

Support For Carers

It is very important that family and carers are kept well informed, so that you know at all times how best you can support and care for your loved one. As a result, your doctor or nurse will provide an explanation about what is happening. Feel free to ask your doctor and nurse as many questions as you need.

Carers and family may also require practical, emotional or psychological support during the process of caring for a terminally ill loved one. Remember to talk to the medical or nursing staff about your needs. It may be possible to access practical options such as carer respite, or other services including counselling or spiritual support.

This fact sheet was produced by Palliative Care Queensland, the peak organisation for Palliative Care in Queensland, representing the interests and aspirations of all who share the ideal of quality care at the end of life for all. To order additional copies of this fact sheet, or to become a member of Palliative Care Queensland, please contact:

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For more information about palliative care services in your local area, please contact:

Palliative Care Information Service (PCIS)

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(Monday to Friday 9am – 5pm)

Website: www.pcis.org.au

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PCIS is a free telephone information and support service available to all Queenslanders affected by terminal illnesses, including patients, family members, carers and health professionals. PCIS provides emotional support, counselling and general information about Palliative Care and end-of-life services in Queensland. Support is provided by trained professionals who have access to a large database of up-to-date information.

Disclaimer

The information contained in this brochure is for general guidance only and is not clinical advice. All efforts have been taken to ensure that the information provided is accurate and up to date at the time of printing. The information provided is intended to help inform patients and their family. Your healthcare decisions are best made in consultation with your doctor.

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**Palliative
Care
Queensland**

About Confusion & Terminal Restlessness

Information for those caring for a terminally ill person

What is Confusion?

Confusion occurs when awareness is altered and thinking becomes unclear.

Confusion can also be accompanied by rambling or incoherent speech. Confused people may misinterpret sights or sounds, and may even become anxious, restless or agitated. In some people, emotional responses may also be exaggerated.

Confusion can often be worse in the evening or at night, especially if there has been a recent change in routine. Being admitted suddenly into hospital and into a strange or unfamiliar environment can often cause or exacerbate confusion in terminally ill patients. Nightmares can also commonly occur in patients with confusion. Confusion can be aggravated by crumpled or uncomfortable bedding or clothing.

Common causes of Confusion

Although it is not uncommon for family or carers to be concerned that mental illness or dementia is the cause of a patient's confusion or changed behaviour, in most cases, confusion in terminally ill patients is caused by a physical problem, such as:

- High temperature or infection;
- Medication;
- Problems with the heart or lungs affecting oxygen level to the brain;
- Brain tumours;
- Strokes;
- Pain;
- Constipation;
- Full bladder, or
- Chemical imbalances.

Personal problems and psychological disorders however may increase the severity of the confusion.

How can the Carer help?

When a terminally ill patient becomes confused, the most important action that can be taken by carers is to ensure that the doctor and nurse are alerted to the change in behaviour as soon as possible – the earlier the better.

It is possible for your treating team to perform investigations that may determine the cause of the confusion. In many cases, treatment may be provided to help clear the confusion quickly. If the confusion is related to medication, doctors will review the type and dose of the medication, and make appropriate changes.

Helpful hints for Carers

- Try not to argue with the patient about their hallucinations or delusions;
- Gently remind the patient where they are and who you are;
- Sit quietly with the patient, talking to them about familiar subjects. Friends, volunteers and other family members may be available to take turns with you doing this;
- Try to avoid rushing the patient in any way;
- Ask only uncomplicated questions and make simple requests;
- Try to keep the patient's surroundings as quiet, peaceful and comfortable as possible;
- It is important to avoid extremes in temperature, so use heating or cooling freely if it is needed;
- As often as possible, check the patient's bed and clothing for irritations such as rumples, objects in the clothing or incontinence;
- Use a "night" light if possible or keep the door open with a hall light on, and
- Turn on some soft background music (some patients may find this annoying).

Terminal Restlessness

Terminal restlessness is a medical term that is used to describe a form of confusion that can often occur in the last few days or hours of life. It is often associated with increased agitation, twitching, or general restlessness, and can be very distressing for relatives and carers. In some cases, patients with terminal restlessness may make noises like groans, moans or grunts that appear to be related to their breathing. They may not even necessarily be aware of their own behaviour.

If the patient shows a significant change in behaviour, including an increased level of agitation, increased confusion or if the patient starts calling out, promptly alert either the nurse or doctor. Your nurse and doctor are best placed to assess the needs of the patient and to decide on the most suitable method of managing the situation.

Treatment of Terminal Restlessness

Often, simple interventions such as changing the patient's position in the bed, can be especially helpful at reducing terminal restlessness, however more complex interventions may be required for some patients.

Special drug treatments, including sedation, can be successfully used to treat confusion and terminal restlessness in terminally ill patients. These drugs are most often used in the terminal phase of a patient's illness, and can be helpful at settling symptoms and making the patient feel more calm.