEASONS 🛞

Thank you for choosing Four Seasons to provide you with the care that matters most to you and your loved ones. For nearly forty years we have provided trusted, innovative care. We are honored to provide care wherever you call home throughout: Buncombe, Cherokee, Clay, Haywood, Henderson, Graham, Jackson, Macon, Polk, Swain and Transylvania.

Your well-being is very important to us, and we believe that our continuum of care services are the best way to provide the most trusted care and compassionate support that you deserve. Four Seasons offers Care Navigation, Home Care, Palliative Care, Hospice Care, Bereavement Support and Clinical Research.

Throughout your journey with Four Seasons, you will have your own personal care team made up of highly trained professionals who will put your goals of care first; keeping you comfortable, managing your symptoms and ensuring that your time with your loved ones is of the highest quality.

A nurse will visit you regularly. You also have access to a certified hospice aide. In addition, a physician, chaplain, social worker, music therapist and professionally trained volunteers are available to help with your care needs.

Illness does not take a break or holiday, nor do we. You or your family can reach us 24 hours a day, 7 days a week. Day or night, a nurse is always on call and available by phone – 866-466-9734.

You will find this manual to be a useful resource, but it should not replace good communication between you and your Four Seasons team. When you have questions or if you are concerned about anything, please talk to a member of your care team. If for any reason Four Seasons has not been able to meet your expectations, we want to know how we can improve. Please call 828-233-0372 and I will be notified immediately of your concern.

You are entrusting us with your care, and we will do whatever we can to help you meet your goals and live fully with respect and dignity in comfort and peace.

It is our privilege and honor to care for you.

Sincerely.

Millicent Burke-Sinclair, Ed.D, MBA, SPHR[®], SHRM-SCP Chief Executive Officer

> 571 South Allen Road Flat Rock, NC 28731

Toll Free: 866-466-9734 Phone: 828-692-6178 Fax: 828-233-0351 www.FourSeasonsCFL.org



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Mission, Vision and Values

Mission

Co-Creating The Care Experience

Vision

Innovate Healthcare. Influence Humanity. Impact Life.

Values:

- COMPASSION We are a Companion for the Journey
- BALANCE Seek Harmony of Body, Mind and Spirit
- **RESPECT** Each Person is Honored
- INTEGRITY Be Trustworthy in All Things
- TEAMWORK Together Everyone Achieves More
- EXCELLENCE We Dream More (than others think is practical) and Expect More (than others think is possible)
- RESILIENCE
 We Recover and Thrive from any Challenge or Change

Our Trusted Care Services

Care Navigation

Four Seasons' Care Navigation service provides trusted guidance during the difficult times following the diagnosis of a serious illness. We fill the gap by helping people navigate care options and choices. We partner with patients and families to complete advanced care plans and understand what's next to prepare for the physical, emotional and spiritual changes in the days, weeks, and months to come.

Home Care

When personal circumstances change and your desire is to remain wherever you call home, Compassionate Home Care is your answer to help with life's simple, daily routines and activities.

With Home Care, an Individualized Plan of Care is Co-Created together with you, to learn what matters most in your care and to select a compatible caregiver. We are on-call 24 hours/day for

support you and your loved ones and provide peace of mind. From an hour a day to around the clock care including personal assistance to companionship and home management; Compassionate Home Care provides the most trusted care and is always available to help you and your loved ones.

Palliative Care

As medical technology and treatments have improved, more people are living longer with serious illness. Palliative care is a medical specialty focused on the needs of people who are living with serious, often life-threatening illness. Support is also provided for family members. In addition to medical care for symptom management, palliative care provides support for the practical, emotional, and spiritual issues faced by those living with illness.

Some common illnesses people request palliative care to assist with are: chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), stroke, Parkinson's disease, Alzheimer's disease, dementia, kidney disease, cancer, and many others.

Hospice

Hospice is specialized care provided to patients at the end-of-life. Patient comfort is the primary goal. Each hospice team of dedicated professionals and volunteers provides pain and symptom management, as well as patient and family support and spiritual comfort.

Anyone who has a physician order or referral and who has a prognosis of six months or less is eligible for hospice services. However, it is not unusual for people who are admitted to hospice to live longer than six months. In fact, recent studies have shown that patients who receive hospice care actually live longer.

Hospice patients may not receive curative/life-prolonging treatment relative to their primary hospice diagnosis at the same time as hospice care. Patients may be unable to use Medicare skilled days for payment of long term care.

Clinical Research

At Four Seasons, we believe innovative treatment and compassionate care go hand in hand. In fact, we are among the few organizations in the country that research and develop comfort care practices and treatments. We lead studies that can help improve our patients' symptoms and, ultimately, their quality of life. We've studied several areas including pain, shortness of breath, weight loss and cancer, constipation, fatigue and depression.

Our patients include current hospice and palliative care patients and referrals from community physicians. We conduct all research according to federal guidelines designed to protect and benefit patients. Participation in a research study is completely voluntary and a decision whether or not to participate does not affect any other care received. Our participants are fully informed about the details of the study prior to giving their written consent.

There are many reasons to participate in a study. Participation can help contribute to medical knowledge, which helps to improve treatments for future patients and define best clinical



practices. It also allows our patients to access new treatments that are otherwise unavailable, often improving their quality of life by reducing pain or other symptoms. Lastly, patients who have participated have expressed a feeling of leaving a legacy.

We are committed to research and continuously see the difference it makes in the lives of our patients. As a part of Four Seasons services, you or your loved one may be contacted about research opportunities related to your illness or symptoms.

Bereavement Support

Four Seasons provides ongoing grief and loss support for our hospice patients, their caregivers, and the community at large. Our Bereavement Team, which is comprised of Music Therapists, Chaplains and Social Workers, specializes in innovative grief and loss support. We provide individual and group counseling sessions that may include a combination of information, educational tools, creative art techniques, ritual and verbal processing.

Getting Started with Four Seasons Services

Referrals for Hospice or Palliative Care Services may come from any of the following:

- Doctor
- Nurse
- Social Worker
- Family or Friend
- Patient

To begin accessing services please call 866-466-9734.

Where can care be provided?

- Private Homes
- Group Homes
- Nursing Facilities
- Assisted Living Facilities
- Hospitals
- Inpatient Facility Elizabeth House

If I call to inquire about services do I have to accept Hospice or Palliative Care Services?

No. Hospice care and palliative care are choices you make with consent, given voluntarily by the patient or their designated representative.

Am I allowed to keep my own doctor?

Yes. Four Seasons does have doctors on staff who can be your primary physician; however, we encourage you to continue to use your existing physician when possible. We will work directly with your physician(s).

What happens if I move away from your areas of service?

Your Care Team will arrange a transfer to another Medicare-Certified hospice and palliative care agency.

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What happens if I no longer want or need your services?

Four Seasons will always honor patient/family wishes for treatment. If services are no longer needed or desired, the patient will need to sign a form in the case of hospice or simply notify the practitioner in the case of palliative care.

What happens if I want hospice services in a long-term care facility?

People who live in a long term care facility may receive hospice care. Long-term care facilities include nursing homes, assisted living facilities or group homes. A team of specially trained hospice professionals who are familiar with the staff at these facilities provide the same support and care for a resident as they would for a person living in a private home. Hospice care enhances the care provided by nursing facility staff. If the patient is eligible for hospice benefits through their insurance, supplies including equipment and medication required for the primary hospice diagnosis will be covered. The charge for room and board is not covered under the Medicare Hospice Benefit.

What happens if I want palliative care services in a long-term care facility?

People who live in a long term care facility may receive palliative care services. Long-term care facilities include nursing homes, assisted living facilities or group homes. A provider specially trained in palliative care and who is familiar with the staff at these facilities provides the same support and care for a resident as they would for a person living in a private home. The only services that are billed for under the palliative care program are those of physicians, physician assistants and nurse practitioners. Private insurance policies normally cover these services. Many patients may have Medicare Part B coverage. Under Medicare Part B, visits are covered.

Notice of Program Accessibility

Four Seasons' Services are Accessible to Persons with Disabilities

Section 504 Notice of Program Accessibility

The regulation implementing Section 504 of the Rehabilitation Act of 1973 requires that an agency/facility "...adopt and implement procedures to ensure that interested persons, including persons with impaired vision or hearing, can obtain information as to the existence and location of services, activities, and facilities that are accessible to and usable by disabled persons." (45 C.F.R. §84.22(f))

Four Seasons and all of its programs and activities are accessible to and useable by disabled persons, including those who are deaf, hard of hearing, blind, or who have other sensory impairments.

Access features include:

- Convenient off-street parking designated specifically for disabled persons.
- Curb cuts and ramps between parking areas and buildings.
- Level access into first floor level with elevator access to all other floors
- Fully accessible offices, meeting rooms, bathrooms, public waiting areas, patient care areas
- A full range of assistive and communication aids provided to persons who are deaf, hard of hearing, blind, or who have other sensory impairments. There is no additional charge for such aids. Some of these aids include:
 - Qualified sign language interpreters for persons who are deaf or hard of hearing
 - Readers and taped material for the blind and large print materials for the visually impaired
 - Flash cards, alphabet boards and other communication boards
 - ° Assistive devices for persons with impaired manual skills
 - NC TTY.TDD: 919-874-2212

If you require any of the aids listed above, please let a Four Seasons staff member know.

Notice Regarding Nondiscrimination & Accessibility for Individuals

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

Four Seasons provides free aids and services to people with disabilities to communicate effectively with us, such as:

- Qualified sign language interpreters
- Written information in other formats (large print, audio, accessible electronic formats, other formats)

Four Seasons provides free language services to people whose primary language is not English, such as:

- Qualified interpreters
- Information written in other languages

If you need these services, contact a member of Your Care Team or:

Melody King, Compliance Manager Phone: 828-692-6178 TTY/TDD: 1-919-874-2212

If you believe that Four Seasons has failed to provide these services or discriminated in another way on the basis of race, color, national origin, age, disability, or sex, you can file a grievance. You can file a grievance in person or by mail, fax, or email with:

Melody King, Compliance Manager 571 S. Allen Road Flat Rock, NC 28731 Phone: 828-692-6178 Email: mking@fourseasonscfl.org or mburkesinclair@fourseasonscfl.org

You can also file a civil rights complaint with:

U.S. Department of Health and Human Services, Office for Civil Rights electronically through the Office for Civil Rights Complaint Portal, available at https://ocrportal.hhs.gov/ocr/portal/lobby.jsf

By mail or phone at:

U.S. Department of Health and Human Services 200 Independence Avenue SW Room 509F, HHH Building Washington, D.C. 20201 Phone: 1-800-368-1019 TDD: 1-800-537-7697

Complaint forms are available at http://www.hhs.gov/ocr/office/file/index.html

- ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-828-692-6178
- 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 1-828-692-6178
- CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 1-828-692-6178
- 주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 1-828-692-6178
- ATTENTION : Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 1-828-692-6178
- ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوافر لك بالمجان. اتصل برقم1-828-692-6178 •
- LUS CEEV: Yog tias koj hais lus Hmoob, cov kev pab txog lus, muaj kev pab dawb rau koj. Hu rau 1-828-692-6178
- ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 1-828-692-6178
- PAUNAWA: Kung nagsasalita ka ng Tagalog, maaari kang gumamit ng mga serbisyo ng tulong sa wika nang walang bayad. Tumawag sa 1-828-692-6178
- સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિ:શુલ્ક ભાષા સહ્ય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 1-828-692-6178
- บุษัฐะ เข็เพิ่อสามุทธิยาม ภาพานัฐ, เพาสัฐษามีสุกภาพ เมาษริยธิสสญญ สีเทธขายเพิ่มปข้ามีมูกๆ ฐะ จูะเพ็ก 1-828-692-6178
- ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 1-828-692-6178
- ध्यान दें: यदि आप हिंदी बोलते हैं तो आपके लिए मुफ्त में भाषा सहायता सेवाएं उपलब्ध हैं। 1-828-692-6178
- ໂປດຊາບ: ຖ້າວ່າ ທ່ານເວົ້າພາສາ ລາວ, ການບໍລິການຊ່ວຍເຫຼືອດ້ານພາສາ,
 ໂດຍບໍ່ເສັຽຄ່າ, ແມ່ນມີພ້ອມໃຫ້ທ່ານ. ໂທຣ 1-828-692-6178
- 注意事項:日本語を話される場合、無料の言語支援をご利用いただけます。1-828-692-6178 まで、お電話にてご連絡ください。

Your Care Team





Once you are admitted to Four Seasons hospice care service, you are assigned a Four Seasons Care Team. Your Care Team meets at a minimum, every fifteen days to update one another and collaborate regarding your care. Your Care Team typically consists of the following members and is flexible based on your needs and preferences for care.

Hospice Care Team Members

You and Your Family

You are the most important member of Your Care Team. The services offered by your Four Seasons Care Team are based on your specific goals, your questions, and your concerns. Your Care Team respects your privacy, personal choices, cultural and/or religious customs, and family traditions.

Physician

Your own doctor will continue in your care and a Four Seasons doctor or nurse practitioner is available to consult with your doctor for your special care needs. If you do not have a doctor, a Four Seasons doctor will be able to provide your medical care as part of your entire Care Team. Your doctor will focus on your overall comfort and daily functional needs.

Nurse

Your Nurse will regularly evaluate your physical symptoms and care needs. He or she can help you with concerns or questions about managing your pain, other symptoms, how to use your medications, and the stages of your illness. Your Nurse will also coordinate the care of your entire Care Team and will frequently talk with your doctor. A nurse is available 24 hours a day, 7 days a week.

Social Worker

Your Social Worker is able to help you identify your primary goals and concerns, to help you strengthen your coping abilities in times of stress, and support your family and significant relationships. He or she can provide useful information about planning for your care, solving problems, community and financial resources, and support for the ones who are caring for you. Your Social Worker can also arrange visits with Four Seasons Volunteers. A Social Worker is available 24 hours a day, 7 days a week.

Music Therapist

Your Music Therapist can help you and your family members further explore and address goals related to physical, emotional, social and spiritual aspects of your care. Music therapy interventions can be designed to increase quality of life, manage stress for both patients and families, alleviate pain, stimulate memories, improve communication, and provide opportunities for important and meaningful interactions. No two sessions look the same. Because music therapy is a powerful and non-threatening medium, unique outcomes are possible. Music Therapists use a variety of techniques, including imagery-work, live music interventions, song-writing, assisted relaxation, and verbal processing. Music therapy is also a





gentle, yet effective way to help people understand and move through grief. After you speak with your Music Therapist, he/she can offer suggestions about how music therapy might be helpful. Sometimes, patients and family members benefit from ongoing music therapy, other times just one music therapy session can be highly beneficial.

Counselor

For families with children and teens, a Counselor who specializes in caring for grieving children and teens is also available to be on Your Care Team. To receive this support, please speak with a member of Your Care Team.

Chaplain

A Chaplain with special training in spirituality and end-of-life care is also available to be on Your Care Team. Your Chaplain can help with questions and concerns regarding your faith, ethical issues, or purpose in life; support your search for meaning and hope, assist with alleviating spiritual distress; read sacred and inspirational writings; pray with you and your family; address ceremonial or ritual needs; help with grief, suffering, and the many emotions that surround facing a terminal illness; and assist with funeral/memorial services. To receive this support, please speak with a member of Your Care Team.

Bereavement Team

In addition to the ongoing support provided by Your Care Team throughout your hospice care, the Bereavement Team is comprised of music therapists, chaplains and social workers who have specialized training in grief and loss. Members of the Bereavement Team are available to offer support throughout the transition toward the end of life and also to help navigate the grief process after a loss.

Hospice Aide/Certified Nurse Aide

As you or your caregivers need additional assistance to meet your personal care needs, a Hospice Aide/Certified Nurse Aide will become part of Your Care Team. The Aide compassionately and respectfully helps you with bathing, grooming, dressing, toileting, nutrition, and skin care needs in collaboration with your Nurse.

Volunteer

A Volunteer can become a member of Your Care Team. Your Volunteer is selected based on similar interests, hobbies and geographic proximity. Your Volunteer could talk with you about topics that interest you, read to you, assist you in writing letters, stay with you for a while so your family caregiver may run errands, and many other possibilities.

Four Seasons relies on a dedicated group of Volunteers to provide special services to our patients and families. Our Volunteers truly give from the heart and in doing so, provide not only physical and emotional support to our patients, but peace of mind to family members. Many of our Volunteers know what it's like to be on the receiving end of hospice services, which make them an invaluable member of Your Care Team.

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Volunteers:

- Receive extensive training classes
- Are evaluated regularly
- Are committed to maintaining your privacy
- Adhere to the Four Seasons Mission and Values
- Bring a great deal of life experience
- Add quality of life to the patient's journey

What Volunteers Can Do For Patients and Families:

- Companionship socialization, friendly conversation, or a listening ear
- Respite staying with a patient while a caregiver runs errands or takes a break
- Pet Therapy bringing a registered pet to visit in a facility
- Pet Grooming taking a patient's pet to be groomed
- Transportation
- Grocery Shopping and Errands
- Letter Writing
- Life Review recording you or your family's story on tape or video
- Helping to organize paperwork
- Helping to celebrate a special occasion
- Helping with special requests

If you have a special request, please talk with your Social Worker. Each team has a Volunteer Coordinator who specializes in matching Volunteers to patient's requests. The above list is not inclusive of all the services that our Volunteers can provide. Let us know how we can make your journey more comfortable and we may have the perfect Volunteer who can help meet your needs.

Clinical Research

Four Seasons participates in clinical research studies investigating medications and therapies that may lead to improvements of symptom management in end of life care. Your Care Team can inform you of research studies that may be of interest or benefit to you. Participation in research studies is voluntary and does not affect care you would otherwise receive. Participation may also be a legacy of improving end of life care for others in the future.

Other Care Team Members

Your Four Seasons' Care Team may contract with other qualified healthcare providers for services necessary for your optimal function and symptom management. These may include:

- Physical Therapy
- Speech Therapy
- Dietary Consultant
- Occupational Therapy
- Respiratory Therapy



Palliative Care Team Members

You and Your Family

You are the most important member of Your Care Team. The services offered by your Four Seasons Care Team are based on your specific goals, your questions, and your concerns. Your Care Team respects your privacy, personal choices, cultural and/or religious customs, and family traditions.

Provider

Your own doctor will continue in your care and a Four Seasons doctor is available to consult with your doctor for your special care needs. Your doctor will focus on your overall comfort and daily functional needs. A physician, physician assistant or nurse practitioner makes 'house calls' if you are unable to come to appointments at the clinic, whether the patient is at home, in the hospital, in a nursing home, or in an assisted living facility.

Social Worker

Your Social Worker is able to help you identify your primary goals and concerns, to help you strengthen your coping abilities in times of stress, and support your family and significant relationships. He or she can provide useful information about planning for your care, solving problems, community and financial resources, and support for the ones who are caring for you. Your Social Worker can also arrange visits with Four Seasons Volunteers. A Social Worker is available 24 hours a day, 7 days a week.

Caring For The Patient





Basic Care

Bathing

- During shower or bath time, provide privacy and warmth by partially covering the patient with a light towel or blanket and washing one small area at a time
- Make sure to wash face, hands, back, underarms and genitals at least once a day
- Wash the face first and work down to the feet. Genitals and buttocks are always last.
- Be gentle when soaping, rinsing and drying the skin
- Apply moisturizing lotion to all areas, as it helps to protect the skin
- Take time to shave, comb, brush or style hair. Grooming can provide an emotional lift.
- Choose loose-fitting, comfortable clothes. If dressing and undressing become more difficult, consider cutting old t-shirts and nightgowns down the back and sewing ties or Velcro to make them easier to remove. Clothing that is tight, has buttons or thick seams can actually injure the skin if the patient is in bed or in a chair most of the time.
- A sponge bath in bed may become necessary when the patient has great difficulty getting to the tub or shower, or if slipping or falling are possible. Ask Your Care Team for instructions on giving sponge baths.
- A hospice aide can come to help with the bathing and grooming
- Your nurse will help arrange additional equipment that will make bathing safe and more comfortable

Mouth Care and Cleaning

- Be sure the patient is in an upright position to prevent choking
- Moisten the mouth first with sips of water, or a damp cloth
- Gently brush teeth and gums with a mild toothpaste or small cloth wet with diluted mouthwash
- A washcloth, towel or a bowl under the chin can help catch fluids
- If rinsing and spitting is difficult, use a washcloth, a "toothette" (disposable foam stick), or a gauze pad moistened with water or diluted mouthwash
- If the patient wears dentures, remove and clean them after eating. Make sure to clean the mouth gently with a soft toothbrush or cloth before replacing dentures.
- For dry mouth, use ice chips, ice pops or lollipops to suck on. Hard candy can be a choking hazard, so lollipops are preferred. A saliva substitute, an item found at most drug stores, may also be helpful.
- Apply lip balm several times daily for chapped lips. If the patient is using oxygen, only use lip balms that do not have petroleum.

Skin Care

- Keep skin clean by washing with warm water and mild soap and rinse thoroughly
- Keep skin dry as much as possible
- Keep skin well hydrated by drinking as much water as can be tolerated
- Avoid friction or rubbing, and use cornstarch to reduce friction
- Use alcohol free lotions for moisturizing
- Do not massage reddened areas

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- Sitting for long periods of time can damage the skin that covers the tailbone
- Move patient around to take pressure off skin
- Keep heels off bed with pillows under calves
- Change bed position at least every two hours; every hour if in a chair
- Have the patient shift their weight every fifteen minutes while they are awake if possible
- Your Care Team can recommend special pads and mattress overlays to help protect skin
- Nutrition is important in skin care but sometimes even normal amounts of food may overwhelm a patient. Offer protein rich drinks and snacks during the day if the patient can tolerate them. See the section on nutrition below.
- Even giving extremely attentive care to the patient, the skin can break down because of the physical changes that occur near the end of life

Call Your Care Team if:

- You have questions or concerns about bathing or grooming, or if you need more help with bathing the patient
- You see a white coating on the tongue or inside the mouth, which can be indicative of a yeast infection
- You notice reddened areas that do not fade, open areas, or blisters on the skin
- Changes occur in the ability to turn or change the patient's position
- You have any other questions or concerns about giving care

Nutrition

Appetite changes are often attributed to illness or medications that treat the illness. Food often tastes different, and discomfort or nausea with eating can occur. Weight loss is common with serious illness. A patient may not necessarily be able to gain weight and feel better just by eating more. You and Your Care Team can focus on ways to make eating and drinking as pleasant as possible.

- Arrange meals and snacks when energy is higher
- Reduce pain when offering food. Sometimes medications for pain about an hour before a meal may help. Your nurse will help guide you.
- Try smaller, more frequent meals with favorite foods
- Use smaller portions and smaller plates, as they are less overwhelming
- Avoid foods with strong odors and coarse textures
- Light foods such as rice and vegetables may be easier to digest than meats, pastas, potatoes and bread
- Choose soft foods if there is difficulty with chewing or swallowing
- Ask Your Care Team about thickeners that can help with swallowing drinks
- Avoid foods that are excessively cold or hot
- Consider larger-handled utensils and "sipper" cups
- Check with Your Care Team or physician to be sure that wine or other alcoholic beverages will not interfere with other medications



- Enrich food and increase caloric intake by adding eggs, cheese, powdered milk, protein powder, or peanut butter to recipes. Consider blended shakes made with ice cream and fruit.
- Use liquid dietary supplements (like Ensure, Sustacal, or instant breakfast mix) between meals
- Nutrition consultations are available, if necessary, especially if the patient has any dietary restrictions, cultural requirements or a history of diabetes

The subject of food and fluids can be an emotional topic for many families. Your Care Team is willing to listen to your concerns and answer questions about food and fluids.

Studies show that artificial fluids such as those delivered by intravenous infusions (IV) and feeding tubes do not increase a patient's quality of life and may actually increase discomfort, fluid overload and the risk of infection.

The goal of care is to increase comfort and well-being. Food and drink can play an important role in comfort. Your Care Team can help you make decisions based on your needs and wishes.

- You notice an increased difficulty in swallowing or incidents of choking
- Patient experiences increased nausea, vomiting or other eating difficulties
- Patient is suffering from abdominal cramping or pain
- You notice significant changes occurring in patient's appetite or amount of food eaten



Safety

Hand Washing

- Always use soap and running water and wash for 15-20 seconds (sing "Happy Birthday" as you wash)
- You do not have to use hot water, which actually may excessively chap hands and injure skin
- You may use an alcohol hand sanitizer to cleanse hands that are not visibly soiled. Apply product to palm of one hand in an amount sufficient to wet both hands. Vigorously rub hands together to cover all surfaces of hands and fingers until hands are dry. Do not use tissue or a towel to dry your hands.

When to wash hands:

 Before and after handling any type of patient equipment, soiled laundry or contaminated materials, even if you have worn gloves



- Immediately before providing care to the patient
- After caring for personal needs, such as toileting, nose blowing, combing hair, sneezing or coughing
- Before and after wearing gloves

Coughing

- Many illnesses and some treatments can make it easier for a patient to get an infection
- Cover your cough or sneeze to help stop the spread of germs that make you and others sick
- Always clean your hands after coughing or sneezing when caring for the patient

Cleaning Spills

- Clean blood and body fluid spills by wiping up with paper towels; always wear disposable gloves
- To clean any bodily fluids or waste: make a bleach solution daily – 10 ounces of water with 1 ounce of bleach. Please note that bleach solution loses its disinfectant ability after 24 hours.



• Place clothes and linens in a securely closed plastic bag until laundered separately

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Laundry and Equipment

- Always wear gloves when handling soiled linens
- Clean personal care items, such as a bedside commode, immediately after use. Clean with the bleach solution made daily – 10 ounces of water with 1 ounce of bleach. Please note that bleach solution loses its disinfectant ability after 24 hours.
- Dilute household disinfectants (such as Lysol) to wipe off equipment if you cannot use the bleach solution
- Wash small items in hot soapy water and dry with clean paper towels
- Wipe glass or plastic thermometers with rubbing alcohol before and after each use unless you have a disposable sleeve as a cover for each use
- Discard body fluids, such as urine or vomit, in the toilet. Wear gloves, and clean the container with the 1:10 bleach solution, rinse and dry.
- Wash patient's soiled laundry separately from other household laundry. Bleach or a disinfectant (such as Lysol) may be added to the laundry.

Trash Disposal

- Always wear gloves when handling trash
- Place disposable items soiled with body fluids or waste in a plastic bag and pour a small amount of fresh bleach solution over the items. Seal the bag securely and place outside in the trash.

Prescription Medication

You can help to prevent drug misuse, abuse and accidental poisonings by following these DOs and DON'Ts:

DOs:

- DO keep medications in the original container and out of sight and reach of children and pets
- DO store your medications in a secure area. Consider a cabinet or drawer that you can lock
- DO check the date on everything in your medicine cabinet and dispose of anything that has passed the expiration date
- DO check to see which medications need to be refrigerated. Make sure they are stored where they will not freeze and where children cannot easily reach them.

DON'Ts:

- DON'T take medications in front of children, since they tend to mimic adults
- DON'T give your medications to others to or take someone else's medications
- DON'T put different medications into one bottle
- DON'T store medications in places that are hot and humid
- DON'T take a medication that look different (i.e. color, shape, size, etc.) than you are accustomed to without first checking with your pharmacist

Proper disposal of medications will keep you, your family, your pets and the environment safe! It will also keep medications from being diverted and used illegally.



Disposing of Prescription Medication

Why do I need to properly dispose of my unused medications?

It is important to dispose of drugs the right way to prevent someone taking them by accident, or through an illegal sale. Protect children and pets from harm caused by accidental ingestion.

Where can I properly dispose of my unused medications?

Check to see if there are any drug take-back programs near you. There is a list of local drug take-back programs in the back pocket of your Confident Caregiving Resource Guide.

Note: Due to the high risk for harm, the Food and Drug Administration (FDA) recommends flushing for certain potent pain medications. A list of these medications can be found by going to the FDA's website (www.fda.gov) and searching for "Disposal by Flushing". Your hospice care nurse also has this information readily available.

If there is not a local drug take-back program in my area, what should I do to safely dispose of my medications?

- Keep prescriptions in the original container. This will help identify the contents if they are accidentally ingested.
- Before disposing, scratch out all identifying information on the prescription label to make it unreadable before throwing out a medicine container. This will help protect your identity and the privacy of your personal health information.
- Add some water or soda to pills to start dissolving them. Mix pills or liquid drugs with something that you cannot eat, like cat litter or dirt.
- Close the lid and secure with duct or packing tape
- Place the bottle(s) inside a non-see through container like a coffee can or detergent bottle
- Tape that container closed
- Hide the container in the trash. Do not put in the recycle bin.

Who can I talk to if I am still unsure about how to properly dispose of my unused medications? Ask your pharmacist or hospice care nurse how to safely dispose of your medications.

Disposing of Sharp Objects (Needles, syringes, lancets, etc.)

- Drop sharp objects in a puncture-proof container with a lid. You can use bleach bottles, detergent bottles or metal containers, or we can provide you with a sharps disposal box.
- Be sure to label the container "Hazardous/Sharp Materials/Do Not Recycle"
- Do not use glass or clear plastic containers
- Do not overfill the containers. Dispose of the container when it is no more than twothirds full.
- Keep container out of reach of children and pets
- DO NOT RECAP needles before discarding them. Many puncture injuries occur when trying to recap a needle. Place the needle or sharp object directly into the punctureproof container.
- Close the lid of the container tightly and seal with heavy-duty tape before placing in the trash

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Oxygen Safety

- Place a "NO SMOKING" sign on the doors leading into your home. The equipment company that brings the oxygen equipment can provide these signs.
- If anyone is going to smoke you must do these things first:
 - 1. Remove the oxygen mask or tubing from the patient's face
 - 2. Turn off the oxygen machine or tank completely
 - 3. Wait 30 minutes before smoking. Oxygen may remain in or on the body and clothing and can cause a fire even if the oxygen equipment has been turned off.
- Avoid petroleum-based products. Use only water-based products for skin care. This includes lip balm, face and body lotion and hair products.
- Keep tubing as short as possible to increase the amount of oxygen the patient receives
- Do not use aerosol sprays near oxygen equipment
- Do not lubricate or clean equipment with oil, grease or chemical products
- Place the oxygen machine (concentrator) on a carpet, rug, or some type of thick pad to reduce the noise
- Handle oxygen tanks carefully and store them in an upright position in the cart or holder supplied. Oxygen tanks have very high pressure and can become dangerous if dropped.
- Do store oxygen tanks in a well-ventilated area and do NOT store tanks in a closet.
- Do not store or use oxygen within 10 feet of an open flame. Open flames and potential fire sources include such items as candles, stoves, matches, cigarettes, heaters, cooking devices and fireplaces.
- Be sure you have a working smoke detector, a working fire extinguisher, and a plan of escape in case of fire
- Make sure that your guests and visitors are aware you have oxygen and follow all of the above safety rules

- The oxygen equipment does not seem to be working correctly
- The patient is short of breath and is not improving
- The patient has nose or ear irritation that sometimes can be caused by the oxygen or the mask or tubing



Power Failure

Prepare yourself and your family for unexpected events such as power outages, fires and natural disasters.

- In case of fire or natural disasters, call 911 first, then Four Seasons
- Keep Four Seasons phone number and a list of emergency numbers beside each phone. This list should include important and emergency phone numbers near each phone:
 - 911
 - Four Seasons at 866-466-9734
 - Your power, water, gas companies. Your hospice social worker can help you compile this list.
- Contact your power company if you rely on an oxygen concentrator or any other electric medical device at home. The power company can put you on a priority list to restore power.
- For your safety, your oxygen equipment company will give you backup oxygen tanks to use in case the power goes out
- Put together an emergency supply kit including:
 - Flashlights

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- Portable radio with batteries
- Plastic bags (with self-locking zippers, such as Ziploc) for medicine and supplies
- Canned food and bottled water
- It is important to have an escape plan and practice it. We can help you develop your plan.
- A sheet can be used as a "sled' to pull someone across the floor if they cannot walk or get into a wheelchair

- You experience a power outage that may impact the care or safety of the patient, such as electric medical equipment, lack of water, etc.
- You have to leave your home due to fire, power failure, etc. Let us know where the patient is so we can continue caring for the patient with you.

Trying to Prevent Falls

Avoiding injury is very important to Your Care Team. Your nurse will pay attention to particular things, such as medications and weakness, and help you work on ways to try to prevent falls. Here are some things you should address to reduce risks of falling inside your home:

- Slippery floors, loose area or throw rugs
- Dark or dim lighting that makes it difficult to see
- Stairs without railings or loose carpeting on steps
- Bathtubs, showers and toilets without grab bars
- Clutter than can be hard to walk around and easy to trip over (for example, stacks of newspapers and magazines)
- Hard to reach items in high locations (the top shelf of a cabinet)
- Electrical or phone cords

Here are some things you should address to reduce risks of falling outside your home:

- Slippery sidewalks, walkways, driveways from ice or snow
- Wearing shoes or boots with little or no traction
- Entrances, walkways and garages with poor lighting
- Walkways that have become uneven with age (like those made of brick)

This information and more is available at the North Carolina Falls Prevention website at www.med.unc.edu/aging/ncfp

Call Your Care Team if:

- The patient falls
- You are concerned about any increased risk of the patient falling
- You want more information about safely using patient care equipment, such as walkers, beds, bedside commodes, etc.

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Symptoms the Patient May Experience and How You Can Help

Anxiety

Anxiety is a concern about an event, person, uncertainty, or feeling of not being able to handle things. Often the reason for the uneasiness may not be known. Anxiety is a common experience. Anxiety may include:

- Fear
- Worry
- Spiritual Questions/Concerns
- Sleeplessness
- Nightmares
- Confusion
- Rapid Breathing or Heartbeat
- Tension
- Shaking
- Sweating
- Nerves
- Jitters

How to help relieve the anxiety:

- Write down thoughts and feelings. These written things can be shared with someone else, or can be kept very private. Just writing what comes to mind often helps.
- Talk with someone you trust
- Engage in relaxing activities such as deep breathing or yoga or listen to soothing music
- Limit the number of visitors, or how long visitors stay, until the patient feels better and more relaxed
- Gently rub arms, back, hands or feet. Wash your hands and warm lotion between your hands before gently massaging the patient.
- Avoid too much caffeine and alcoholic beverages
- Exercise regularly; even a few minutes of walking daily, or stretching and moving in bed or chair if walking is not possible can help to ease anxiety.
- Use medications as prescribed. Your nurse will give you guidance on safe use of medications.
- Your Care Team will be able to offer many other suggestions, like massage, relaxation exercises, or music therapy, to reduce anxiety

- There are problems with relationships with family or friends
- There are spiritual concerns
- The symptoms of anxiety are getting worse

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Bleeding

Anticoagulants (blood thinners) like Coumadin (warfarin) or Heparin keep your blood from clotting. These drugs may prevent conditions such as deep vein thrombosis (clots), stroke or pulmonary embolism. If your physician has prescribed an anticoagulant, it is important for you to know how to stay safe, be aware of possible side effects, and what foods can interfere with the effectiveness of the medication.

Safety tips while on anticoagulant (blood thinner) inside the home:

- Use an electric razor
- Use a soft toothbrush
- Do not use toothpicks
- Take extra care trimming toenails (your nurse can assist with nails)
- Do not trim corns or calluses
- Be very careful using knives and scissors
- Wear shoes or non-skid slippers at all times
- Follow fall prevention suggestions
- Tell your physician about all the medications you are taking some medications interact with blood thinners
- The patient may wear a medical information tag, such as a Medic Alert bracelet, to alert others of the anticoagulants

Safety tips while on anticoagulant (blood thinner) outside the home:

- Always wear shoes to help prevent falls
- Wear heavy gloves when working outside or with tools
- Avoid activities and sports that can cause injury, especially cuts or bruising
- Be very careful with sharp tools.

Possible side effects of anticoagulants:

- Most side effects relate to how the medicine works, by preventing clotting, which makes bruising and bleeding more common
- Blood is tested routinely so the amount of medication can be adjusted to lower the risk of excessive bleeding
- Minor bleeding may occur even when the medicine is working properly. For example, you may notice small bruises or slight gum bleeding when you brush your teeth.

- There are any falls
- There is increased bleeding from nose or gums
- Patient has bleeding from cuts or scrapes that do not stop after applying gentle pressure for 20 minutes
- Patient has bloody or tar-like stools, or stools that look like coffee grounds
- Patient has bloody urine



Bowel and Bladder Issues

Changes in bowel or bladder habits are a result of many things like inactivity, change in eating habits, medication and lack of privacy.

Constipation: a longer-than-normal period between regular bowel movements or unusually hard stool. A patient should have a bowel movement at least every 3 days, even if not eating very much.

- Drink fluids as much as possible
- Walk daily if possible
- Eat foods high in fiber, such a vegetables and fruits, if the patient can still drink several glasses of fluids each day
- Only use fiber laxatives, like Metamucil, if the patient can drink several glasses of fluids each day
- Vegetable laxatives and stool softeners, such a senna and docusate, are preferred, especially if the patient is taking pain medications

Diarrhea: frequent, watery stools that may be accompanied by stomach cramping.

- Drink liquids such as water, apple juice, non-caffeine sodas, or chicken broth until the symptoms end
- Avoid dairy products such as milk, cheese or ice cream
- Gradually offer the BRAT diet (bananas, rice, applesauce, toast) as the diarrhea begins to stop

Urine: Many patients become incontinent, or cannot control emptying their bladder. Some have difficulty emptying their bladder enough and become very uncomfortable or restless.

- Waterproof pads or adult briefs will protect clothing and furniture
- Keep the patients skin clean and dry often to avoid skin irritations
- Sometimes a catheter (a thin, soft tube) is inserted into the bladder to drain urine. Your nurse can do this if it becomes best for the patient.

For all bowel or bladder issues:

- Allow for privacy, with doors closed, curtains pulled, or privacy screens
- Stay close by for the patient's safety, in case they need assistance
- Use a bedside commode, bedpan, or urinal if walking to the bathroom is not safe or too difficult. Your Care Team can arrange for this equipment.
- Sitting upright, gentle rocking back and forth is more comfortable than straining

- Patient has not urinated or emptied bladder for 12-18 hours
- Patient experiences abdominal pain or burning when urinating or when emptying bowel
- Patient's abdomen becomes hard, or swollen
- Patient's urine is discolored, dark, or contains blood
- Patient is unable to control urination
- Patient does not produce a bowel movement in 3 days, even with very little or no eating
- Patient has 2-3 episodes of diarrhea within an 8-hour period
Infections

- Read the prior section on safety, beginning on page 14, for ways you can help reduce some of the chance of infections
- Many illnesses and some treatments can make it much easier for a patient to get an infection
- Your Care Team will be cautious to wash their hands or use hand sanitizers when visiting. They will wear gloves when giving care to the patient. They will keep their equipment and supplies clean. They will not knowingly visit when they are sick.

Call Your Care Team if:

- Patient develops an increased cough with spitting up sputum or mucus
- Patient develops a sore throat, colored mucus in nose or throat, or red, itchy eyes with crust on the eyelashes
- Patient develops new red, streaked, puffy, or warm areas on skin
- Patient's skin cuts or wounds begin to drain
- Patient's urine begins to smell bad or look cloudy
- Dressings on skin, or places where tubes or needles enter the skin that begin to look irritated, red, swollen, wet, or smell bad
- Patient develops a fever over 101 degrees

Medications

Medication is often an important part of managing distressing symptoms and improving quality of life. Be sure to tell Your Care Team about all medications or drugs that you are using, including all prescribed by a doctor, all "over-the-counter " medicines that you can buy without a prescription, vitamins, supplements, herbal or homeopathic remedies, tobacco, alcohol, and 'street' drugs. It is very important to share this information with Your Care Team so that they can keep the patient as safe and comfortable as possible.

Medication Plan:

- Your nurse will help you write the patient's medications, what they are for, when and how to give them
- Members of your team will review this plan regularly and update it as necessary
- Consider keeping your medication plan inside the pocket at the back of this manual
- At each visit, your nurse will go over your medication list. You can talk about how well the medications work, and any problems the patient has in taking the medications.
- The nurse will want to check medication bottles in order to be sure you have plenty, and to see if the list is correct

Preferred Drug List

Four Seasons uses a preferred drug list. This list is routinely reviewed and approved by our medical director and a pharmacist and is current with clinical evidence about the effective and safe use of medications. If a patient is on a medication that is not on Four Seasons' preferred



drug list, your nurse and doctor will discuss changing the medication to one that is on the list. Keeping the patient comfortable and safe is our first priority.

Managing medications:

- Read the labels before taking any medications
- Ask your nurse if you have any questions regarding how or why to use the medication.
- Take medication exactly as ordered by your doctor
- Do not stop taking any medication abruptly, even if you feel it does not help
- Talk with your nurse or doctor before stopping any medication
- Store medications in a child-safe location according to safety and temperature guidelines recommended on the containers
- Refills will often be every two weeks. We do this to avoid waste since medications can change often.
- Dispose of out-of-date or no longer used medicines safely. Ask a member of Your Care Team for information on how to dispose this medication properly.

Tips for taking medications:

- The patient should sit up as straight as possible and wet their mouth with a small drink of water before taking medication
- A little jam, applesauce, pudding or ice cream on a spoon with the medications can make swallowing much easier (and tastier!)
- Give medicines for nausea (upset stomach) about 30 minutes before other medicines

Payment for medications:

- Your hospice nurse will provide you with information on who pays for each of your medications. Be sure to inform your nurse of any new medications your physician orders.
- Medications related to your terminal illness and approved by hospice will be paid for by hospice if you have elected the Medicare/Medicaid benefit or if your insurance pays hospice to cover medications.
- Medications not related to your terminal illness will continue to be paid for as they were prior to hospice admission. This may include Medicare Part D or another insurance.
- Medications related to your terminal illness, but not approved by hospice, will be your financial responsibility.

Call Your Care Team if:

- You increase use of medication for symptoms (pain, nausea, anxiety, etc.) by one dose per day for more than three days
- A refill will be needed in three five days
- You should spill your medication or if you seem to be running out before the planned refill is due
- Gagging, choking, or coughing occurs when the patient is trying to swallow medications
- Any unusual or uncomfortable symptoms occur that you think may be associated with taking medications such as nausea, rash, trouble breathing, itching, etc.



Nausea and Vomiting

Nausea and vomiting are common problems. Medical treatments, medications, anxiety, or the illness itself can cause nausea or vomiting.

- Limit movement when feeling nauseated or queasy or sick to stomach
- Rest and avoid rapid changes in position
- Take medications to prevent or treat nausea at least 30 minutes before eating or before other medications
- Turn the patient to their side to prevent choking with vomiting
- Slowly sip ginger ale, peppermint or ginger tea, or suck on a peppermint candy if choking is not a risk
- Drink only clear fluids (drinks you can see through) for at least 24 hours ginger ale, apple juice, Sprite or 7-Up, sports drinks like Gatorade, or popsicles, broth, Jello, etc.
- Slowly begin eating small amounts of a BRAT diet: Bananas, Rice, Applesauce, Toast (plain)
- Rinse mouth thoroughly after vomiting. Use a watered-down mouthwash or brush teeth if possible
- Avoid:
 - Eating sooner than two (2) hours after vomiting
 - Heavy or fatty meals
 - Lying down after eating
 - Caffeine (ex. coffee, sodas, black tea)
 - Strong smells

Call Your Care Team if:

- Nausea or vomiting is a new symptom
- Vomiting does not stop even when only drinking clear liquids
- Vomit is bright red or dark brown (like coffee grounds)
- The patient is having trouble swallowing



Pain

Only the person having pain can describe what it is like. Here are some descriptions of physical pain:

- Mild, moderate, or severe
 - Your Care Team will often ask the patient for a "score" to rate the pain.
 '0' means no pain, and '10' is the worst pain. The patient is the only one who can give an accurate number to their pain.
- Sharp, dull, aching, stabbing, throbbing, hot, burning, needles, gnawing, cramping, etc.
- Comes on very fast, or slowly builds up
- Constant, or comes and goes
- Worse with activity, or increases if staying still
- Occurs any place in the body, or in many places in the body

Your Care Team is skilled at evaluating pain and treating pain. You will hear them ask the patient about pain very often. We want the patient to be as comfortable as possible. As we help you get any pain under control, then the patient and others who care for them will have a much better quality of life. Four Seasons values life and does not use pain medications or any other treatment to shorten life.

For people who may have a hard time describing their pain, or for children, or for patients with dementia, you may see changes in their actions, such as:

- Fidgeting, restless movements, pacing
- Crying, moaning, or frowning
- Curling up, or rocking back and forth, or holding onto a part of their body
- Acting cranky, grouchy, or irritable
- Wanting to be left alone, or covering up like they are trying to sleep

How to help:

- Watch for some of the above signs and ask the person if they are uncomfortable
- Give medications as ordered by the doctor. Your nurse will explain when and how much to use pain medications.
- It is important to give pain medications before the pain gets severe. It takes much less time and medicine to get mild or moderate pain under control than is does for severe pain.
- Pain medications may be "long-acting" or "short-acting"
 - Usually the long-acting types are ordered to take on a regular schedule with the goal of preventing pain
 - Short-acting medications are often ordered to take when the pain begins to increase
 - Your nurse will clearly explain what types and how to use the pain medications ordered
- Changing position in the chair or bed may help
- The patient may be able to tell you if something warm or cool over the painful area sounds comforting
- Soothing music, or a very quiet room
- Dim lights

• Your Care Team will be able to offer many other suggestions, like massage, relaxation exercises, or music therapy, to reduce pain

Common side effects from pain medications:

- Dry mouth
- Drowsiness
- Upset stomach
- Constipation
- Temporary confusion

Most side effects from pain medications do not last very long. Many side effects get better or go away with simple actions. Your nurse will help you learn what you might expect and what to do about any side effects until they go away.

Spiritual and emotional concerns may also cause pain. You may see this type of pain expressed through:

- Questioning the meaning of life, your belief system, or the meaning of suffering
- Being afraid to fall asleep at night, or other fears
- Feeling a sense of emptiness or loss of direction
- Talking about your feelings of being left by God/higher power, or being angry with God/higher power
- Having pain and/or other physical symptoms
- Distress and/or despair anxiety related to the struggle to find meaning in the experience of illness, suffering, death and dying

Call Your Care Team if:

- The patient develops new pain
- The patient experiences an increase in pain
- The patient is unable to take pain medications for any reason
- There are increased signs of discomfort for patients who cannot speak
- The patient experiences any side effects from medication
- The patient's pain continues in spite of medication or other efforts



Seizures

A seizure is a sudden surge of electrical activity in the brain that affects how a person feels or acts for a short time. On rare occasions, a seizure may last for several minutes. Before some seizures, there may be warning signs. A person may have a sense that something is wrong (have a strange feeling, tingling) and sometimes seizures come with no warning. A seizure can affect people in different ways; some may be barely noticed, while others may cause the person to have uncontrolled movements of the whole body. Seizures may cause the person to fall to the floor or even become unconscious. After a seizure the person may be very sleepy. This may last for a few seconds, minutes, or hours.

Some possible causes of seizures:

- Medical condition or a disease
- Prior head injury
- Infections
- Medications
- Fever

Some things you may see during a seizure:

- Muscle jerking, twitching
- Stiffening of the body
- Bladder emptying, wetting
- Blurred vision
- Not able to talk
- Unconscious, passed out
- Eyes rolling back
- Confusion, short memory loss
- Blank stare

How to help:

- Move any objects that the person may fall or bump into
- Turn the person on his/her side if vomiting occurs
- Gently support the head by placing a pillow underneath
- Remove eye glasses if possible
- Do not put anything in their mouth and do not try to hold their tongue
- Give medications if ordered

Call Your Care Team if:

- The patient has a new or unusual seizure or behavior after a seizure
- There is any injury to the patient during or right after a seizure
- The patient's seizure is not stopping
- There is an increase in how often or how severe the patient's seizures are
- The patient's supply of medications for seizures becomes low

Shortness of Breath

Shortness of breath is also called dyspnea. Patients often describe it as a feeling of not getting enough air or a feeling that you cannot catch your breath, as if the room is closing in or that there is not enough air in the room.

Being short of breath can cause:

- Fear, anxiety
- Gasping
- An inablity to keep doing an activity
- A need to sit upright
- Blue or grey color in lips, fingertips or toes, end of nose, or ears

Stay calm and breathe slowly while you help the patient do the following things:

- Sit up in a chair or recliner
- Raise head on pillows when lying in bed
- Sit with hands on knees or on the side of the bed leaning over
- Take slow, deep breaths, breathing in (inhale) through the nose and then breathe out (exhale) slowly and gently through pursed lips (lips that are "puckered" as if you were going to whistle). This breathing exercise is like blowing bubbles, and will help get good, slow, deeper breaths into the lungs.
- Open a window, use a fan or an air conditioner, gently fan a piece of paper several inches from the patient's face
- Apply a cool cloth to head or neck
- Use oxygen if ordered, making sure it is turned on, the tubes or mask are in the right place on the patient's face, nothing is kinking the tubing, and no one is smoking
- Give medication, including inhalers, nebulizers, pills, or liquids as ordered. Your nurse will teach you how to use the medications appropriately. Many times a small dose of liquid morphine is the best medication to use.
- Keep area quiet to decrease feelings of anxiety
- Use relaxing activities such as prayer, meditation, calming music, massage, or other things that have helped the patient be calm in the past. Your Care Team will be able to offer suggestions, like massage, relaxation exercises, or music therapy, to help.

Call Your Care Team if:

- The patient experiences shortness of breath increases or does not get better with the usual treatments or medicines
- The patient needs to use more than the normal amount of medicine or treatments to relieve shortness of breath
- You think you need to increase the oxygen DO NOT make any adjustments without consulting Your Care Team first

References:

Berry P. Management of other symptoms at the end of life. Hospice and Palliative Nursing Assistant Core Curriculum. Pittsburgh, PA: The Hospice and Palliative Nurses Association; 2009:24:25. Core curriculum for the Generalist Hospice and Palliative Nurse. 3rd ed. Dubuque, IA: Kendall/Hunt Publishing Company; 2010.



Travel Information

Four Seasons recognizes that some patients may want or need travel while receiving hospice care. The Medicare Modernization Act of 2003 allows hospices to arrange with a different hospice to help meet patients' needs when they do travel for short periods to other areas. Your Care Team will work with you to help meet the patient's needs while traveling outside of our area. Please notify your team of any expected travel as soon as possible. Your Care Team needs time to contact another hospice and provide them with enough information to provide any support or care needed during travel.

Travel is typically 14 days or fewer. Longer stays out of the area are possible, but Your Care Team needs to discuss your plans and help you make the best arrangements.

Call Your Care Team if:

- You are planning any travel that would take the patient out of the local area
- At least one week notice is preferred so Four Seasons can be certain all necessary things are in place for a safe and comfortable trip for the patient

As Care Needs Increase

Your Care Team can help avoid unwanted hospital stays, keeping the patient at home as much as possible, or in a facility where Your Care Team is still very much involved. Four Seasons' nurses are available 24 hours a day, 7 days a week to respond to your urgent needs or other issues that concern you. We can arrange for a nurse to visit you, even in the middle of the night if necessary.

Continuous Care

If changes in the patient's condition require more intense care than is typically provided, it is sometimes best for Four Seasons' nurses and nurse aides to remain for a few hours or more in the patient's home. The Medicare hospice benefit calls this "continuous care". This is for 'crisis' periods, for a limited time, and the patient must meet certain criteria.

The Four Seasons team will:

- Teach and assist family caregivers in giving medications, providing personal care and treatments, or other specific procedures ordered by your physician
- Reposition (if reasonable) bedbound patients and bathe/change incontinent patients frequently for comfort and to prevent skin breakdown
- Bring their own food and beverages and will not smoke while in your home
- Be allowed a 30-minute meal break and up to two 10-minute breaks during an 8–12 hour shift
- Remain awake and alert at all times
- Conduct themselves as guests in your home, and will be courteous and respectful at all times
- Provide regular visits by the usual Care Team in addition to the continuous care being provided to the patient

How you can help:

- Stay involved in the patient's care
- Be part of making decisions that you feel are in the best interest of the patient, such as not turning in bed, refusing medications, etc. Please discuss these decisions with Your Care Team.
- Please be available for visits from Your Care Team
- Assist in planning for the patient's care when the current symptoms are under control and continuous care ends
- Ask questions freely and as often as needed

Inpatient Care for Symptom Management

Four Seasons can arrange for a transfer to our specialized hospice inpatient unit, the Elizabeth House. If necessary, or if the patient chooses, we can arrange for admission to several area hospitals, with whom we contract, while continuing to receive the support of the hospice team.

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More About Four Seasons' Elizabeth House:

When symptoms need more intense attention than can be managed at home, we can offer you the option of 24-hour care at our hospice inpatient facility, the Elizabeth House. You will receive specialized round the clock care in a safe, homelike environment. If you would like to speak with someone at Elizabeth House, please call 828-692-9633.

Rooms at Elizabeth House are private with the exception of one. All rooms are equipped with sleeper sofas for family members who wish to stay overnight. Visitors may come 24 hours a day, 7 days a week; children as well as pets may visit, within certain guidelines. A family kitchen, laundry, great room, meditation room and garden are available for patient and family use.

Specially trained hospice nurses, social workers, spiritual care providers and volunteers staff Elizabeth House around the clock. Physicians are available around the clock and make rounds at the Elizabeth House at least six days a week to meet the medical needs of patients.

The team at Elizabeth House will help the patient and family be prepared to return home if at all possible. Sometimes patients will go to an assisted living or nursing facility after their stay at Elizabeth House. Either way, the patient will still have a Care Team after they leave Elizabeth House.

There is a chance, of course, that the patient may die while at Elizabeth House. The Care Team gives support to family and friends. Family and friends are allowed to be present as much as they and the patient choose, respecting other patients and families that are present.

Respite Care

Respite care is a period designed to relieve the family member or other persons caring for the patient. The patient is admitted to a nursing facility, sometimes Elizabeth House, only on an occasional basis, for no more than five consecutive days at a time. The hospice Medicare benefit also pays for this short stay.

When More Help is Needed to Give Care at Home

Giving care takes much time and energy. Sometimes it is good for the family to hire professional caregivers. Quality, private-duty personal care is available with other community agencies or individuals. Talk with your social worker for more information. Hiring, supervision, and payment of professional caregivers is the responsibility of the patient's family. Your Care Team will gladly work closely with caregivers you choose to hire.

Death is a process of physical, emotional, social, and spiritual changes. The end-of-life may approach rapidly or more gradually over many days. Each person is unique, and the transition towards death is often very much like the person's life and personality. The goal is to honor and respect these changes and to comfort and support all of you through this process. Four Seasons also values life and does not hasten nor prolong the natural process of dying.

Physical signs of approaching death:

- Increasing sleep, though night and day sleep may switch
- Increasing weakness, more time resting in bed or in a comfortable chair
- Time and usual routines become less important
- Withdrawal from other activities, such as visiting, watching TV, reading
- Decreased eating and drinking
- Slower or irregular breathing
- Skin may be cool, become grey-blue, or be splotchy (mottled)
- Skin may be very warm
- No control of emptying bowels or bladder
- Decrease in the amount of urine
- A relaxed face and forehead suggests that the patient is comfortable. Frowning or grimacing suggest they are having some type of discomfort.
- Limited or no swallowing, causing drooling or noisy breathing because of saliva in the mouth/throat
- Visions, often of people who have died, are often comforting to the patient

How you can help:

- Create a quiet, peaceful, private area
- Limit visitors or lengths of visits if the patient seems agitated
- Continue to offer words of love, support, care, forgiveness, and encouragement that the family will be sad, but ok. Hearing is the last sense that leaves us, so be aware the patient will likely hear all that is said nearby even when they cannot respond.
- Gently continue to provide personal care, keeping skin clean, and the mouth moist. See the earlier sections on basic care, beginning on page 11.
- Continue medications if possible and with the guidance of your nurse and doctor. Many medications can safely be stopped, but some should continue to provide comfort.
- Elevate the patient's head slightly with pillows or by raising the head of the bed, especially if noisy breathing or vomiting occurs
- Take care of yourself: eat a little several times a day, rest, drink fluids, and ask for the help you want

The Timing of Death

Sometimes you may encounter your loved one existing in a sleep-like state for many days and wonder how long this can go on. Death is a process and is unique to each person. During this process, you can benefit greatly from the companionship of skilled professionals who can

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explain what the changes mean and help you enhance comfort during this time. We are here to help you through this journey. Please tell us if there are additional ways we can help.

Sometimes friends and family are present for the death event; sometimes they have literally just left the room and then discover that the patient has died in their absence. For family or friends, this may be frustrating or cause feelings of guilt. Our experience is that sometimes people seem to wait for family to leave before they let go and die.

Some families and friends feel they must give their loved one "permission" to die; yet it can be very difficult to say, "It's okay, you can go." There are no rules or scripts that you must follow. We encourage friends and family simply to be honest in their grief and in this experience. Do what is comfortable for you. It may make more sense to say "I love you and I'll always hold you in my heart" or "I will be okay and I will miss you" or to say nothing at all. This is a time of profound change and there is no right or wrong way to handle this situation. It is normal to feel speechless during this time.

How you will know when death has occurred:

- No response to gentle shaking
- No breath for several minutes
- No heartbeat heard or felt
- Eyelids often slightly open, but eyes do not move
- Relaxed jaw and mouth slightly open
- Color of the skin changes

If you believe that death has occurred, or if you are ever concerned and need physical or emotional companionship at this time, call Four Seasons right away.

A Four Seasons' nurse will:

- Make a home visit at any time of the day or night
- Determine if death has occurred
- Clean the body and clothe them as you wish
- Call the funeral home when you are ready
- Contact other members of Your Care Team as needed
- Inform the patient's doctor
- Arrange for medical equipment to be picked up, and properly destroy medications

When death has come, please do not rush if you feel that you need time. It is okay to touch, hold, talk and be with your loved one after he or she dies. Do whatever feels natural – whether that means crying, talking, praying, or bathing the body.

References:

Core Curriculum for the Generalist Hospice and Palliative Nurse. Dubuque, IA: Kendall/Hunt Publishing Company; 2005. Ferris F. International Palliative Wound Care Initiative. Consensus Statement on Palliative Wound Care. Journal of Palliative Medicine, November 2007.

Core curriculum for the Generalist Hospice and Palliative Nurse. 3rd ed. Dubuque, IA: Kendall/Hunt Publishing Company; 2010; Tips to Manage Anxiety and Stress. Anxiety Disorders Association of America. Available at www.adaa.org. Accessed: June 27, 2011.

Caring For The Caregiver





Self-care

Caring for yourself during this time is as important as the care you provide to others. We encourage you to utilize *all* members of your team; we find that families benefit if they allow all the team members to be involved.

As a caregiver, you may have concerns or questions about caregiving or feel stressed, overwhelmed or even angry at times. Caregiving is a challenging job and requires much hard work and commitment. We want to be able to support you and your family and help you in ways that are meaningful in order to ease any burden you may feel.

You may find these suggestions helpful:

- Ask family members or friends to help you. By asking for help, you will find some muchneeded relief, and your friends and family will feel good about helping you.
- Many people may offer to help. Do not turn them away. In fact, give them a job to do! They can help with laundry, grocery shopping, meal preparation, etc.
- Simplify communication with your extended family and friends by utilizing an interactive web-based program such as *CarePages*. (Visit www.carepages.com for more information.)
- Try to get some regular exercise and sleep. Light exercise and sufficient rest provide physical and psychological rejuvenation. If your loved one sleeps a lot during the day, you may be able to take some time to rest too. A neighbor, friend or one of our trained volunteers may be able to sit with your loved one so you can get some sleep or exercise. This may benefit both you and your loved one. You also may find that hiring someone to provide additional help can give you time to rest or exercise. Sometimes families hire nighttime help so that they can sleep without interruption and be more rested the next day. If you are finding it difficult to get sufficient rest, please talk with Your Care Team.
- Eat balanced meals to nurture your body. Don't skimp or eat poorly when you are under stress. Choose healthy snacks.
- Try to take a few hours away on a regular basis. The time away often will give you
 renewed energy and motivation to care for your loved one. Asking friends, neighbors
 or members of your faith community to help is one way of getting the assistance you
 need. You also can have your hospice volunteer stay with your family member while
 you go out. Sometimes just a walk, a trip to the library or a cup of coffee out with a
 friend can be the "breather" that you need.
- Make a list of names and phone numbers of friends and family to call when you are feeling overwhelmed. Maintaining social contacts is essential to your well- being. Try to keep up with at least some of your own activities. Get out, see friends and continue with your special interests.
- Keep a journal and write down your thoughts and feelings. This helps give you perspective on your situation and serves as an important release for your emotions.
- If you find that you are overwhelmed with feelings of anxiety and worry, or if you
 cannot sleep well and awaken frequently through the night, please be sure to tell Your
 Care Team. The stress of caregiving can sometimes lead to depression. Talk with your



social worker, chaplain, or music therapist about scheduling some time to talk about your feelings.

- Do not be afraid to ask questions when you are unclear about care and safety instructions, medication management, etc. No question or concern is too small. You are a valuable member of your loved one's Care Team, and your concerns are valid.
- Seek support and open yourself to help. Utilize support groups and companionship.
- Trust your instincts. Most of the time they will lead you in the right direction.

Dealing with Criticism

Receiving criticism is never a pleasant experience. Whether it is a sibling judging how you care for a relative or complaints from the person you are caring for, you may feel suddenly flooded with difficult emotions – perhaps anger, shame, or confusion.

We can't stop others from giving criticism. But we can become wiser about how to deal with it. Try these tips:

- *First, pause.* Criticism can feel like an attack. To avoid saying something you'll regret, stall with a remark such as, "Hmmm. That's an interesting comment."
- *Then, explore.* Without denying it or buying into it, get clarification. "Just to be sure I understand, you are concerned about how I ____?" or, "You would like me to ____?"
- Consider what may be true. Is Mom's checkbook actually a mess? Instead of crumbling in shame or being defensive, acknowledge what's yours. That sets a constructive tone. Say you'll look into some solutions. Or ask them to join you in finding solutions. Do they have specific suggestions about what could be done differently? (Privately, remind yourself about all that you are doing well, too.)
- **Consider what may be theirs**. Is your sister's lashing out really deflecting her shame about doing so little for your mom? Or possibly your dad's fault-finding represents his frustration with poor health. If so, disregard what's unfair and let it go. Calmly acknowledge the comment by saying, "Gotcha, Dad. I'll give that some thought."
- Maintain appropriate boundaries. Valid criticism focuses on something you've done, not on who you are. Meanness, such as being told, "You're lazy," is never okay. Set a limit: "I am happy to listen to feedback about how I do things, but not to judgments about me."
- *Turn it into an opportunity*. Ask the person who is criticizing to help with solutions by sharing or taking on the task himself or herself.

You are not alone. We are always just a phone call away. Registered nurses are working 24 hours a day, 7 days a week. If you need assistance, support or guidance, contact us.



Respite Care

What is respite care?

There are times when caregivers need a break. Respite (or rest) care gives the caregiver the opportunity for time off or to attend a family event. Respite care supports the caregiver and is part of the benefit provided by Medicare, Medicaid, and most insurances. Respite care can be provided by trained volunteers on a weekly or as needed basis.

How is respite obtained?

The inpatient respite level of care is available to patients in a contracted facility or in Elizabeth House (Four Seasons' owned inpatient unit) on an as needed basis. Situations indicating a need for respite care may include, but are not limited to injury or impairment of the caregiver and or the caregiver requires or requests an interval (5 days or less) of rest or relief from providing continual care to the patient. The social worker or RN case manager assesses the need for respite care, arranges inpatient respite care with a contracted facility, arranges transportation if needed and informs the rest of the team and necessary agency departments.

Respite can last up to 5 days and is offered as needed. The patient will receive all medications and treatments based on the hospice plan of care. The physician may stop by, but this is not necessary since team members will provide the facility with all necessary care instructions. Remember, when using respite care, the setting is different but the care does not change.

How should the patient/caregiver prepare for respite?

Bring all medications (except narcotics) in labeled medicine bottles. Bring supplies, such as diapers, ostomy supplies and dressing supplies. Pack the patient's personal items (brush, comb, toothbrush, etc.) as well as any clothing the patient wants.

How should the patient get to the facility?

If at all possible, the family should take the patient and pick them up. If this isn't possible, discuss transportation needs with the social worker and RN case manager on your team.



Talking with Children

Children benefit from being involved in the experience of illness and death; exclusion from these life experiences can lead to confusion, fear or anger. Children may ask many questions and be very curious about what is happening. They may be affected by changes to your home routine and the anxiety or worry of the adults around them.

Some tips:

- Children may ask many questions and struggle to cope with what is happening. Your answers should be simple, honest and in words they will understand. Our staff members are available for additional guidance about how to talk with your child.
- Try to maintain as normal a routine as possible. If the child shows increased anxiety about being away from you, offer encouragement and adjust routines slightly to decrease anxiety.
- Sometimes spending a little extra time away from the home together may help. Utilize your hospice volunteers to provide respite so you can spend time with your family.
- Do not try to protect them from your emotions or hide your feelings. This can actually create more confusion and anxiety for a child. It is okay to cry with your child or share worries in an age-appropriate way. Maintain open communication. Set a time to check in each day about how everyone is feeling.
- Children may wish to "help" with caregiving. Certain tasks and/or decorating the bed or room can help them feel included.
- It is usually beneficial to notify your child's school and teacher about the changes in your home situation
- We suggest that you not force children to be involved if they do not wish to be. Offer choices.
- Children may ask to see the body of their loved one after the death. Try to prepare them for how the person will appear and to accompany them.
- We recommend that you avoid using phrases such as such as "he has gone away" or "she has fallen asleep" to explain death. It is better to use the word itself.

Grief Support

Coping with a loved one's death can be overwhelming and in some instances very isolating. While the process of grief is a normal and natural response to loss, it is also often extremely difficult and full of life changing realizations. For many, the process of moving through grief is one of the most challenging parts of life. Our grief support programs are here to arm you with information, assist you as you walk through painful emotions, and to provide comfort and hope along the way. *You are not alone.*

We offer a wide variety of grief support options. Are you curious about "what's normal?" Are you in need of support as you process confusing and difficult emotions? Do you need help navigating the highs and lows associated with the roller coaster of grief? We offer individual and group support options that are tailored to your specific needs.

Heart Songs is a service that specializes in working with children and teenagers who are anticipating or have experienced the death of a parent, sibling, other relative or friend. This grief support program helps young people successfully move through the crisis of loss and adjust to living without a loved one. The program works with children and teenagers, ranging from 3 to 18 years of age, as well as their families. Our trained professionals are available to your family. They can provide individual and family counseling and lead support groups with the help of specially trained volunteers. Services can be provided within the school system as well. Your Care Team can discuss your options for accessing support.

Each summer, we offer *Camp Heart Songs*, a grief support program for children who have lost a loved one. Through the help of trained counseling services providers and volunteers, campers participate in enjoyable camp activities while also learning about and sharing feelings associated with losing someone close to them.

An integral part of Four Seasons' grief support is provided through *community outreach*. Our bereavement specialists help grieving individuals and groups in many settings, including: schools, faith congregations, neighborhoods, and hospitals based on need.

For more on grief support provided by Four Seasons' see the section of this manual beginning on page 71. Feel free to ask a member of Your Care Team for more information regarding these grief support programs.

The cost of grief support programs is included with your hospice benefit coverage (with Medicare or private insurance) and also funded with community donations. We provide bereavement support for at least 13 months following the death and longer if necessary. One of Your Care Team members can connect you and your family with a member of the Bereavement Team.



Additional Information and Resources

You may find some of the resources below helpful. For a more detailed listing or other resources please contact a member of Your Care Team.

Websites

- www.FourSeasonsCFL.org Four Seasons
- www.nhpco.org National Hospice and Palliative Care Organization
- www.caringinfo.org Caregiver information and tools for end-of-life care
- www.elderweb.com Online eldercare sourcebook
- www.nfcacares.org National Family Caregivers Association
- www.helpingcaregivers.com Includes resources and links for opportunities to help caregivers
- www.seriousillness.org Caregiver information and tools for end-of-life care

Resources

Ask Your Care Team for a free copy of these resources:

- Caregiving Resource Kit Includes useful resources for caregivers
- Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness by H. Dunn (available in English and Spanish)
- *Gone from My Sight, The Dying Experience* by Barbara Karnes (available in English, Spanish, Polish and Russian)
- *Five Wishes*, published by Aging with Dignity (available in English, Spanish, Polish, Russian and Japanese other language versions can be ordered)

Books for caregivers

- I'm Here to Help A Guide for Caregivers, Hospice Workers and Volunteers by Catherine M. Ray
- Caring For Yourself While Caring For Your Aging Parents: How to Help, How to Survive by Claire Berman
- Helping Yourself Help Others by Rosalynn Carter
- Taking Time for Me: How Caregivers Can Effectively Deal with Stress by Katherine Karr
- Handbook for Long-Distance Caregivers Available in print by sending \$5 to Family Caregiver Alliance, 180 Montgomery Street, Suite 1100, San Francisco, CA 94104, or download it for free at www.caregiver.org

Other resources

• The National Council on the Aging - www.BenefitsCheckUp.org (online benefits screening)

Many of your concerns can be addressed by a member of Your Care Team; so, please contact us if you are unable to find the information that you need.

Four Seasons provides websites and other resources as a service for our patients and their families. We do not intend any endorsement and make no representations about the sites or their owners, products or services. We are not responsible for the content of the sites. All trademarks or service marks are the property of their respective owners.

Important Information





Emergencies

General Guidelines for Emergencies in the Home

(Weather emergencies, explosions, power outages, water outages, sheltering-in, other disasters)

- Follow recommendations of local authorities
- Listen to the radio or TV for up-to-date news
- Notify local police or fire departments as indicated
- Be prepared to leave quickly
- Plan ahead in case of a situation or disaster that requires the patient to leave the home
- Develop a plan for where the patient may be moved to and have a backup plan in place in case primary plan is not an option when need arises
- Decide specifically who will do what and be sure to communicate the plan to everyone involved
- If a crisis occurs, call 911
- Call Four Seasons and speak with someone who may be able to assist you with emergency respite for the patient

Fire Safety

- There should be one functioning smoke detector for each level of your home
- Develop an evacuation plan for fire that includes how to evacuate those who need help to walk or who may be confined to bed
- Develop secondary escape plans in case the primary plan cannot be carried out
- Include other family members, neighbors and/or friends in the evacuation plan as needed
- Be certain to communicate the evacuation plan to all involved
- Make sure all pathways are clear, NEVER BLOCK AN EXIT
- Fireplaces and space heaters should not be left unattended while in use
- Fireplaces should have screens or doors which are kept closed

Weather Emergencies

Tornado Safety

- Listen to your radio or TV for the latest weather updates. TORNADO WATCH means that local weather conditions exist for a tornado to develop. For TORNADO WARNINGS, seek shelter immediately.
- Remain calm
- In the event of a tornado move to the lowest level or basement of the home
- If there is no basement, move to an interior room or hallway that does not have windows
- If the patient is unable to leave their room or go to another level of the home, he/she should be moved towards an inner wall and covered up with blankets
- Close all blinds and drapes in the room to aide in reducing flying glass if the window(s) break
- If crisis occurs, call 911



Flooding

Follow General Guidelines for Emergencies in the Home

Electrical Outage

- Follow General Guidelines for Emergencies in the Home
- Call and report problem to the electric company
- If using an oxygen concentrator, switch to back-up oxygen tanks
- Notify staff at Four Seasons so that we can alert the oxygen company to provide additional oxygen as needed
- If an alternative power supply is available, use it
- Keep a flashlight with working batteries ready for use

Water Outage

- Follow General Guidelines for Emergencies in the Home
- Call the water company
- Use bottled-water for drinking if available
- Restrict use of available water

Personal Planning and Advance Directives

Patient Self-Determination Act

In accordance with North Carolina law, Four Seasons is providing information concerning the Patient Self Determination Act of 1991.

Four Seasons supports the competent adult's right to make decisions regarding the acceptance or refusal of medical or surgical treatment in accordance with North Carolina laws.

All patients will be asked if they have advance directives. The patient's response will be documented in his or her medical record. The Patient Self Determination Act does not require patients to have or fill out an Advance Directive. It does require health care organizations to tell patients that they have the right to fill one out in accordance with existing state law.

- When a copy of the patient's advance directive is provided, the admitting nurse will place it in the patient's medical record
- If a copy of the patient's advance directive is not available, the admitting nurse will request that the patient's family provide a copy of the advanced directive
- If the patient does not have an advanced directive in effect and would like to execute one, the patient will be furnished with the appropriate forms and given the opportunity to discuss its meaning and ask questions

Medical Care Decisions and Advance Directives – What You Should Know *Who decides about my medical care or treatment?*

If you are 18 or older and mentally competent, you have the right to make decisions about your medical treatment. You should talk to your doctor or other health care provider about any treatment or procedures so that you understand what will be done and why. You have the right to say yes or no to treatments recommended by your doctor. If you want to control decisions about your health care, even if you become unable to make or express them yourself, you will need an "advance directive."

What is an "Advance Directive?"

An advance directive is a set of directions you give about the health care you want if you lose the ability to make the decisions for yourself. There are three ways for you to make your directions known:

- 1. Living Will
- 2. Health Care Power of Attorney
- 3. Advance Instruction for Mental Health Treatment

Do I have to have an Advance Directive, and what happens if I don't?

Making a living will, appointing a health care power of attorney or making an advance instruction for mental health treatment is your choice. If you become unable to make your own decisions and you have no living will or a person named to make medical care decisions for you (health care agent), your doctor or health provider will consult with someone close to you about your care.

What is a Living Will?

In North Carolina, a living will is a document that tells others that you want to die a natural death if you are terminally and incurably sick or in a persistent vegetative state from which you will not recover. In a living will, you can direct your doctor not to use heroic treatment that would delay your dying, for example by using a breathing machine (respirator or ventilator), or to stop such treatments if they have been started. You can also direct your doctor not to begin or to stop giving you food and water through a tube (artificial nutrition or hydration).

What is a Health Care Power of Attorney or health care agent?

In North Carolina, you can name a person to make medical care decisions for you if you later become unable to decide for yourself. This person is called your "health care agent." In the legal document you name who you want your agent to be. You can say what medical treatments you would want and what you would not want. Your agent then knows what choices you would make. Your health care agent may also be designated in a Durable Power of Attorney document.

How would I choose a health care agent?

You should choose someone you trust. Discuss your wishes with that person before you sign the power-of attorney form. The person chosen must be mentally competent and at least 18 years of age.

How do I make an Advance Directive?

You must follow several rules when you make a formal living will or appoint a health care power of attorney. These rules are to protect you and ensure that your wishes are clear to the doctor or other provider who may be asked to carry them out. Your directives must be written and signed by you while you are able to understand your condition and treatment choices and to make those choices known. All types of advance directives must be witnessed by two qualified people and be notarized.

Are there forms I can use to make an Advance Directive?

Yes. These forms meet all of the rules for a formal advance directive. Using the special form is the best way to make sure that your wishes are carried out. Your Care Team can provide you with these forms.

When does an Advance Directive go into effect?

The powers granted by your health care power of attorney go into effect when your doctor states in writing that you are not able to make known your health care choices. When you sign a health care power of attorney, you may name the doctor you would want to make this decision. A living will goes into effect when you are going to die soon and cannot be cured or when you are in a persistent vegetative state.

What happens if I change my mind?

You can cancel a living will both by destroying all the copies of it and by informing your doctor that you want to cancel it. You can change your health care power of attorney or attorney-in-fact by destroying all the signed copies or signing another one, and by telling your doctor and each health care agent about the change.

Whom should I talk to about an Advance Directive?

You should talk to those closest to you about an advance directive and your feelings about the health care you would like to receive. Your doctor or healthcare provider can answer medical questions. A lawyer can answer questions about the law. Some people also discuss the decision with clergy or other trusted advisors.

Where should I keep my Advance Directive?

Keep a copy in a safe place where your family members can get it. Give copies to your family, your doctor or other healthcare provider, your healthcare agent and any close friends who might be asked about your care should you become unable to make decisions.

What if I have an Advance Directive from another state?

An advance directive from another state may not meet all of North Carolina's rules. To be sure about this, you may want to make an advance directive in North Carolina also. Or, you could have your lawyer review the advance directive from the other state.

Note:

This document has been developed with information provided by the North Carolina Division of Medical Assistance in cooperation with the North Carolina Department of Human Resources Advisory Panel on Advance Directives.



Patient Rights and Responsibilities

Mission Statement: Four Seasons' mission is to provide goal-oriented, holistic and life-affirming care to our patients and families. Patients and families enrolled in the Four Seasons hospice program have the following rights and responsibilities:

- 1. To exercise my rights as a patient of Four Seasons.
- 2. To not be subjected to discrimination or reprisal for exercising my rights.
- 3. To be informed and participate in my plan of care.
- 4. To have my property and person treated with respect, consideration, and dignity, with full recognition of my individuality and right to privacy.
- 5. To receive care and services that are adequate, appropriate, and in compliance with relevant Federal and State laws and rules and regulations.
- 6. To be informed of the process for acceptance and continuance of service and eligibility determination.
- 7. To receive effective pain management and symptom control from Four Seasons for conditions related to the terminal illness.
- 8. To have my Advance Directives honored as permitted by local, state, and federal law.
- 9. To accept or refuse services, care, or treatment, and be informed about the consequences of such action.
- 10. To choose my attending physician.
- 11. To receive a copy of Four Seasons' Notice of Privacy Practices describing my privacy rights.
- 12. To have my personal and medical records kept confidential, and not be disclosed without appropriate written consent or in accordance with the Notice of Privacy Practices.
- 13. To request confidential communications.
- 14. To inspect and copy my health information in accordance with the Notice of Privacy Practices.
- 15. To object to a disclosure of my health information to the NC Department of Health Service Regulation for purposes of validating Four Seasons' compliance with state law as I have indicated in the Consent for Hospice Services or have amended in writing.
- 16. To be informed of the agency's on-call service.
- 17. To be informed of supervisory accessibility and availability, and be advised of the agency's procedures for discharge.
- 18. To receive a reasonable response to my requests of the agency.
- 19. To receive a written statement of services provided by the agency and the charges I am liable for paying.
- 20. To receive information about the services covered under the hospice benefit.
- 21. To receive information about the scope of services Four Seasons will provide and specific limitations on those services.
- 22. To receive health teaching and education in a language or form that I can reasonably be expected to understand.
- 23. To be involved in resolving ethical issues or conflicts about care or service.
- 24. To be notified within 10 days when the agency's license has been revoked, suspended, canceled, annulled, withdrawn, recalled, or amended.



- 25. To be advised of the opportunity to request a copy of the agency's policies regarding patient rights or responsibilities.
- 26. To 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 Four Seasons, and not be subjected to discrimination or reprisal for doing so.
- 27. To receive care without regard to race, color, national origin, religion, disability, gender, sexual orientation, age, type of illness, source of payment or ability to pay.
- 28. To be advised of the address and telephone number for information, questions, or complaints about services provided by the agency:

Melody King,Compliance Manager	OR	Millicent Burke-Sinclair, President/CEO
Four Seasons		Four Seasons
571 South Allen Road		571 South Allen Road
Flat Rock, NC 28731		Flat Rock, NC 28731
8:30am – 4:00pm EST (Weekdays); Closed Holidays		

828-692-6178; 866-466-9734 (Toll Free)

NC TTY/TDD: 919-874-2212

29. To be advised of the address and telephone number of the section of the Department of Health and Human Services responsible for the enforcement of the provisions of this part and the Division of Health Service complaints hotline number or the Department of Health and Human Services Careline number as well as the Joint Commission.

Acute Care, Home Care and CLIA Branch Licensure and Certification Section Division of Health Service Regulation 2712 Mail Service Center Raleigh, NC 27699 919-855-4620 Phone; 919-715-3073 FAX

Complaint Intake Unit NC Division of Health Service Regulation 2711 Mail Service Center Raleigh, NC 27699 1-800-624-3004 (within NC) or 919-855-4500

Office for Civil Rights 61 Forsyth Street SW, Suite 3B70 Atlanta, GA 30323 404-562-7886 Phone; 404-331-2867 TDD Joint Commission 8:30am – 5:00pm CST 1-800-994-6610 Or online: complaint@joingcommission.org

- 30. To be provided a copy of the declaration of Patient Rights and Responsibilities in advance of care being furnished.
- 31. To be free from mistreatment, exploitation, neglect, or verbal, mental, sexual, and/or physical abuse, including injuries of unknown source and misappropriation of patient property.
- 32. To expect that the agency shall investigate, within 72 hours, complaints made to the agency by a client or the client's family.
- 33. To know that my family or guardian may exercise my patient rights if I have been judged incompetent by a court of law.

Specific to Elizabeth House:

- 34. To unlimited contact with visitors and others in keeping with the security, privacy, and rights of others in the facility
- 35. To keep and use personal clothing and possessions.
- 36. To privacy and security of myself and my possessions.

I have the responsibility:

- 1. To notify Four Seasons of changes in my address, health status, medications, physician, or admission to a health care facility.
- 2. To notify Four Seasons of my inability to keep a scheduled appointment.
- 3. To notify Four Seasons when I feel my rights are not being respected.
- 4. To sign a release when refusing medications, treatments, the recommended plan of care, or when refusing home care services.
- 5. To notify Four Seasons if I have any changes in my health insurance benefits, such as considering a Medicare Advantage plan, HMO, etc.
- 6. To cooperate with my physician and Four Seasons in my treatment program.
- 7. To provide a safe home environment in which care can be given.
- 8. To provide Four Seasons with a current copy of my Advance Directives.
- 9. To express any concerns regarding the course of treatment or my ability to comply with instructions.

Grievance Procedures

Four Seasons is committed to respond to all complaints. We encourage you to speak to us regarding any problem affecting your care.

If you have a complaint about the care provided, we urge you to take the following steps:

- Talk over the problem with your nurse case manager and social worker. Most problems will be resolved this way.
- If you have further concerns or are unable to have that discussion, call the Four Seasons office at 866-466-9734 and request to speak with the clinical leader for your team
- If the problem occurs during the weekend, holiday or in the evening, request the administrator on-call when calling the Four Seasons after hours number at 828-692-9633
- After taking the above steps, if you feel that your complaint has still not been addressed to your satisfaction, call the Chief Executive Officer at 828-692-6178 or toll free at 866-466-9734, NC TTY/TDD: 919-874-2212
- If you are not satisfied with the result of the steps taken above, you the have the right to refer the problem to:

Complaint Intake Unit Division of Health Service Regulation 2711 Mail Service Center Raleigh, NC 27699 Or call the toll free hotline: 800-624-3004

Corporate Compliance Plan

Standards of Conduct

In an effort to conduct business according to the highest ethical standards and in compliance with Federal and State laws and regulations, Four Seasons maintains a corporate compliance program. The compliance program is designed to identify and prevent potential areas of fraud, waste or abuse and correct any instances of non-compliance. Four Seasons will not tolerate fraud, waste or abuse in conducting our business or in delivering services to our patients and families. Everyone has the responsibility to act in a manner which upholds the laws, to actively participate in and promote compliance as an employee or volunteer of Four Seasons Compassion for Life, and to report any activity they become aware of that violates any law or regulation.

Anyone can report concerns regarding a lack of compliance to the Compliance Manager in person, by writing, via voicemail, e-mail or by calling the Compliance Hotline voicemail box.

How to Contact the Compliance Manager?

Four Seasons Compassion for Life Compliance Hotline voicemail box is in place for use by staff, independent contractors, patients and families seven (7) days a week, 24 hours a day. Individuals can leave a confidential message for the Compliance Manager if they become aware of an alleged wrong doing or if they have any concerns regarding unethical or illegal conduct at, by or involving Four Seasons Compassion for Life. Individuals will be asked to leave their name so they can be contacted for follow-up if necessary. However, anonymous messages will also be accepted.

Melody King Compliance Manager Four Seasons Compassion for Life 571 South Allen Road Flat Rock, NC 28731 Phone: 828-692-6178 Email: mking@fourseasonscfl.org Compliance Hotline: 828-233-0399

Notice of Privacy Practices

This notice describes how medical information about you may be used and disclosed and how you can get acess to this information. Please review it carefully.

I. OUR LEGAL DUTY

Four Seasons is required by law to maintain the privacy of your health information. We are also required to provide you or your representative with this notice about our privacy practice, our legal duties and your rights concerning your health information. We must abide by the terms of this notice while it is in effect. We reserve the right to change the terms of this notice and to make the new notice provisions effective for all health information that we maintain. If we change this notice, we will make a copy of the revised notice available to you or your appointed representative at our website, www.FourSeasonsCFL.org

II. USES AND DISCLOSURES OF HEALTH INFORMATION

Four Seasons may use or disclose your health information for purposes of treating you, obtaining payment for your care and conducting health care operations. Four Seasons has established policies to guard against unnecessary uses or disclosures of your health information.

- A. <u>To Provide Treatment</u>: Four Seasons may use your health information to coordinate care within Four Seasons and with others involved in your care, such as your attending physician, members of the Four Seasons interdisciplinary team and other health care professionals who have agreed to assist Four Seasons in coordinating your care. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications. Four Seasons may also disclose your health care information to individuals outside of Four Seasons who are involved in your care including family members, clergy whom you have designated, pharmacists, suppliers of medical equipment or other health care professionals that Four Seasons works with order to coordinate your care.
- B. <u>To Obtain Payment</u>: Four Seasons may disclose your health information to collect payment from third parties for the care you may receive from Four Seasons. For example, Four Seasons may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or Four Seasons. Four Seasons may also need to obtain prior approval from your insurer and may need to explain to the insurer your need for care and the services that will be provided to you.
- C. <u>To Conduct Health Care Operations</u>: Four Seasons may use and disclose health care information for its own operations in order to facilitate the function of Four Seasons and, as necessary, to provide quality care to all Four Seasons' patients. Health care operations include, without limitation, such activities as:
 - Quality assessment and improvement activities (e.g., combining your health information with other Four Seasons' patients to evaluate ways to improve

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services);

- Activities designed to improve health or reduce health care costs;
- Protocol development, case management and care coordination;
- Contacting health care providers and patients with information about treatment alternatives and other related functions that do not include treatment;
- Professional review and performance evaluation (e.g., to evaluate staff performance);
- Training programs including those in which students, trainees or practitioners in health care learn under supervision;
- Training of non-health care professionals;
- Accreditation, certification, licensing or credentialing activities;
- Review and auditing, including compliance reviews, medical reviews, legal services and compliance programs;
- Business planning and development including cost management and planningrelated analyses and formulary development; and
- Business management and general administrative activities of Four Seasons.
- D. <u>Inpatient Facilities</u>: If you are a patient of a Four Seasons inpatient facility, Four Seasons may include certain information about you in a directory, including your name, your general health status, your religious affiliation and where you are in the Four Seasons facility. Four Seasons may only disclose this information to people who ask for you by name. Please inform us if you do not want your information to be included in the directory.
- E. <u>For Fundraising Activities</u>: Four Seasons may use information about you to contact you or your family to raise money for Four Seasons. Four Seasons will only use the following information for fundraising purposes: your name, address, phone number, age, gender, and date of birth; the dates you received care at Four Seasons; the department providing your care; the name(s) of your treating physician(s); information related to the outcome of your care; and your health insurance status. Four Seasons may also release this information to a related Four Seasons foundation for fundraising purposes. You have the right to opt out of receiving fundraising communications. If you do not want Four Seasons to contact you or your family, call us at 866-466-9734 and indicate that you do not wish to be contacted.
- F. <u>Family, Friends and Others Involved in Your Care or Payment</u>: Unless you object, we may disclose your health information to a family member, friend or any other person you involve in your care or payment for your health care. We will disclose only the information that is relevant to the person's involvement in your care or payment.
- G. <u>Business Associates</u>: Four Seasons may disclose your health information to its business associates that perform functions on its behalf or provide it with services if the information is necessary for such functions or services. Four Seasons' business associates are required, under contract with Four Seasons, to protect the privacy of

your information and are not allowed to use or disclose any information other than as specified in its contract with Four Seasons.

III. OTHER USES AND DISCLOSURES ALLOWED UNDER FEDERAL PRIVACY RULES WITHOUT PATIENT CONSENT OR AUTHORIZATION

- A. <u>When Legally Required</u>: Four Seasons will disclose your health information when it is required to do so by any Federal, State or local law.
- B. <u>For Public Health Activities</u>: Four Seasons may disclose your health information when authorized by law to do so for public activities and purposes, such as 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.
 - To 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.
 - To notify a person who has been exposed to a communicable disease or who may be at risk of contracting or spreading a disease.
 - To an employer about an individual who is a member of the workforce as legally required.
- C. <u>To Report Abuse, Neglect or Domestic Violence</u>: Four Seasons may disclose your health information to government authorities if we believe you are the victim of abuse, neglect or domestic violence. Four Seasons will make this disclosure only when specifically required or authorized by law or when the patient agrees to the disclosure.

<u>To Conduct Health Oversight Activities</u>: Four Seasons may disclose your health information to a health oversight agency for activities including audits, civil administrative or criminal investigations, inspections, licensure or disciplinary action. Four Seasons may not, however, disclose your health information if you are the subject of an investigation and your health information is not directly related to your receipt of health care or public benefits. Four Seasons may disclose your health information to the North Carolina Department of Health Service Regulation to validate Four Seasons' compliance with North Carolina law. You have the right to object to a disclosure of your health information to the North Carolina Department of Health Service Regulation for this purpose. Such objections shall be made in writing on your Consent for Hospice Care upon admission or to the Four Seasons Privacy Officer at the address listed in Section VI below.

D. In Connection With Judicial and Administrative Proceedings: Four Seasons may disclose your health information in the course of any judicial or administrative proceeding in response to an order of a court or administrative tribunal as expressly authorized by such order or, in response to a subpoena, discovery request or



other lawful process, but only when Four Seasons makes reasonable efforts to either notify you about the request or to obtain an order protecting your health information.

- E. <u>For Law Enforcement Purposes</u>: Four Seasons may disclose your health information to a law enforcement official for law enforcement purposes as follows:
 - As required by law for reporting certain types of wounds or other physical injuries pursuant to the court order, warrant, subpoena or summons, or similar process;
 - For the purpose of identifying or locating a suspect, fugitive, material witness or missing person;
 - Under certain limited circumstances, when you are the victim of a crime;
 - To a law enforcement official if Four Seasons has a suspicion that your death was the result of criminal conduct including criminal conduct at Four Seasons; or
 - In an emergency in order to report a crime.
- F. <u>To Coroners and Medical Examiners</u>: Four Seasons 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.
- G. <u>To Funeral Directors</u>: Four Seasons may disclose your health information to funeral directors consistent with applicable law and, if necessary, to carry out their duties with respect to your funeral arrangements. If necessary to carry out their duties, Four Seasons may disclose your health information prior to and in reasonable anticipation of your death.
- H. <u>For Organ, Eye or Tissue Donation</u>: Four Seasons 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.
- I. <u>For Research Purposes</u>: Four Seasons may, under very select circumstances, use your health information for research. Before Four Seasons discloses any of your health information for such research purposes, the project will be subject to an extensive approval process. Four Seasons will ask your permission before any researcher will be granted access to your individually identifiable health information.
- J. <u>In the Event of a Serious Threat to Health or Safety</u>: Four Seasons may, consistent with applicable law and ethical standards of conduct, disclose your health information if Four Seasons, 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.
- K. <u>For Specified Government Functions</u>: In certain circumstances, the Federal regulations authorize Four Seasons to use or disclose your health information

to facilitate specified government functions relating to military personnel and veterans, national security and intelligence activities, protective services for the President and others, medical suitability determinations, and inmates and law enforcement custody.

L. <u>For Worker's Compensation</u>: Four Seasons may release your health information for Worker's Compensation or similar programs.

IV. AUTHORIZATION TO USE OR DISCLOSE HEALTH INFORMATION

Other than as stated above, Four Seasons will not disclose your health information without your written authorization. If you or your representative authorizes Four Seasons to use or disclose your health information, you may revoke that authorization in writing at any time, except to the extent that Four Seasons has already acted upon your authorization. Four Seasons will obtain your authorization prior to: (a) disclosing your Psychotherapy Notes, if applicable; (b) using your health information for most marketing communications, except face-to-face communications, whenever Four Seasons is paid by a third party for making such communications; or (c) disclosing your health information in a manner which constitutes the sale of such information under the Health Information Portability and Accountability Act of 1996 (HIPAA) and its implementing regulations.

V. YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION

You have the following rights regarding your health information maintained by Four Seasons:

- A. <u>Right to Request Restrictions</u>: You have the right to request restrictions on certain uses and disclosures of your health information. For example, you may request a limit on Four Seasons' 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 Four Seasons form. Except in limited circumstances, Four Seasons is not required to agree to your request. Except as otherwise required by law, Four Seasons must agree to a restriction request if: (i) the disclosure is to a health plan for purposes of carrying out payment or health information pertains solely to a health care item or service for which you, or another person other than the health plan on your behalf, has paid Four Seasons in full. This restriction will apply only to those health care records created on the date that you received the item or service for which you, or another plan on your behalf, paid Four Seasons in full, and which document the item or service provided by Four Seasons in full. and which document the item or service provided by Four Seasons on such date.
- B. <u>Right to Request Confidential Communications</u>: You have the right to request that Four Seasons communicate with you in a certain way. For example, you may ask that Four Seasons only conduct communications pertaining to your health information with you privately and with no other family members present. All
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requests for confidential communications must be made in writing using the appropriate Four Seasons form. Four Seasons will not request that you provide any reason(s) for your request and will attempt to honor your reasonable requests for confidential communications.

- C. <u>Right to Inspect and Copy Your Health Information</u>: You have the right to inspect and copy your health information, including billing records. All requests to inspect and copy health information must be made in writing using the appropriate Four Seasons form. If you request a copy of your health information, Four Seasons may charge a reasonable fee for copying and assembling costs associated with your request. In limited circumstances, Four Seasons may deny your request to inspect and copy your health information; however, you may request a review of the denial by a licensed health care professional who Four Seasons has designated as a reviewing official and who did not participate in the original decision to deny the request.
- D. <u>Right to Request Amendment of Your Health Information</u>: If you believe that your health information records are incorrect or incomplete, you have the right to request that Four Seasons amend the records. That request may be made as long as the information is maintained by Four Seasons. A request for an amendment of records must be made in writing using the appropriate Four Seasons form, and must contain a reason to support the requested amendment. The request may be denied if your health information records were not created by Four Seasons, if the records you are requesting are not part of Four Seasons' 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 Four Seasons, the records containing your health information are accurate and complete.
- E. <u>Right to Request an Accounting of Disclosures</u>: You have the right to request an accounting of disclosures of your health information made by Four Seasons for any reason other than for treatment, payment or health operations. The request for an accounting must be made in writing on the appropriate Four Seasons form. The request should specify the time period for the accounting starting on April 14, 2003. Accounting requests may not be made for periods of time in excess of six years. Four Seasons 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.
- F. <u>Right to a Paper Copy of this Notice</u>: You have the right to a separate paper copy of this notice at any time even if you have received this notice previously. A copy of the current version of the Four Seasons Notice of Privacy Practices is also available at our website, www.FourSeasonsCFL.org
- G. <u>Right to Receive Breach Notification</u>: You have the right to receive notice of a breach of your unsecured health information. This notification may be delayed or

not provided if so required by a law enforcement official. You may request that this notice be provided by electronic mail. 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 we know the identify and address of such individual(s).

VI. QUESTIONS OR COMPLAINTS

For all issues or questions regarding patient privacy and your rights under the Federal Privacy Standards, including requests for or complaints about your rights, you may contact:

Privacy Officer		Millicent Burke-Sinclair, President/CEO
Four Seasons		Four Seasons
571 South Allen Road	OR	571 South Allen Road
Flat Rock, NC 28731		Flat Rock, NC 28731
828-692-6178		828-692-6178

You, or your representative, have the right to express complaints to the Privacy Officer or President/CEO of Four Seasons and to the Secretary of Health and Human Services if you, or your representative, believe that your privacy rights have been violated. Any complaints to Four Seasons should be made in writing to the Privacy Officer or President/CEO. We encourage you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

If complaints regarding your privacy rights are not resolved satisfactorily, you may notify:

Secretary of Health and Human Services 200 Independence Ave. SW Washington DC 20201 877-696-6775 (Toll Free)

VII. EFFECTIVE DATE

This notice is effective 9/23/2013.







Four Seasons operates a nonprofit, community-based, Medicare-certified hospice program.

Questions and Answers

How do I pay for services?

Four Seasons' services are covered through Medicare, Medicaid, and many private insurance plans. Thanks to the generosity of our donors, we're able to provide services to all patients who need them. Additionally, proceeds from the Hospice Home Store help fund our programs.

What is the Hospice Medicare/Medicaid Benefit (HMB)?

Our hospice is certified as a Medicare/Medicaid provider. Patients who meet the admission criteria and are Medicare/Medicaid eligible can elect this benefit. In addition to the services already mentioned the Hospice Medicare Benefit provides medications, medical equipment and supplies, inpatient hospice care, hospitalization pre-approved by hospice team and respite care relating to the life-limiting illness are also available.

The Hospice Medicaid Benefit provides a special program for persons needing hospice care. This program covers services, medications, supplies, and equipment needed for the comfort of patients. The services and items provided must be needed to treat the serious illness.

What is pre-authorization?

All services, medications, supplies, or equipment related to serious illness for which hospice has been ordered must be pre-authorized by Four Seasons Compassion for Life. Medicare pays Four Seasons directly at specified daily rates for care provided. Therefore, Four Seasons Compassion for Life delivers care based on the plan of care and is not responsible for care obtained for the patient outside of this plan of care. Remember that these restrictions apply only to the seriously ill diagnosis for which you or your loved one was admitted to hospice. Unrelated medical problems may be treated in your usual manner with your insurance coverage.

Who is eligible for this benefit?

- The patient who has Medicare Part A or full Medicaid coverage
- The patient whose doctor has confirmed the serious illness
- The patient who chooses to focus on symptom management rather than curative care
- The patient who signs a statement choosing hospice care benefits
- The patient who receives care from a Medicare-approved hospice
- The patient who has months rather than years to live

How long is someone eligible for hospice services?

A patient can have hospice care as long as the physician and hospice team determine the patient continues to meet medical requirements and the patient continues to choose comfort care. The hospice team can make referrals to other agencies if a patient is no longer eligible for hospice services.

If a patient is discharged from hospice either for medical reasons or by patient choice, they can be readmitted to hospice care any time the patient meets admission requirements.



What is a benefit period?

The Medicare Hospice Benefit consists of two 90-day benefit periods followed by an indefinite number of 60-day periods. At the end of each period, the team must agree that the patient is seriously ill. If the patient is improving or the illness has stabilized, the hospice team will discuss alternatives to hospice care with the patient and family.

What if I stop hospice care before a period is over?

Medicare allows the patient to discontinue the Medicare Hospice Benefit. The days left in that period are lost. The next time the patient enters the Medicare Hospice Benefit, they will enter the next period.

How does the Medicare Hospice Benefit cover hospitalization?

If a patient has symptoms that are proving difficult to manage at home, a few days in a hospital or inpatient hospice unit may be necessary. The need for this must be assessed by a hospice nurse. The types of problems that may warrant a trip to the hospital or inpatient hospice unit like Elizabeth House are increased pain, acute nausea, vomiting, or shortness of breath. If such a trip out of the home is needed, the hospice team members will help you arrange transportation. The Medicare Hospice Benefit requires the pre-authorization of any hospital stay related to the serious illness, including the emergency room. Remember, call hospice day or night!

How can the caregiver get a break?

Short breaks of an hour or two can be arranged with the help of a volunteer. If a longer break is necessary, a period of up to five days will be arranged by the nurse or social worker at a contracted facility or inpatient hospice unit like Elizabeth House. This "break" is referred to as respite. Consider respite care if there is a family emergency, a need for the caregiver to go away, or as a needed break from caregiving.

How does the patient pay for hospice care?

Medicare pays hospice directly for each day hospice is responsible for care. During hospice care, you should not receive a bill for services covered by Medicare. If any questions come up regarding billing, ask your nurse or social worker for help.

How is my doctor paid?

Medicare Part B will continue to cover the cost of your attending physician's visits. Any labs or procedures you have in your attending physician's office that are related to your terminal illness must be preapproved and will be paid for by hospice.

Medicaid

Does Medicaid cover hospice services?

Yes, the Medicaid Hospice Benefit provides the same coverage as Medicare. Your Medicaid card will be used to confirm your eligibility for this benefit. Medicaid asks that we verify eligibility every month as well.

Private Insurance

What hospice benefits are available through my private insurance?

Many, if not most, private insurance carriers have hospice coverage within their program. We will obtain your insurance information from you and contact the insurance company regarding the coverage. Contact your hospice team if you have any questions regarding your insurance coverage. Please contact your primary nurse with any changes to your healthcare coverage.

Insurance Coverage

Will I have to pay a co-pay or deductible?

Four Seasons will bill you for any amount applied toward your personal deductible and/or co-pay after the partial payment has been received from your insurance company.

If a person has no form of insurance, will hospice and palliative care be available?

It is Our Mission to provide comfort care to those who are seriously ill regardless of their ability to pay. Thanks to the generosity of our donors, we're able to provide services to all patients who need them. Additionally, proceeds from the Hospice Home Store help fund our programs provided to patients and families without insurance. Contact our billing department if you need to discuss payment options or have concerns related to your insurance coverage.

Patient/family guidelines for the hospice benefit:

The hospice benefit provides coverage for palliative, comfort-oriented care and services. A hospice benefit is provided by Medicare, Medicaid, and some private insurances. The hospice nurse can determine if you are eligible for one of the benefits. The following services are covered by a hospice benefit when pre-authorized by the hospice team:

Home care visits

All home care visits/services provided by the Four Seasons Care Team as well as preauthorized services provided by your attending physician are fully covered under the benefit. Physical, occupational and speech therapies are provided as based on the patient's plan of care.

Physician Services

Visits to consulting physicians pre-approved by the hospice team are covered when related to the terminal illness. Attending physician services are covered under Part B if the physician is not employed by hospice.

Medications

Pre-authorized medications that are related to the diagnoses for which hospice care is being rendered to you are fully covered. A list will be provided to you. Medications covered under this benefit must be obtained from a pharmacy designated by hospice.



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Prescriptions will be filled with generic equivalents based on Four Seasons Formulary and approved substitutions.

Supplies

Supplies that are pre-authorized by the hospice nurse and are related to the serious illness for which hospice is needed are fully covered. Supplies must be ordered by the hospice nurse and obtained from a hospice contracted supplier.

Hospitalization

Although most pain and symptom management problems can be managed at home, occasionally a short hospitalization may be necessary to control symptoms. Hospitalization must be facilitated by the hospice nurse with your physician's approval and provided in a contracted hospital or at an inpatient hospice unit like Elizabeth House. The hospice nurse will provide you with specific information and directions if hospitalization is needed.

Respite

Respite care can be provided for the caregiver by admitting the patient into an inpatient facility like Elizabeth House or a nursing home or where Four Seasons Compassion for Life has a contract. Respite care is usually provided for up to five days.

Benefit periods

There are two (2) ninety day benefit periods followed by an indefinite number of sixty day periods. Recertification by the primary care physician is required at the beginning of each new benefit period which may require a face to face evaluation by a Four Seasons hospice physician or nurse practitioner.

Pre-authorization

All health care services must be pre-authorized by Four Seasons Compassion for Life to be covered under the hospice benefit. If you elect to receive medical or hospital services which are not directly provided or authorized by the Four Seasons, you may either self pay for that service or revoke the hospice benefit. Re-election of the hospice benefit is available.

* The most important thing to remember to ensure coverage under the hospice benefit is to contact your hospice nurse to assist you with questions and/or concerns.





Necessary Duties, Tasks and Checklists

In the midst of emotional upheaval brought on by the prolonged illness and death of a loved one, the surviving family members confront the additional burden of the complex of legal, financial, and social tasks incident to the death. This information offers some suggestions for getting through this difficult period and a checklist of tasks.

- Your life has changed fundamentally, and you are under the severe emotional strain
 of grief and loss. The advice heard most often from those who have passed down this
 road ahead of you: "Avoid any drastic decisions, changes or moves for at least a year.
 Deal with each day's needs one at a time. Be patient with yourself. Give yourself time to
 heal and to find out what you need and want for the future."
- The immediate need for every survivor is an adequate and accessible source of funds. Check with your bank to see how the death of your loved one has affected any joint accounts. Depending upon how these accounts have been set up, you may be able to withdraw 50%-100% of the funds before the estate is settled. The survivor's individually held accounts are not affected.
- You must decide which tasks to undertake yourself and which to leave to the
 professionals. This can be difficult. There are healing benefits in taking up immediately
 the day-to-day duties of the independent life, which lies before you. At the same time,
 it is easy to get beyond one's depth in legal and financial complexities. When in doubt,
 turn to your attorney, banker, or tax advisor. If your circumstances are not complicated,
 ask your lawyer to guide you and do as much as you can yourself.
- Unscrupulous people read obituary notices and prey on grieving families. Be wary of anyone offering attractive deals, or claiming the deceased promised or owed him/ her money. Before you sign anything, accept delivery on anything, or give money to anyone, consult your lawyer, your minister, your hospice volunteer, or a knowledgeable and trusted friend.

Top Priority Tasks Checklist

Since survivor needs differ, we suggest you place a check mark in the circle to the left of those items that do apply in your case, decide who is going to do each task and put that person's initial after that item. Enter a completion date as each task is completed.

- O If some family member has not kept a list of people who have sent food, flowers, memorials or showed some other kindness, try to compile such a list from memory as soon as possible.
- O Dispose of any unused drugs prescribed for the deceased. Ask a member of Your Care Team for information on how to dispose this medication properly.
- O Begin the process of probating the will. (See Legal Tasks below.)
- O Obtain death certificates from the funeral home and/or the Register of Deeds at the County Courthouse where the deceased person lived. You will need one for every piece of property, bank account, insurance policy, certificate of deposit (CD), individual retirement account (IRA), or other asset owned by the deceased. There is normally a per copy charge. Most families need about 6-10 copies.

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- O For each life insurance policy, notify the local agent of the death, and ask what procedure you need to follow. Also request a copy of Federal Form 712, which you will need later for tax purposes.
- O If the deceased was retired and receiving a pension from the federal or state government, or from a private corporation, the payer(s) of the pension(s) should be informed of the death promptly. Ask about survivors' benefits and the continuation of health coverage. Return any pensions checks payable to the deceased.

Legal Tasks

The following information is provided to acquaint families with the process and some of the terminology involved in settling an estate. Call the office of the Clerk of the Superior Court, Estate Division, in the county where the deceased person lived.

Definitions

Will: A document that specifies how one wishes his or her possessions to be disposed of after death.

Intestate: "Without a will." If there is no will, the estate is divided among the family members according to the provisions of the North Carolina law of intestate succession.

Administrator of the Estate: The one handling the estate of a person who dies intestate.

Administrator of the Estate:__

Executor of the Will: The person designated in the will to be responsible for the estate. If you are the person so designated, you will need to pay a fee, be sworn in by the Clerk of the Court, and in some cases, post a bond. You will receive testament letters empowering you to handle the affairs of the estate.

Executor of the Will: _____

Duties of the Executor

- 1. Establish a checking account for the estate. (A customer service representative at your bank will help you.)
- 2. Make inventories of the estate to be submitted to the Estate Auditor in the office of the Clerk of Court.
- 3. Publish a classified newspaper notice of the death to notify creditors. The Clerk of Court can provide information about how often and for how long this notice must run. The newspaper will provide a statement that the ad has been run. This must accompany the 90-day inventory submitted to the Estate Auditor.
- 4. Pay creditors.

Tax Tasks Checklist

O State and federal income tax returns for the deceased must be filed at the usual time, and real estate belonging to the deceased must be listed for both county and city taxes, A state inheritance tax and a federal estate tax may be due. Consult your attorney or tax preparer.

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O Keep receipts of all bills or medical and funeral expenses and for grave markers, in addition to the usual record of deductible expenses and contributions. Establish a record of any outstanding accounts (money owed to the deceased) on the date of death.

Deeds and Titles Tasks Checklist

Jointly owned real estate in North Carolina automatically goes to the spouse, regardless of the will, provided (1) the property was acquired during marriage and (2) both names appear on the deed.

- O If the deceased's name is listed on the mortgage to your home, notify the company holding the mortgage. Inquire if the deceased had mortgage insurance, and ask what procedure to follow.
- O Titles on vehicles owned by the deceased must be transferred to the new owner, and any remaining indebtedness settled. A copy of the letter testamentary or letter of administration, and the vehicle registration are needed for a transfer of title. There is a fee for this service. Contact the local license plate agency for more information.
- O The auto insurance company must be notified of a change in the title.

Financial Tasks Checklist

Bank Related

O A safe-deposit box held jointly or solely by the deceased can be opened only in the presence of a representative of the clerk of court, who will make an inventory of the contents.

Insurance Related

O Phone or write each company with which the deceased had a health insurance policy. Ask the agent what changes need to be made to continue coverage of you. Ask if there is any premium refund due to you. Be sure to complete all necessary forms within one year of the death.

Survivor's Benefits

- O If the deceased had been employed, ask the employer's personnel department to inform you of any benefits due to you. Ask about group life insurance, unused vacation credits, CDs, stocks, and IRAs that the deceased might have had with the firm.
- O Most families are eligible for survivor's benefits from Social Security. If you think you may be eligible, call the local Social Security office. In some cases, the benefits begin from the date of death. Act promptly, and mail all applications "Registered Mail-Return Receipt Requested." Return, and do not cash, any Social Security checks bearing the name of the deceased even if you are a copayee.
- O Many families are also eligible for survivor's benefits from the Veterans Administration. Contact the local VA office or the regional office in Winston-Salem. The VA will also provide a cemetery marker and flag for a deceased veteran at no charge.



Personal Tasks Checklist

- O Review your will and make any necessary changes.
- O Review your own life insurance policies and make any necessary changes in beneficiaries and coverage.
- O Credit cards: Return the deceased's card with your next bill, cut in half, and request that his/her name be removed from the account.
- O Auto insurance. Cancel policies in the name of the deceased. If you have sold the vehicle, ask for a prorated refund of premium. If you plan to use the car, ask for a new policy in your name.
- O Cancel unwanted memberships and request a prorated refund of dues.
- O If you feel that your family's pledge is too large for you to pay in your new circumstances, discuss this with your minister or church treasurer.

What Do I Do Now?

Personal Information and Records Checklist

		Location	
🗌 Living Will			
Durable Power of	Attorney for Health Care		
🗌 General Durable P	C A (A (()		
Attorney			
·			
	Phone:		
🗆 Will			

If you do not have a will, your first priority is to prepare one. If you do have a will, it is a good idea to review it at this time.

Insurance Policies and Policy Numbers

□ Life insurance (group and/o	r individual)	
Health insurance		
Home insurance		
Auto insurance		
Disability insurance		
Renter's insurance		
Insurance Agent/Broker	Name:	
	Address:	
	Phone:	
Real Estate Deeds		
Location of property		
☐ Title's in name of		

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		Location
□ Mortgages/records/paymer	nt information	
Stocks/bonds/certificates of	f deposit	
🗌 Brokerage firm/broker	Name:	
	Address:	
	Phone:	
Savings account	Name:	
	Account #:	
Checking account	Name:	
	Account #:	
Safe Deposit Box		
\Box Location of box and key		
□ Name box is under		
City/State/Federal tax		
Returns for the past sever	ral years	
🗌 Birth Certificate		
Social Security Card		
☐ Marriage/Divorce Certificat	es	
Automobile Titles <i>When you are no longer ab</i>	le to drive, transfer	of title and change in primary insured is recommended.
☐ Military Discharge Papers		
Contracts (e.g., installment purc	hase agreements)	
Business Records		
🗌 Receipts for furs, jewelry, e	tc.	
🗌 Credit Cards		

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Notes	



Veterans' Death Benefits

All Veterans honorably discharged from the military are entitled to certain death benefits. Burial is a sensitive subject; however, Veterans and their families should be aware of the burial benefits before they are needed. Family should prepare in advance by discussing cemetery options, collecting the Veteran's military information, and most importantly the proof of military service (DD 214), and discussing preferences.

Burial Benefits

Any Veteran, except those dishonorably discharged, are eligible for burial in a Department of Veterans Affairs National Cemetery.

- Veterans are entitled to burial in a Veteran's cemetery where space is available. (It is important to discuss preferences with the Veteran, so their wishes can be honored.)
- Veterans may be entitled to a one-time death benefit that goes toward the cost of burial. The VA will pay up to \$300 toward burial and funeral expenses, and a \$300 plot-interment allowance.
- A government head stone or marker will be issued for burial in a Veteran's or private cemetery
- Veterans may select "burial at sea," through the US Navy Mortuary Affairs
- The VA provides an American flag for services to be given to the next of kin or close associate, at no cost, to drape the casket or accompany the urn of the Veteran. If an extra flag is needed, some service groups such as the VFW may provide one.
- A Presidential Memorial Certificate honoring the Veteran's service (signed by the current President) is provided to the family

Burial with Military Honors

The rendering of Military Funeral Honors for a Veteran is free of charge and mandated by law. The honor detail will perform a ceremony which includes folding and presenting of the flag to the next of kin and the playing of Taps.

The funeral director will contact the appropriate Military Service to arrange for a funeral honors detail.

Spouses of Veterans

- Can be buried next to the Veteran
- Dependents may also be eligible

How do I access the Benefits?

- American Flag (VA form 40-1330) http://www.cem.va.gov/bbene/bflags.asp (A flag may be obtained at any VA Regional Office or US Post Office, generally the funeral director will help or call 1-800-827-1000)
- Veterans Cemetery locations http://www.cem.va.gov/cems_nmc.asp and to schedule a burial http://www.cem.va.gov/bbene/need.asp
- Monetary death allowance (VA form 21-530) http://www.cem.va.gov/bbene/benvba.asp

- Government Headstone or marker (VA form 40-1330) http://www.cem.va.gov/hm_ hm.asp
- Burial at sea information http://www.npc.navy.mil/CommandSupport/ CasualtyAssistance/MortuaryServices/Burial+At+Sea.htm or call 1-866-787-0081
- Presidential Memorial Certificate (VA form 40-0247) http://www.cem.va.gov/pmc.asp or call 1-866-787-0081
- Military honors funeral http://www.militaryfuneralhonors.osd.mil/intro.html
- Spouse burial information http://www.vba.va.gov/bln/dependents/spouse.html
- DD 214 (proof of military service) should be kept with all of the Veteran's important papers. Copies may be obtained at http://www.archives.gov/veterans/military-servicerecords

VA forms listed above can be found at http://www.va.gov/vaforms

For VA benefits information and assistance, call 1-800-827-1000.

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Funeral Planning Form

Pre-planning funerals provides an opportunity for all involved parties to state their needs and ideas at a less stressful time. Most funeral home directors welcome the opportunity to answer questions. Contact the funeral home of your choice to arrange a meeting. The funeral home director can also assist with an "Irrevocable Burial Contract." This is a pre-planned and prepaid funeral. This will bring peace of mind and may also secure the price. Also, the purchase of an "Irrevocable Burial Contract" is considered a legitimate way to spend down liquid assets if qualifying for Medicaid.

Speak with the hospice social worker or spiritual care coordinator if you need assistance with funeral planning.

If you have made funeral arrangements or wish to use the services of a specific funeral director, record that information here:

Funeral home:		
Funeral director:		
Address:		
Telephone:		
Cemetery:	Plot:	
Specific instructions:		

If a family member is flying into town during your illness and/or plans to attend the funeral service, notify the airline of the reason for the flight when making the reservation. Most airlines will issue the ticket at a reduced rate.

Obituary Planning Form

Supporting our families in many stages of dealing with a serious illness is a vital part of our mission. One of the many ways we are able to do this is to offer assistance in planning for the time ahead.

Having accurate memorial information available for newspapers and the funeral director is an important task, most of this can be done in advance. Four Seasons staff members are willing to help you in any way possible. This is best done prior to the death of your loved one, when there is time to think and talk, and gather complete information. The completed form can then be forwarded to the funeral director who is responsible for placing obituary notices and making other arrangements.

Patient Information:

Name:		
Address:		
Birthplace:		
Came to area from:	When:	
Occupation:		
Major/Area employer:	# of years:	
Church/Religious affiliation:		
Organizations/Offices:		
Major achievements/honors:		
Military service/recognition:		



Probate

Probate is required whenever a person dies owning assets in his or her name, regardless of whether the decedent had a valid will. After a person dies, probate is the legal process of administering the estate (i.e. the possessions and liabilities) of the deceased person, who is referred to as the "decedent." The person who administers the estate is called the "executor" or "personal representative." In North Carolina, the probate process is overseen by the Clerk of Superior Court. Sometimes probate is also referred to as "estate administration."

The probate process starts when a family member or personal representative of the decedent files the decedent's will and other forms and documents with the Clerk of Superior Court in the county of the decedent's personal residence. If the decedent did not have a will, then he or she is considered to be "intestate" and a separate form is filed requesting permission from the Clerk of Superior Court to administer the decedent's estate.

During the Probate Process

During the probate process, the personal representative is required to notify all beneficiaries of the estate, gather all of the decedent's assets, file an accounting of all of the decedent's property, settle any debts the decedent owed to creditors, and pay any taxes or administrative expenses owed by the estate. The role of the Clerk of Superior Court is to oversee the process and ensure that the personal representative properly carries out his or her duties and obligations.

Not All Assets Are Subject to Probate

Some assets are excluded from the probate process in North Carolina. Assets that are held in joint ownership with rights of survivorship, such as a marital home, will pass automatically to the survivor without being subject to probate. Any assets that are controlled by a beneficiary designation, such as some retirement accounts, 401(k)s, IRAs, life insurance policies, or annuities, are generally not subject to the probate process. Finally, if assets are held in a trust, they may not be subject to the probate process.

Concluding of the Probate Process

The probate process ends when all of the decedent's debts, taxes and administrative expenses have been paid and all of the decedent's remaining possessions have been distributed to the decedent's beneficiaries. At such time, the Clerk of Superior Court will release the personal representative from his or her duties and issue what is referred to as a "closing letter" indicating that the probate process is complete.

Additional Resources

Hospice Home Store

Your loved one's personal and household belongings are special and parting with them can be one of the hardest things to face after a death. Sorting through and deciding what to do with clothing, furniture and other items, while part of the grieving process, is often emotional and can be overwhelming. We are here, if you need help.

For your convenience and support, Four Seasons can help by picking up large furniture, appliances, boxed household items, and bagged clothing for donation to the Hospice Home Store. Donating items to the Hospice Home Store is a great way to honor the memory of your loved one and ensure that the items will continue to be valued and cared for in the future. And your donations make a difference in the lives of others as all proceeds from the Hospice Home Store are used to make care possible for other Four Seasons patients and their families.

The Hospice Home Store accepts donations during business hours at the store in downtown Hendersonville from 9:30 am to 5:00 pm, Monday through Saturday. There is a convenient drop-off gate behind the store (from Church Street). You may have only a few items or an entire house full of contents. For assistance with large item pick-up or for more information on how we can help, please call or email our Home Store Manager, Bobby Bennett:

> Hospice Home Store 215 North Main Street Hendersonville, NC 28792 (828) 696-0625 bbennett@fourseasonscfl.org www.HospiceHomeStore.org

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Four Seasons







Grief Support in Hospice Care

Grief is the natural response that we have to loss. Grieving can also be one of the hardest journeys that we go through as human beings. While no two people experience or move through grief in the same way, grief is a process that we are faced with both when we are anticipating a loss and after a loss has occurred. We are here to provide compassion and support as well as information and resources. We know that the more empowered we are with tools that support us, the more likely we are to move through the complex process of grief. The more we know about grief even prior to a loss, the better equiped we are to manage the most difficult waves associated with the grieving process.

There are as many ways to grieve as there are people in this world. Four Seasons provides support for each unique grieving journey. Our compassionate and knowledgeable Bereavement Team members are available from the start of hospice services until thirteen months after a loved ones pases, to guide families through this complex process.

Our grief support services include:

- Individual visits with patients and family members, before and after the death
- Grief education sessions
- Grief support groups
- Holiday grief support workshops
- Inspirational Celebration of Life memorial services
- Regular mailings that provide guidance in health grieving
- Support calls from the Bereavement staff and volunteers
- Printed and on-line reading materials
- Other specialized grief support events

The Mourner's Bill of Rights

by Alan D. Wolfelt, Ph.D.

- 1. You have the right to experience your own unique grief.
- 2. You have the right to talk about your grief.
- 3. You have the right to feel a multitude of emotions.
- 4. You have the right to be tolerant of your physical and emotional limits.
- 5. You have the right to experience "griefbursts."
- 6. You have the right to make use of ritual.
- 7. You have the right to embrace your spirituality.
- 8. You have the right to search for meaning.
- 9. You have the right to treasure your memories.
- 10. You have the right to move toward your grief and heal.



Heart Songs: Grief Support for Children and Teens

Since children and teens also grieve in their own ways, Four Seasons provides the Heart Songs program – a grief and support program just for children and teens. A counselor who specializes in caring for grieving children, teens and their families, coordinates the Heart Songs program.

In Heart Songs, children and teens can meet with a counselor who values them as they are, understands what they are experiencing, and provides individualized care. The Heart Songs Counselor also supports parents of grieving children and teens and provides resources to help parents and guardians care for their children.

The Heart Songs program includes:

- Individual sessions with children and teens
- Camp Heart Songs, a two-day camp for grieving children, ages 5 through 15
- Healing with Horses, an event for teens in partnership with Horse Sense of the Carolinas
- LIFT (Life in Forward Transition), a six-session support group for families with children and teens
- Printed and on-line resources
- Other specialized services for grieving children, teens and their family members
- School grief groups

The Heart Songs Counselor is available from the time of admission to hospice care and for thirteen months after the death of a family's loved one. Heart Songs services can be continued beyond the initial thirteen months if needed.

The Bill of Rights for Grieving Children and Teens

You have the right to:

- know the truth about the death, the deceased, and the circumstances
- have questions answered honestly
- be heard with dignity and respect
- be silent and not tell your grief emotions and thoughts
- not agree with others' perceptions and conclusions
- see the person who died and the place of the death
- grieve any way you want without hurting self or others
- feel all the feelings and think all the thoughts of your own unique grief
- not have to follow the "stages of grief" as outlined in a high school health book
- grieve in your own unique, individual way without censorship
- be angry at death, at the person who died, at God, at yourself, and at others
- have your own theological and philosophical beliefs about life and death
- be involved in the decisions about the rituals related to the death
- not be taken advantage of in this vulnerable mourning condition and circumstances

Children's Development Stages and Reactions to Death

Ages	Common Developmenta Characteristics	l Grief Reactions	Helpful Approaches
2 – 5 years	 Magical, fantastical thinking Active fantasy life Highly egocentric May blame self for bad things May not be able to verbalize needs and fears Reversibility of concepts; need to repeat things 	 Confusion/agitation at night; may be afraid to go to sleep Child may be able to appreciate a profound event has occurred, buy may not understand permanence of death May seem unaffected Repeated questions 	 Simple, honest words and phrases Reassurance Secure and loving environment Drawing, reading books, playing together, active play Support play as form of expression Include in the funeral plans
5 – 8 years	 Child can think concretely and logically Ability to use language increases Increased memory capacity, both long and short term Increased awareness of feelings and expectations of others Peers important 	 Want to understand death in a concrete way Denial, anger, sorrow Distress May act as though nothing happened Desire to be like peers May repeat questions May need physical activity regularly 	 Answer questions simply and honestly Look for confused thinking Offer physical outlets Reassurance about the future Drawing, reading, playing together Include in the funeral plans
8 – 12 years	 Enjoy games, and competing Begin to have increased understanding of self and relationship to world Increased propensity for language Able to reason through situations using problem solving skills 	 Shock, denial, anxiety, distress Try to cope Understand the finality of death May have morbid curiosity, or want to know specifics about death and dying May need regular physical activity Want to be like peers 	 Answer questions directly and honestly Reassurance about the future Create times to talk about feelings and questions Offer physical outlets Reading Include in the funeral plans
12 – 18 years	 Need independence Can think abstractly Puberty usually has begun by now May have false sense of immortality Peer group important May begin to have intimate relationships 	 Shock, anger, distress May become depressed or withdraw May react similarly to adult, but have fewer coping mechanisms May feel isolated, especially from peers 	 Allow and encourage expression of feelings Encourage peer support Groups may be helpful Utilize other adults Maintain consistent environment Include in the funeral plans

Bereavement

Adapted from Doughy Center Handbook



Speak with Your Care Team Members

If you are a hospice patient or family member and would like to speak with a Bereavement Team member, please let us know.

If you have children or teenagers who would benefit from support provided by the Heart Songs Program, please let a member of Your Care Team know. They will arrange for the Heart Songs Counselor to contact you and schedule a visit.

Ways To Remember





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We are honored to serve you and your family during this time. We would be grateful if you would consider supporting Four Seasons by spreading the word about our services, volunteering your time, or making a gift.

Each year it takes 5,000 donors, 15,000 volunteer hours and \$1.5 million in gifts for us to cover unreimbursed care for 3,200 hospice and palliative care patients in 150 communities. We can't do it without you. Your generous support can benefit others.

Volunteer

Four Seasons relies on a dedicated group of volunteers to provide special services to our patients and their families. Your gift of time as a Four Seasons volunteer will make a difference in the lives of others. Many opportunities are available including: assisting at Elizabeth House, helping with office work, planning and executing fund raising events and working at the Hospice Home Store. Volunteers at Four Seasons include people of all ages and from all walks of life. There is no need for prior medical or counseling experience; training will be provided before placement. Volunteers are asked to wait one year after the death of a loved one before working directly with patients.

Spread the Word

If someone you know faces a serious illness or needs home-based care, please tell them about Four Seasons. For information and services, the person can call 866-466-9734. Additional information about the programs and services we offer is available online at www.FourSeasonsCFL.org.

Giving Opportunities

Gifts may be made in a variety of ways. Four Seasons appreciates all gifts, whether they are in the form of a check or credit card, stocks, mutual funds, bequests, life insurance, property or life estate gifts, sponsorships or donations to our Hospice Home Store.

Consider Four Seasons as the primary recipient of memorial gifts

Charitable contributions allow us to provide care to others who face the end of life or the death of a loved one. You could indicate in an obituary that donations in memory of a loved one be made to Four Seasons in lieu of flowers. We will send you the names and addresses of people who have made memorial gifts so that you can express your gratitude to them.

Honor someone special

This is a special way to not only thank a person who has touched your life in a meaningful way but also support the programs and services Four Seasons offers to our community. You may wish to honor a member of your loved one's Care Team by making a donation to Four Seasons in his or her name. Or, you could make a gift to celebrate a special event, such as a birthday, graduation or anniversary. Engraved bricks and pavers are also available for purchase to honor that special someone.



Select a permanent gift of tribute

These programs include bricks and pavers that are used to line the walkway of Greatrex Place, our administrative building, and the walkway of Elizabeth House, our inpatient facility. These giving opportunities range from \$200 to \$1,000.

Name Four Seasons as a beneficiary in your will or estate plans

A lasting legacy such as a bequest can be established for a specific dollar amount or for a percentage of your estate. In many cases, you can accomplish this through an amendment called a codicil. We also greatly appreciate gifts of stock, real estate and other marketable, tangible personal property. Please consult your attorney or financial advisor for guidance and direction if you would like to contribute to Four Seasons in this way.

Sponsorships

Sponsorship opportunities are available for a variety of events, programs and resource materials.

Support the Hospice Home Store

Donations of gently used clothing, furniture, collectibles, housewares, linens and more can be made to Four Seasons' Hospice Home Store. Pick-up and delivery services are available by calling 828-696-0625. The store is conveniently located at 215 North Main Street in downtown Hendersonville with free parking at the back of the store (accessible from Church Street).

If you have any questions about ways to give, please contact:

Four Seasons Foundation 221 N. Main Street Hendersonville, NC 28792 828-513-2440

Four Seasons is a 501(c)(3) nonprofit organization as determined by the Internal Revenue Service. Contributions that are made without receiving goods or services in exchange are tax deductible as allowed by law. Direct gifts may be made in the form of cash, checks, credit cards, direct debit, stock, or in-kind contributions.





Notes
FOUR-SEASONS
A nurse is available 24 hours a day, 7 days a week. Call 866-466-9734.

Notes
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A nurse is available 24 hours a day, 7 days a week. Call 866-466-9734.

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	A nurse is available 24 hours a day, 7 days a week. Call 866-466-9734.



IT'S YOUR Choice. USE YOUR VOICE. Call FOUR SEASONS today!

Co-Creating The *Best* Care Experience is what we're all about at Four Seasons...

Since 1981, Four Seasons has been providing a high level of compassionate and professional care for people facing serious life-limiting illness in Western North Carolina. We are a non-profit organization led by a dedicated team of health care professionals, social workers, spiritual care professionals and volunteers.

Specializing in end-of-life care is our passion. And, this passion is reflected in all that we do to care for our patients and their loved ones. We offer an extensive range of services to help people cope with the challenges that end of life can bring. Our broader view of what end-of-life care can do makes us a trusted resource for physicians, other healthcare professionals, patients and their loved ones.

Wherever a patient calls home – a family residence, an assisted living facility, an inpatient unit, a hospital or Elizabeth House on our Flat Rock campus – we deliver comprehensive services to them around the clock.

We place a premium on delivering care that's compassionate AND innovative. We are among the few facilities in the country that researches and develops comfort care practices and treatments.

Our services are covered through Medicare, Medicaid, and private insurance plans. Thanks to the generosity of our donors, we're able to provide services to all patients who need them.

Four Seasons is a non-profit organization, deeply committed to serving the community through fulfilling its mission of *Co-Creating The Care Experience*.

We are always available...

to answer questions, address needs or provide care and support. A nurse is on call 24 hours a day, seven days a week to respond to your questions or concerns. If you need assistance, support or guidance by phone, or if you want to arrange for a nursing visit, please contact us:

866-466-9734