



Restlessness

Information for the carers and loved ones of someone with a life-limiting illness.

It is not uncommon for people who are in the final days of their life to become restless. You may hear this being described as terminal restlessness, terminal agitation, terminal delirium, terminal anguish, or confusion at the end of life. This fact sheet aims to help you understand what is happening to your loved one and how they can be supported.

What is terminal restlessness?

It is common for people with a terminal illness to experience restlessness in the days or hours before their death. They may experience anxiety, agitation, and confusion. This occurs in approximately 25–85% of people ¹.

What does terminal restlessness look like?

Signs and symptoms may include some of the following:^{2,3}

- Jerking and muscle twitching.
- Aimless movements – reaching out, fidgeting, picking at clothes or bed sheets.
- Distressed vocalisation – calling out or moaning.
- Agitated behaviour – sometimes including anger and aggression.
- Increasing confusion and incoherence – not knowing who you are or where they are, not being able to tell you what is wrong.
- Hallucinations – appearing to see, hear or feel things that aren't there or communicating with people who are not present.
- Trying to get in and out of bed or wandering.
- Being unable to relax or get comfortable.

These signs and symptoms may be distressing for your loved one, yourself and other family and friends.

What causes restlessness?

Restlessness and agitation in the terminal phase may be the result of:^{3,4,5}

- Metabolic changes when the body's organs begin to fail.
- Laboured breathing and a lack of oxygen.
- A raise in pressure around the brain.
- Fever, infection, and sepsis.
- Medication interaction or toxicity.
- Uncontrolled pain.
- Urinary retention or severe constipation.
- Withdrawal from drugs, alcohol or nicotine.
- Emotional and existential distress.

When should I ask for help?

It is important to talk with the doctors and nurses as soon as you begin to notice a change in the behaviour of your loved one⁶. The treating team will aim to identify and treat any underlying reversible causes of distress, for example, uncontrolled pain or urinary retention⁷. Following this, they will be able to provide appropriate treatment for your loved one's symptoms, optimise their comfort levels, and offer guidance and advice³. PalAssist is also here for you 7am–7pm, 7 days a week if you require further support.

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We're here, and we care.

Can medications help?

In situations where symptoms persist despite comfort measures being put in place, medication may be needed to ease restlessness and agitation. The type of medicine chosen may depend on the symptoms the person is experiencing. Medicine doses will be adjusted accordingly. In the final stages of a person's life, medications can be given through a syringe pump or a small plastic needle that is placed just under the skin.

What can I do to help?

Supportive measures may be beneficial. In some cases, they may not treat the cause of the restlessness, but they may make the agitation less distressing. Some supportive measures may include:

- Reassuring your loved one, sitting with them, holding their hand and talking to them in a loving and gentle manner.
- Repositioning your loved one and adjusting the lighting, the room temperature or blankets as required.

- Creating a safe, calm, comfortable and familiar environment. This may include having familiar people in attendance, playing music they like, placing familiar objects around them, or using complementary therapies such as aromatherapy.
- Telling them what you are doing when you are tending to their needs, even if you don't think they can hear you.
- Reducing or removing anything that may be causing them irritation or discomfort³.

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