Caring for a Loved One in Hospice

FAMILY CAREGIVER'S GUIDE





Make the Most of the Time Remaining

When a loved one is approaching the end of life's journey, it's hard on everyone. You've cared for them well and now it's time for a different kind of care—one that's focused on comfort and increasing their quality of life. At Interim HealthCare® Hospice, we're here to support you in the caring process and help you make the most of the time remaining.

As their caregiver, you've seen them through many stages of their disease. And, you've stood by their side and helped them manage their condition to the best of your ability. The care and support you've provided has been significant and now, you need someone to be there for you. Our Hospice Family Caregiver's Guide is designed to provide you with the knowledge and insights you need to help your loved one live out their days with dignity, comfort and meaning.

At Interim HealthCare Hospice, we're able to provide the compassionate care your loved one needs to stay comfortable and meaningfully engaged during the final months of life. And, we'll be there to provide the care and support you and your family need as well. Let us take this journey with you so you can treasure the time that remains.



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Care Changes During the End Stages of a Disease

When a loved one is approaching the end stages of a chronic disease, their condition will begin to decline and care regimens will lose their impact. As their disease progresses, it becomes increasingly difficult to manage the symptoms and gain control of their health. The tried and true care methods that worked before must adapt to their changing condition to remain effective. When the end stage of their disease is evident, it's time to change the course of care from active disease management to comfort-based care. Interim HealthCare Hospice can provide the compassionate care and support they need to stay comfortable and meaningfully engaged during the final months of life.

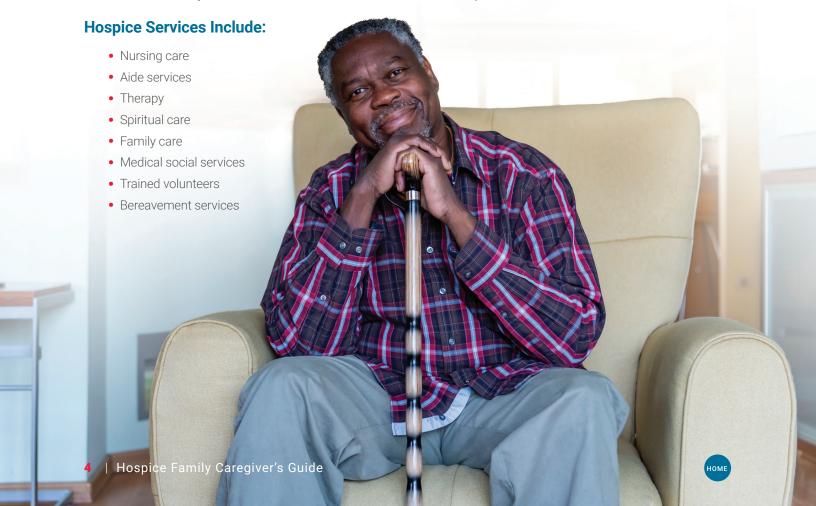
How Can Hospice Help?

At the end stage of a disease, the focus of care must shift from curative in nature to comfort-based measures. This is where hospice can make a significant difference in your loved one's life. Hospice is not a decision to die; but rather a decision to do what still can be done—improve their quality of life in the time remaining.

Hospice is a special form of end-of-life care designed to provide comfort and support to patients and their families facing the advanced stages of an illness. Unique to other types of care, hospice is focused on making the final months of life a time of joy and cherished moments for the individual and their family.

What Makes Hospice Different?

- · Offered during the last six months of life
- Focused on improving the quality of a person's life
- Comfort-based care for pain and symptom management
- Offers emotional and spiritual care to the patient and their family
- Can be provided wherever a patient calls home
- · Dedicated care team supporting the patient
- Comprehensive care planning tailored to the patient's needs and end-of-life goals
- Preparation for the final months of life



Hospice Myths and Truths

Often, there is a great deal of confusion about what hospice is and how it works in comparison to other types of care. Understanding what's true about hospice and what's not can help clear up any questions and guide your loved one in the decision that's best for them. There are so many benefits that this extended form of care can offer them—and their family.

HOSPICE MYTHS	HOSPICE TRUTHS
Hospice is a place.	Hospice is specialized care involving a team of caregivers focused on quality of life. It can be provided anywhere a patient calls home, including skilled nursing, assisted living and retirement facilities.
Hospice care is only for cancer patients.	Hospice care is for any person who is expected to live for six months or less if the disease progresses as expected.
Hospice care is only for the last six months of life.	Hospice care is not limited to six months; care continues as long as the patient meets the requirements and chooses hospice care.
The patient and their family must be ready to accept impending death to receive hospice care.	Hospice, while not curative in nature, is not a decision to die. Its focus is to provide physical, emotional and spiritual comfort. While a patient may choose hospice care at any point, some studies have shown patients who choose hospice earlier, live longer.
Patients must stop treatments and give up medications to qualify for hospice.	The Medicare Hospice Benefit does not require that the patient stop any treatments necessary to provide comfort. Treatments and medications will be continuously evaluated and adjusted based on the patient's needs and goals.
A patient must have a do-not- resuscitate (DNR) order to be eligible for hospice.	The regulation actually requires that hospices not discriminate against patients because of any advance directive choices they have or have not made.
A physician's order is required to visit with a patient to discuss hospice services.	Patients can choose to meet and discuss the benefit of hospice without a physician's order; however, hospice care cannot be provided to a patient without one.
The patient must stop seeing their physician.	Hospice patients have the right to choose their own physician and that physician may continue to bill for services as appropriate.
Hospice is the course you take when nothing else can be done.	Hospice is a choice to do what still can be done. When curative care is not working, hospice provides comfort-based care enabling patients to live their life to the fullest.

Their Goals Become Our Goals

Part of hospice care is helping your loved one fulfill any end-of-life goals and final wishes they may have. As they approach their final days, this can help bring peace, happiness and closure to aspects of their life that mean the most. At Interim HealthCare Hospice, we are committed to helping individuals live out their days in the most fulfilling way possible and achieving these goals is an important part of that. These goals may come in many different forms, such as:

- Connecting with people they want to talk to or visit
- Seeking resolution and forgiveness in relationships
- · Traveling to places they want to visit
- Enjoying new experiences
- Identifying special belongings they want to give away
- · Writing letters to special people in their life
- · Sharing meaningful life stories
- Identifying spiritual needs they may have
- Helping plan their memorial service and expressing their burial wishes

When your loved one is ready to discuss these things, our hospice staff will assist them in making a plan that includes these special goals and end-of-life preparations. As their caregiver, you will play an important part in the process too. As you surround them with love and support, you can help them through these decisions and create meaningful memories that you will cherish forever.

Discover the Difference Interim HealthCare Hospice Makes

When it's time for hospice, you have a choice in the home care provider you use. At Interim HealthCare Hospice, we are dedicated to making your loved one's care experience the best it can be. As the nation's first home care company, we understand the importance of personalized care at home and what it means to put our clients' needs first. Since 1966, we've been helping individuals find the compassionate end-of-life care they need to live a quality life in the time remaining. If you are just getting to know us, here's what makes Interim HealthCare Hospice different:

- First home care company in the U.S.
- National industry leader with 50+ years of expertise
- Holistic approach to care that optimizes the client experience
- Experienced in an extensive range of health conditions and illnesses
- Full continuum of care with a wide spectrum of specialties
- Local owners and staff who are committed to delivering excellent care
- Hospice professionals who are equipped to help those in the final stages of life

A Higher Standard of Care

When a loved one is facing an advanced illness, the care they receive can make a significant difference in the quality of life they enjoy. At Interim HealthCare, we're committed to the hospice philosophy of care founded on improving a person's quality of life during their final months. As their disease progresses, we'll be here to support them, and your family, in the special care needs and preparations ahead. You are not alone, we'll be with you each step of the way.





A Holistic Approach to Care

At Interim HealthCare Hospice, we believe in care for the whole individual, not just one part—and it is embedded in every aspect of our care model. Our HomeLife Enrichment® (HLE) standard of care thoughtfully engages the mind, body, spirit and family to ensure an optimal care experience.

Let's take a closer look at how care for the whole individual can improve your loved one's quality of life and enable them to live out their final days with meaning and joy.





MIND

Care for the mind involves understanding what's happening, how the care process changes and what to expect in the days ahead.

Understanding What's Happening

Until now, curative treatments have been the main focus of care. But when it's time for hospice, the goal of care changes to ensure comfort and improve their quality of life. As their caregiver, it's important to understand what's happening to your loved one and how it affects the care process. Everything you did before to help them may change now that the intent of care is to keep them comfortable and engaged.

There's also a shift in what care looks like and a willingness for the family to embrace it—from clinicians and aides to social workers and chaplains regularly visiting your home to offer support. Hospice is a special form of care for a special phase of life. Understanding its focus and the benefits it provides can make the transition to hospice easier on everyone.

A Whole Support System of Care

The beauty of hospice is that it is designed to be a support system for you and your loved one. What you are going through is really hard and we understand the questions, challenges and emotions that come with it. Caregivers need care too, and we will be there to help you through it. Each hospice patient has a dedicated care team that includes a physician, nurse, aide, social worker and volunteer ready to serve their needs, and yours. At Interim HealthCare Hospice, we'll be a support system of care surrounding your loved one and your family as you walk this difficult road.

Changes Impacting their Mind

During the final stages of life, every part of a person's being is impacted, including their mind. You may notice your loved one is confused at times, even disoriented. It's important for you to know, this is normal, but it can be disheartening and emotionally taxing on the family. Their mind is winding down and the impact of their disease is taking effect.

Confusion and disorientation can take on many forms, from time and location to the identity of loved ones surrounding them. They may appear to be seeing things that are not there or talking to people who are no longer alive. While this can be upsetting for the family, these symptoms are all part of the dying process. If this happens, here are some things you can do to help:

> Inform their hospice nurse about any confusion or disorientation so they can assess it Don't correct them or try to clear up their confusion Permit them to have these experiences without getting upset Reassure them that you are there and that you will take care of them Limit the number of people visiting to help lessen their confusion Listen closely for anything special they may be trying to share

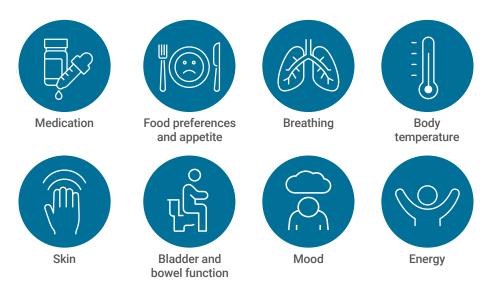




BODY

Care for the body focuses on diet, changes in bodily function and pain management during the end stage of a disease.

When a loved one is approaching the end of life, their body begins to change—and so does the care required to keep them comfortable. Diets, medications and care regimens that used to be critical to managing their condition now begin to fade and new care protocols take their place. As a caregiver, it can be hard to understand why so many aspects of essential care are no longer important, but as the body begins to shut down, the way they respond to these things changes significantly. The biggest differences you will notice include changes in:



Adjustments to Medication

In hospice, the goal of medication is to help manage pain and provide comfort to your loved one. For this reason, long-time medication regimens that are more curative in nature will change and new comfort-based medications will be added. This is important for caregivers and their family to understand and it is one of the primary differences you will see in hospice care. While their disease may be progressing, hospice can offer the palliative care they need to stay comfortable and meaningfully engaged during their final months of life.

Changing Food Preferences

As your loved one's body begins to change, their food preferences and appetite will start to change as well. You may discover, they suddenly do not like foods they used to love. And, foods they never liked before may now be appealing. As the body slows down, digestion changes and food interests will too. While these changes can be surprising to the family, it's all very normal.

Easing of Food Restrictions

While your loved one was actively fighting their disease, they probably had a restrictive diet to help manage their condition. In hospice, the goal is to keep them comfortable and allow them to have experiences that bring them joy and happiness. So, if they want to enjoy some type of food or drink that was previously off-limits, it's okay. Now is the time to ease up on the restrictions and allow your loved one to be the guide in what sounds good to them.



Less Appetite

As your loved one approaches the final stages of life, their appetite for food will begin to lessen. As their body slows down, digesting food becomes more difficult. Food may be less satisfying and their desire to eat will fade as their body function changes, resulting in weight loss. You might notice them spitting out food, turning their head or clamping their mouth shut. These are all signals that they don't want to eat. While this can be tough for family to understand and accept, it's all part of the dying process. Here are some ways you can help:

- Do not force your loved one to eat if they seem uninterested
- Try not to get upset in front of them, understand that their body is shutting down
- Puréed food or liquids are easier to swallow than solid foods
- If they are drinking fluids, give a little at a time by dropper
- Swab their lips/mouth with water if they are thirsty and unable to drink
- Offer small chips of ice to keep their mouth refreshed



Breathing Changes

As your loved one's disease progresses, their breathing patterns will change. This is all part of the body slowing down. You may notice difficulties in their breathing such as wheezing, a series of rapid, shallow breaths or even labored breathing. As their body weakens, you may hear a rattling in the back of their throat where saliva is gathering. These are all natural responses as your loved one nears the end of life, but they can be frightening for the family. As their caregiver, there are several things you can do to help:

- · Remain calm and don't panic, it might scare your loved one
- · Carefully reposition their head to allow any secretions to drain out
- Elevate their pillow or raise the top of their bed
- Talk to their nurse about medications that may ease breathing or dry up secretions
- Near the end, they may experience labored breathing or rapid breaths followed by 15 – 45 seconds of apnea (no breathing); Notify their nurse immediately if this occurs



Elevated Body Temperature

During this time, your loved one's body temperature will start to change. They may have an elevated temperature (up to 104 degrees) or feel sweaty and clammy to the touch. As their body begins to shut down, their temperature may fluctuate up and down. As their caregiver, there are a few things you can do to help keep them comfortable when their temperature rises:

- Notify their nurse if they get a high fever
- Give Tylenol to help reduce fever
- Remove any blankets or warm bed coverings
- Apply a cold compress to their forehead or back of their neck
- Adjust room temperature and ensure good ventilation
- Dress them in cool clothing





Cooling of Skin

During the end stage of life, your loved one's skin will begin to cool and change colors. This is due to decreased circulation in their arms and legs. Parts of their body may begin to perspire while other areas become darker in color. Their skin may be cold to touch and you may see a blueish tone around their mouth and nails. Even their pulse will be more difficult to feel. These are all natural responses of the body during the final months of life. Here are few things you can do to keep them warm:

- Lay warm blankets over them (no electric blankets)
- · Dress them in warm clothing
- · Gently reposition them in their bed
- Adjust the temperature in the room
- Massage their body to offer comfort



Bowel and Bladder Issues

One of the toughest changes for patients and their family to handle is the loss of control over bowel and bladder function that happens near the end of life. As your loved one's condition worsens, their fluid intake lessens and their urine output decreases. The color of urine is noticeably darker and may have a strong smell to it. Though food consumption may be very little, their body is still producing waste matter. This can cause constipation, diarrhea and skin irritation which can be very uncomfortable for your loved one. When these things occur, good perineal care is important. Often, this can cause distress on the family as they struggle to provide this type of care. It's best to discuss these issues with their hospice nurse so they can help offer solutions. Here are a few practical things you can do to help:

- Talk to their nurse about laxatives to help with constipation
- Use disposable briefs and underpads on their bedding
- For skin irritation, inquire about soothing creams or lotions
- Respect their privacy when changing briefs/pads
- Discuss perineal care solutions with their hospice nurse and family members



Mood Changes

While in hospice, your loved one may experience abrupt changes in their mood and behavior. They may seem restless and agitated for no reason, performing repetitive movements, pulling at their clothing and bed linens, and unable to remain still. This is a common response for those who are dying and may be caused by physical discomfort, pain and slowing circulation in their body. It often manifests in the form of outbursts and aggressive behavior that is uncharacteristic for your loved one, which can be very upsetting to the family. If you notice these behaviors, here are some ways you can help:

- Don't react to irrational behavior; try to redirect them instead
- Make their hospice nurse aware of these behavioral changes
- Offer to assist or provide support if they seem frustrated
- Hold their hand gently and reassure them that you are there
- Speak softly and calmly in order to soothe their reactions
- Read an uplifting book or letter to them
- Play soft, inspirational music in the background
- If agitation is severe, discuss medication options with their nurse
- Keep a close eye on them for safety; if moving a lot, consider bed rails
- Engage a chaplain or social worker to offer spiritual and emotional support







Unexpected Surge of Energy

In the final days before death, your loved one may experience an unexpected surge of energy. After days of being disoriented and withdrawn, they may suddenly become alert and want to do things they couldn't do before. They may even desire to eat after a period of time where they showed no interest. This can be really confusing to you and your family as it almost appears your loved one is improving. While short-lived, this surge of energy and mental clarity can be a real gift to you and your family as you prepare to say goodbye. Here are some ways you can make the most of this treasured time:

- Seek closure on any unresolved issues
- Say the things that need to be said
- If apologies and forgiveness need to be extended, do so
- Hold hands and share your heart openly
- Reminisce about times you've had together
- Take this special time to say your goodbyes

SIGNS AND SYMPTOMS OF APPROACHING DEATH

ONE TO THREE MONTHS:

- Withdrawal from people and activities
- Communicating less
- Eating and drinking less
- Sleeping more

ONE TO TWO WEEKS:

- Disorientation and confusion
- Talking to others not present in the room
- Physical changes:
 - Increase or decrease in pulse
 - Decrease in blood pressure
 - · Changes in skin color
 - Irregularities in breathing
 - Changes in body temperature, hot/cold
 - Not eating, taking little or no fluids

DAYS TO HOURS:

- Sleeping most of the time
- Surge of energy
- Restlessness
- Difficulty swallowing
- Further discoloration of skin
- Ongoing changes in breathing (long pauses between breaths)
- Rattling breath sounds
- Weak pulse
- Further decrease in blood pressure
- Decreased urine output or no urine
- Eyelids no longer able to close completely

MINUTES:

- Shallow breaths with longer pauses
- Mouth open
- Non-responsive

Source: When the Time Comes: A Caregiver's Guide, Quality of Life Publishing Co.





SPIRIT

Care for the spirit in the final stages of life is the most compassionate form of care there is. It uplifts the spirit, comforts the heart and inspires joy during a very difficult time.

When a loved one is admitted into hospice, it can be difficult for everyone. As they come to terms with what it all means, there is a real need for emotional and spiritual support. At Interim HealthCare Hospice, care for the spirit is embedded into every aspect of our care philosophy, and a big part of what makes it so special. Your loved one may be approaching the end of their journey, but we will be right there beside them—and your family—to provide the comfort, support and spiritual care needed each step of the way.

Nurturing their Spirit

End-of-life care impacts the spirit in a significant way. As you and your loved one prepare for what's ahead, there may be spiritual questions and concerns that need to be addressed. In hospice, this is all part of the care process. If you or your loved one would like to have a chaplain come by and visit to offer spiritual care and support, that's available to you.

Add Joy to Each Day

At Interim, we want to help you and your loved one make the most of the time remaining. Whether it's gathering with family to share meaningful time together or helping your loved one achieve an end-of-life goal, we will do whatever we can to create these special memories. Look for things you can do together to add joy to each day, such as:

Listening to music Playing a game Engaging in a favorite hobby Reading an inspiring book Looking at family pictures Visiting a special place Watching a movie Reading cards and letters Going to virtual locations, museums and concerts **Sharing favorite memories** Making a craft

Acceptance of Impending Death

One of the toughest challenges you and your loved one will face is the reality that their life is coming to an end. While this can be emotionally gripping for you, it's important that you and your family members understand the dying process so you can help your loved one accept what's ahead. As a son or daughter, it's okay to put your caregiver role aside and allow our hospice care team to take over, so you can treasure every moment with them. We understand how hard this can be and if you need the assistance of a social worker or chaplain, hospice can provide you with that support.

Recognizing Signs of Depression

When a loved one is admitted into hospice, they may experience stress and anxiety, which left unchecked, can lead to depression. As their caregiver, it's important to recognize the signs and notify their hospice nurse if you notice a change in their behavior. Depression can cause your loved one to shut down, leaving many things unsaid during a time when communication is crucial.





Symptoms of depression vary from person to person, but may include:

Trouble Fatigue Insomnia or Lack of appetite concentrating sleeping too much Feelings of guilt **Aches and pains** Unable to **Irritability** that remain Worthlessness remember details Loss of interest Feeling sad **Difficulty making** Helplessness in things and empty decisions **Pessimism Overeating Suicidal thoughts**

Withdrawal from Others

As your loved one approaches the final weeks and days of life, you will notice them beginning to withdraw from close friends and family. This is all part of the dying process, but it can be very difficult to understand and accept. They are not trying to hurt you, they are just preparing for what's ahead. The best thing you can do is love them right where they are and respect their boundaries.

When they are alert and engaging, make the most of the time you have together. If you notice they are more apt to interact at certain times of the day, plan family visits around those timeframes. Here are a few things to keep in mind if your loved one is withdrawing:

- Try not to get upset, just understand what's happening
- Do not raise your voice to get their attention; it's not an issue of hearing
- Always say who you are and what you will be doing so you don't startle them
- Be mindful of what you say in front of them; though they seem distant, they can hear you
- Respect their boundaries and encourage family members to do the same

When It's Time to Say Goodbye ...

Saying goodbye is not easy, but when the time comes, it can be such a special time between you and your loved one. Knowing when the right time is or how to approach the topic may be uncertain, but when you are ready, it can be very healing to your heart and theirs. Here are some things to keep in mind as you prepare to say goodbye:

- Choose a time when they are the most alert to say goodbye
- Tell them what you love about them most and how much they mean to you
- Talk about favorite memories and times you've shared together
- Tell them what you will miss about them the most
- Let them know how grateful you are for them
- Tell them how they impacted your life or lessons you learned
- Say you're sorry if you need to and extend forgiveness freely
- Don't leave anything unsaid that needs to be said
- Hold their hand and tell them how much you love them
- · Lay next to them and hold them as you share your heart
- Don't hold back the tears; it's all part of the healing process
- Journal any special words, memories or thoughts shared during this time





FAMILY

Care for the family involves educating and supporting those caring for a loved one in hospice. It fosters understanding and engages the family in every facet of the care process.

Hospice care is a compassionate form of care designed to bring comfort and meaning to your loved one during their final months of life. At Interim HealthCare Hospice, engaging the family in our plan of care is what makes it so special. It's all part of our HomeLife Enrichment philosophy and family plays a big part in the care process. As their caregiver, we understand how hard this can be for you, and we're here to support you and your family as you take this journey together.

Family-Centered Care

As your loved one transitions from active disease management to passive, comfort-based care, there will be many changes and a whole new level of support for your family. We understand that with these changes, come many questions and our staff are here to answer all of them and address any concerns you may have concerning our services, changes in medication, diet and other care regimens. In addition, you'll be supported by a dedicated team of hospice professionals ready to help your loved one, and your family, make this transition and find comfort in the days ahead.

Understanding Hospice and How We Can Help:

- Helping you make the most of the time remaining
- · Working together to establish a personalized plan of care
- Helping you understand changes in medication and diet
- Understanding how our hospice caregivers can support you
- Offering respite care when caregivers need a break
- Supporting your loved one with end-of-life goals
- Helping with memorial service and burial preparations
- · Providing bereavement services for family and friends

Care for the Caregiver

You've been a strong source of support for your loved one all along, but it can take a toll on you. As they begin this final phase of care, it's important that you take care of yourself too, so you can stay strong for them. At Interim HealthCare, we're here to support you with hospice care aides that can provide the respite care you need to take a break when you need it most. When a loved one's time is drawing near, emotions can run high and sometimes you just need a little fresh air or time alone to reset. Be careful not to neglect your own needs and don't be afraid to ask for help from family and friends.

Emotional and Spiritual Care for the Family

At Interim HealthCare Hospice, we know how difficult this time can be for you and your family. We're here to support you in any way we can—from medical social workers who can provide emotional support and guidance through the grief process to chaplains who can meet with you to discuss spiritual matters important to you and your loved one. You are not alone; we will be with you each step of the way!







Support Doesn't Stop After Your Loved One Passes ...

When the time comes for your loved one to go, the grief can be overwhelming. This is the time you need more support than ever, and we'll be right by your side to help you through it. At Interim HealthCare Hospice, we offer bereavement services for family and friends for 13 months following the death of a loved one. Whether you need someone to talk to about your grief or you need help organizing a memorial service, we can provide the support you need to get through it. Our services include:

- Emotional and spiritual support for family and friends
- · Periodic check-ins with the family every 30 days
- Help with memorial services or family gatherings
- · Therapist referrals for high-risk individuals
- Encouragement to take care of yourself

When it's time for hospice, we'll be right beside you.

When a loved one is admitted into hospice, it can be overwhelming. In a time when spirits may be low, there is a new perspective about life and the importance of cherishing every moment. At Interim HealthCare Hospice, we will be a source of comfort and support to you and your family as you take this journey together.





Care Notes

Document any special directives and notes from your loved one's physician or nurse here.





Founded in 1966, Interim HealthCare is the nation's first home care and healthcare staffing company. A recognized leader in their industry, Interim understands the importance of providing quality care in a place that's ideal for the individuals they serve. Distinguished by their HomeLife Enrichment® signature standard of care, they engage the mind, body, spirit and family in a personalized plan of care that ensures an optimal experience for their clients.

Operating through a network of more than 300 locally owned franchises, Interim HealthCare offers a comprehensive range of home care, hospice and healthcare staffing solutions. From skilled nurses and therapists to aides and companions, they provide an average of 25 million hours of home care to 190,000 people every year.

interimhealthcare.com