**Recognizing Terminal Restlessness at the End of Life**

Terminal restlessness, also known as terminal agitation or terminal delirium, is a syndrome that may occur near the end of life. People experiencing terminal restlessness show signs of physical, emotional, and/or spiritual restlessness, as well as anxiety, agitation, and cognitive decline in the days leading to death.1﻿

It can be distressing to watch your loved one go through this, and you may wonder if there is something you should do about it. If you and your family already know and have accepted that your loved one is dying, you can be reassured that responding calmly and doing what you can to promote your loved one's comfort is of value in these final days.

Signs and Symptoms

The behaviors that manifest when someone has terminal restlessness can include outbursts, rejection, aimlessness, and lack of attention.2﻿ It is believed that the behaviors stem from discomfort and physiological changes in the body, rather than genuine anger or hostility.

The signs and symptoms of terminal restlessness can be characterized by aggressive behavior or by calm, lethargic behavior. The aggressive, often hostile behavior is more difficult to watch from an emotional standpoint, as well as more difficult to manage.

Terminal restlessness is characterized by the sudden appearance of incongruent behaviors rather than the anger, depression, or other emotions commonly experienced during the stages of dying.

Many of the behaviors are characteristic of dementia (a decline of mental function).3﻿ A person who has terminal restlessness may seem uncomfortable, constantly pulling at clothes, bedsheets, and intravenous (IV) lines.

Some people may seem indecisive, looking for items or asking for something and then turning away from it. And others may seem mean-spirited, accusing people of wrongdoing that may or may not make sense.

Sometimes, the restlessness appears briefly and then resolves on its own. A number of other well-recognized end-of-life symptoms, such as pulling away from intimacy and talking about dead family members, typically continue when a person is experiencing terminal restlessness.

Differentiating Conditions

Psychologists will typically describe the stages of dying as denial, anger, bargaining, depression, and acceptance (DABDA), during which a person may experience outbursts, irrational, and contradictory behaviors.

The stages of dying are can be differentiated from terminal restlessness in that the behaviors occur once a terminal diagnosis is received. With terminal restlessness, they occur in tandem with the end-of-life decline.

With that being said, terminal restlessness and DABDA can occur at the same time.

Terminal restlessness is sometimes confused with nearing death awareness during which a person may appear to be confused or hallucinating as if having visions or conversations with loved ones who are deceased.2﻿ Again, depending on the circumstance, terminal restlessness and nearing death awareness can co-occur and often be difficult to differentiate.

Causes

There are many different causes of terminal restlessness. Many of the physiologic changes that accompany dying can lead to this type of delirium. Some causes of terminal restlessness are easily reversed, while others are not.

The most common causes include:

* **Medications:**Opioids and anxiolytics are a few of the medications often used for comfort at the end of life. They are known to increase the risk of delirium, and, in the context of multi-organ failure, their delirium-inducing effects can be amplified.1﻿
* **Cancer treatments:**Chemotherapy medications and steroids are tough on the body, and someone who is dying is even more likely to experience the negative effects, including restlessness.
* **Poorly managed pain:**Often, dying patients can't describe their pain. And even with pain treatment, there is a delicate balance that needs to be struck. Overuse can lead to toxicity, while under-use permits pain and discomfort to worsen, further exacerbating terminal restlessness.
* **Organ failure:**As organs such as the liver and kidney begin to fail, metabolic alterations and electrolyte problems affect brain function. Similarly, heart and lung failure, which commonly occur in the days before death, lead to decreased oxygen levels. All of these systemic effects exacerbate terminal restlessness.
* **Medical problems:**Dehydration, anemia (decreased red blood cells), infections, and fevers are all effects of terminal medical illnesses that weaken the body and impair brain function, contributing to terminal restlessness.
* **Lack of voluntary activity:** Urinary retention (the inability to void urine) and constipation are very common near the end of life, as the sensations and muscle movements that control these functions are impaired.2﻿ Pain and severe discomfort result.
* **An emotional response to dying:** Often, people who are dying of terminal illness are aware of it. As death nears, fear, anxiety, and emotional turmoil can manifest in a number of ways, including restlessness.

If your loved one is exhibiting signs of terminal restlessness, work with the doctors to explore remedies to ensure your loved one is comfortable and treatable conditions are not being ignored.

Terminal restlessness is usually only treated if the behaviors place the person or others at harm or an authorized third-party requests treatment. Options include mild tranquilizers called benzodiazepines and anti-psychotics called phenothiazines.

Coping

It is important to keep in mind that the manifestation of terminal restlessness—whether it is hostile words or actions, or calm reflection of memories—is not necessarily consistent with a dying person's personality or how they feel about you.

Beyond the emotions that can come in response to what is said or done, as well as the fact that death is imminent, watching terminal restlessness may make you feel guilty about how you are handling your loved one's dying process.

We all want death to be a comfortable and peaceful experience but, if your loved one is dealing with terminal restlessness, their final days appear just the opposite. Some causes of terminal restlessness can be treated easily. However, in most cases, treatment is challenging.

Often, there are many additive causes of terminal restlessness, and it can be hard to identify just one. If you and your loved one has reached this stage, comfort is often a priority. Addressing pain or discomfort as gently as possible, often with professional guidance, can help make the last few days easier for everyone involved.

Many families opt to work with a hospice team because experienced end-of-life professionals can let you know what to expect and what types of interventions are needed.2﻿ Close friends and other family members can also help you make it through this difficult time.

Families are often caught off guard by terminal restlessness. Most people go through episodes of sleepiness, peacefulness, and restless delirium in the days before dying from a chronic illness.

Few families, if any, may have mentioned the restlessness to you. Simply put, it is not a memory that many care to revisit. This can make you wonder if your experience is unique, leaving you worried that you are not doing something you should be doing. You should rest assured that terminal restlessness is fairly common.

Adapted from: https://www.verywellhealth.com/terminal-restlessness-1132271#:~:text=Terminal%20restlessness%2C%20also%20known%20as,the%20days%20leading%20to%20death.