What should I know about restlessness?

As end of life nears, some people might experience restlessness. Family and friends may be surprised when a usually calm person becomes restless or agitated. The depth of this restlessness can vary greatly. You may be unsure about what to do if there are mood swings or personality changes.

Sometimes people may experience delirium, which means they may not be thinking clearly and may have less awareness or reduced attention with what is happening around them.

Patients may be very weak, but insist on changing positions often. They may yell out and show anger toward people around them.

Some people with delirium are afraid, and may want to go to the emergency room or call the police because they believe someone unseen is trying to hurt them. They may not recognize familiar people or seem to be living in the past.

All of this can be very upsetting to family and friends at the bedside with the person who is dying. You may feel helpless to know what the dying person is trying to say or don’t know how to help them. The situation feels out of control.

This experience can be very difficult for everyone involved, even for professionals.

Why should I know about restlessness, if it may not occur?

Restlessness, like pain, is best treated early. So, it helps to know what to look for. If you see changes in the dying person’s mood, behavior or ability to sleep at night, report it to your hospice nurse. Sometimes, the symptoms can be improved with use of medications and changes to the environment.

What causes restlessness or delirium?

We can’t always know the exact cause. A number of changes happen when a person nears death. Body organs fail and waste may build up in the person’s system, causing confusion and behavioral changes.

Pain can be a cause of delirium and so can dehydration, anemia, infection, fever or brain injury. Some cancer treatments can also be a factor.

Medications might be over-used or under-used and the combination of certain drugs can cause problems. Emotional upset or fear can contribute to terminal restlessness.

Some causes of delirium are reversible. If a cause for the delirium can be identified, we will attempt to treat the
cause, when consistent with goals of care. Our job as a team of family, caregivers and hospice professionals is to do everything possible to make the dying person more comfortable.

What does restlessness look like?

Look for changes, such as:

- Aimless movements, like picking at the sheets or clothing, looking disturbed, frowning, grunting, looking surprised or afraid
- Changes in speech
- Irritability or agitation, mood swings or difficulty focusing
- Changes in alertness, difficulty in sleeping or not being aware of surroundings
- Increased or changing confusion (when previously clear), poor memory or short attention span
- Not recognizing you, not knowing 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, not being able to tell you what’s wrong, profanity, undressing, trying to get out of bed or out of the room

What will the hospice nurse do?

There is a wide range of treatments available for restlessness. The nurse will carefully assess the person and situation to find the most likely cause of these new symptoms. If a cause can be found, the symptoms may be lessened or reversed.

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

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 restlessness or delirium, this can be difficult. We look for messages hidden in confused words. We try to imagine what they might be trying to tell us. But, we can’t always find meaning in the words and actions of a person in distress. What you see and hear is not necessarily a message or symbol, but just the body letting go.

This is the time to step away from the bedside and talk honestly with your hospice nurse about the situation. He or she will listen to 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.

Your hospice team will assist you during these difficult times. By starting hospice care as early as possible, you will have a relationship that allows our team to know your loved one and your family and to help you through these troubling times.

The important thing, 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 ways the body lets go of life.

■ What should I do?

First, know that sudden changes like these will make anyone feel anxious and upset. There are several things you can do:

- Stay calm. If you are anxious, it can affect behavior of the dying person.
- Contact the hospice nurse, because early assessment and treatment are important.
- Quietly keep the person safe.
- Gently remind them 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.”
- Don’t ask questions, just reassure.
- Do whatever feels calming and appropriate: gently wipe the face with a warm cloth, brush her hair, play his favorite music, quietly sing or hum familiar songs, or simply hold hands.
- Try to keep the usual routine in place.
- Provide a quiet, peaceful setting.
- Keep low lights on at night.
We are a not-for-profit organization offering a range of services for people of all ages and at all stages of serious illness.

Our programs include:

▶ **Advanced Illness Support** — in-home consultation services to help guide you through complex healthcare systems and medical decisions

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▶ **Kansas City Hospice** — comfort, care and compassion at home or in a nursing home

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▶ **Kansas City Hospice House™** — inpatient care in the comfort of a homelike setting

▶ **NorthCare Hospice House** — compassionate inpatient care in the Northland

▶ **Solace House** — a center for grief and healing offering a nurturing place for children and adults following a death

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**Kansas City Hospice**
816.363.2600
kchospice.org

**NorthCare Hospice**
816.691.5119
northcarehospice.org