

## Managing the symptoms of terminal agitation in dementia



People living with dementia can experience death and dying differently. As the person nears the end of their life they may experience changes and fluctuations in behaviour. These behaviours, known as terminal agitation, can be mistaken for behaviours and psychological symptoms of dementia (BPSD), and may include disorientation, increased confusion, verbal and/or physical aggression, restlessness, agitation and perceptual disturbance (seeing or hearing things). The following information may be useful once it has been medically confirmed that the person with dementia is in the process of dying.

Terminal agitation is often increased by physical, environmental and psychosocial factors. Recognition and management of terminal agitation can help to ensure optimal quality of life for the person living with dementia.

**The following information may help keep a person living with dementia comfortable, and increase their quality of life, as they approach the end of life.**

### Physical needs

- Look for signs of pain, such as changes in facial expression, groaning, crying, rocking or attempting to move or protect limbs. Non-medication strategies may be useful such as warm heat packs, massage, and physical supports (such as repositioning and supporting a limb). If pain is not relieved by these non-medication strategies it is important the person's registered nurse and/or GP is notified.
- Maintain mouthcare using moistened swabs regularly throughout the day. Consider using the person's favourite drink (such as iced tea or orange juice) to moisten the mouth and provide flavour and enjoyment. Lip balms and mouth sprays or gels may also help to provide comfort.
- If the person experiences dry eyes, a warm facecloth or towel can be used to provide moisture and comfort. Alternatively, over-the-counter artificial tear drops can be used.
- A small fan blowing cool air onto the person's face may help address symptoms of breathlessness. If symptoms of breathlessness are not relieved by these strategies it is important the person's registered nurse and/or GP is notified.
- If constipation is suspected contact the person's GP for support and advice. Regular monitoring of bowel function can help with the early detection and management of constipation.

- Ensure the person has passed urine. Urinary retention (difficulties with emptying the bladder) can be highly distressing and uncomfortable.
- If the person experiences nausea (feeling sick) avoid the use of smells and fragrances that may cause discomfort and distress. A cool damp cloth at the back of the neck may help to reduce feelings of nausea. Alternatively, the person's GP may be able to prescribe medications to reduce nausea. Try offering small ice chips to suck.
- Monitor for the presence of pressure sores or other similar injuries. Consider a review by an Occupational Therapist to provide advice on positioning the person and the use of specialised equipment, particularly if the person is spending most of their time in bed.
- Medications can cause adverse side effects, make symptoms worse and/or no longer serve a purpose for the person at the end of life. A GP review is important for a person who is approaching the last days of life, to ensure medications that are no longer necessary are stopped, and that medications that might be needed for comfort are available and able to be administered in a timely way.

## Environmental needs

- Ensure the environment is relaxing, calm, warm and peaceful. Minimise noise and where possible have the person in a single room.
- Consider using a low bed if the person is physically agitated and distressed. This can help reduce the risk of falls and injury.
- Provide familiar and comforting objects from the person's home as this will help promote a sense of comfort and security. These objects may include personal bedding and linen, photographs, and books.
- Play the person's favourite music in the background for periods of the day. Remove the music if the person appears to be distressed by the sound.

## Psychosocial needs

- People living with dementia may experience fear, distress and anxiety when approaching death. Use of simple physical contact such as holding the person's hand, massage or sitting with the person. Providing physical contact can provide reassurance and a sense of comfort and security.
- Consider use of spiritual and/or religious items, music or rituals which may be a source of comfort for the person and their families.
- Consider providing an animal or child representative item (such as a doll or robotic dog/cat). This may help provide a sense of companionship and comfort. Support the person to engage with visiting animals.

## Resources

Further information on palliative care evidence and practice can be accessed via the palliAGED website at [www.palliaged.com.au](http://www.palliaged.com.au)

There are several resources that may assist you in supporting a person living with dementia who is experiencing terminal agitation. Available from the HammondCare e-shop at [www.hammond.com.au/shop](http://www.hammond.com.au/shop)