



# SAFE PASSAGE

*When Terminal Restlessness Occurs*

Kansas City Hospice & Palliative Care  [kansascityhospice.org](http://kansascityhospice.org)

*“You know, dying is something like being born — sometimes it’s easy and sometimes it’s hard work. It can be a fight to let go of your life.”*

## ■ *What is terminal restlessness?*

“Terminal restlessness/delirium” are terms that encompass a range of symptoms that sometimes, but certainly not always, occur at the end of life.

The symptoms can vary, from mild agitation and anxiety through full-blown delirium. Delirium is characterized by cognitive failure, hallucinations (seeing or hearing things that are not there) and/or delusions (believing things that are not real). These symptoms can be particularly distressing to those who are at the bedside with the person who is dying.

When terminal restlessness or delirium occurs, we as caregivers feel helpless to determine what the dying person is trying to communicate. We don’t seem able to intervene in the negative process and, at times, the situation feels out of control.

All of these feelings, however normal, can make terminal restlessness and delirium a very difficult experience for everyone involved.

## ■ *Why should I know about terminal restlessness, if it may not occur?*

The symptoms of terminal restlessness, like the symptoms of pain, are best treated early. For that reason, it helps to know what to look for.

Should the symptoms arise, you can promptly describe changes in the dying person’s mood and behavior to your hospice nurse. Sometimes, though not always, the symptoms can be decreased.

## ■ *What does terminal restlessness look like?*

This condition shows itself through a variety of changes, such as:

- Irritability or agitation, aimless movements or inability to focus
- Mood swings; looking disturbed; grimacing, grunting; looking startled or alarmed
- Changes in consciousness, whether overly alert or lethargic; reduced awareness of the surroundings; difficulty in sleeping or being awake all night
- Increased or varying confusion (when previously clear); impaired memory and attention span
- Uncharacteristic speech, whether loud or soft, fast or slow
- Not recognizing you, seeming not to know where he or she is
- Appearing to see, hear or feel things that aren’t there; motioning or calling out to people who aren’t there
- Crying out for help, sometimes repeatedly; not being able to tell you what’s wrong; uncharacteristic profanity; disrobing, trying to get out of bed or out of the room

## ■ *What should I do?*

First, know that relatively sudden behavior changes like these will make anyone feel anxious and unsettled. Even so, there are several things you can do:

- Contact the hospice nurse, because early assessment and treatment are critical.
- Quietly keep the person safe.
- Gently remind the person who you are and what you are going to do. (“Mother, it’s Betty. I’m right here with you, and I’m going to straighten the covers for you.”) Reassure, rather than asking questions.
- Do whatever feels calming and appropriate: gently wipe the person’s face with a warm cloth, brush her hair, play his or her favorite music, quietly sing or hum familiar songs, or simply hold the person’s hand.
- Try to keep the usual routine in place.
- Provide a quiet, peaceful setting.
- Keep low lights on at night.

## ■ *What causes terminal restlessness/delirium?*

We can’t always pinpoint the exact cause of terminal restlessness or delirium. Sometimes urinary retention is a contributing factor, and urinary retention can be caused by the disease process, bladder spasms, catheter issues or other malfunctions.

Untreated pain can contribute to terminal restlessness, as can dehydration, anemia, infection, fever or brain swelling. Certain cancer treatments can also be a factor.

Medications can play a role whether over-use, under-use or the interaction among certain drugs. There also are wide variations in how well the body tolerates certain medications or narcotics.

Emotional turmoil or fear also could contribute to terminal restlessness; but, as you can see, a good deal of guesswork is involved in trying to determine a cause of the symptoms.

What we do know is this: Multiple chemical and metabolic changes occur as various organs begin to fail. Whatever the result, our job as a team family,

caregivers, hospice professionals is to do everything possible to make the dying person more comfortable.

## ■ *What will the hospice nurse do?*

The symptoms of terminal restlessness are addressed with a wide range of treatments.

The nurse will carefully assess the person and situation to determine the most likely cause(s) of these new symptoms. If a cause can be easily determined, the symptoms may be lessened or reversed.

The nurse may try several different approaches to determine which treatment might be most effective.

In the meantime, you should do whatever you feel is most calming and reassuring for the person who is dying and also for yourself.



■ *How should I interpret such distress at the end of life? What does it mean?*

It's important to understand that sometimes, no matter what we do, the dying process for a loved one is not as peaceful as we had hoped.

Part of our being human is wanting to make sense of things but, in the case of terminal restlessness or delirium, it is usually over-reaching to ascribe psychological or symbolic meaning to the words and behaviors of a body in distress. The symptoms you are seeing are more likely...simply biological.

This is the time to step away from the bedside and talk candidly with your hospice nurse about the situation. He or she will understand your concern. Talking freely with an experienced person can release, in a safe way, some of the tension that naturally builds up in such a situation.

The important thing, even when the dying process is difficult, is that you are there, providing reassurance and support. The value of a life fully lived and of care lovingly provided should not be diminished by the unpredictable peculiarities of how the body lets go of life.

*“Remember, your very presence and caring, even if you feel unsettled, are profound gifts of love.”*





## Kansas City Hospice & Palliative Care

Kansas City Hospice & Palliative Care is a nonprofit organization offering a range of services for people of all ages and at any stage of serious illness. Since 1980, we've been enhancing life for the seriously ill and their families in the greater Kansas City area.

Our programs include:

- Kansas City Hospice, providing comfort and care at home or in a nursing home.
- Palliative Home Care, comfort care for people pursuing curative treatments or who are not ready for hospice.
- Carousel, pediatric palliative care.
- Kansas City Palliative Medicine, full-time physicians specializing in comfort care and symptom management.
- Kansas City Hospice House, an inpatient facility offering expert medical and nursing care 24 hours a day in the comfort of a homelike setting.
- Passages, counseling and resources for difficult transitions in life.
- Solace House, a counseling center for grieving children and their families, as well as for individuals.

For more information or to schedule a free assessment to see if one of our programs may be helpful to you, call Kansas City Hospice & Palliative Care at 816-363-2600.

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