Objective

The intentional induction and maintenance of controlled sedation for the purpose of relieving profound, refractory symptoms including agitation and delirium, in children who are near the end of life.

When an experienced clinician has assessed that the child’s symptoms are refractory, that their disease is irreversible and advanced, and death is expected within hours to days. Advice from specialists in paediatric palliative care is strongly recommended.

Introduction

Whilst most children will follow a path of increasing drowsiness, fluctuating consciousness, and a comatose state before death, there will be a small number who have a more distressing journey characterized by restlessness, agitation, confusion and delirium. This can be extremely distressing to the family and staff involved. These symptoms may be mistaken for pain and, when increasing the pain medication does not resolve the situation, it leaves everyone feeling more distressed and helpless.

There is often concern expressed by families and staff that by giving sedation to a child at the end of life it will somehow hasten their death. The intention of sedation at this stage is to relieve the agitation being experienced. Appropriate sedation does not hasten death.

There needs to be good communication with the child/young person’s family/whanau prior to starting terminal sedation.

Definitions

Terminal agitation, terminal restlessness and terminal delirium are all used to describe this state of confusion, restlessness and agitation that can present at the end of life. It may be due to increasing hypoxia, organ failure with resultant deranged metabolism, and/or pain, fear and anxiety.

Management

Follow the steps below to manage a terminally ill child who is experiencing severe agitation.

1. Assess the child.
2. Address any symptoms that may be increasing their agitation such as pain relief, managing thirst, access to bedpans, urinals and so on. Take appropriate actions to reduce these symptoms.
3. General environmental measures aimed at reducing anxiety and disorientation should be employed, such as maintaining a familiar environment (child’s own clothes, belongings, presence of family members) consistency of staff and reducing the level of noise.
4. Discuss situation with primary consultant and/or paediatric palliative care team.

5. Discuss plan with the family, eliciting any concerns they have around sedation. Ensure they understand the irreversibility of the situation and the reasons for giving sedation.

**Medication**

Midazolam is considered the first line benzodiazepine due to its short half-life and ability, therefore, to be titrated easily. It can be given via IV, subcut, buccal or intranasal routes. Senior doctor should prescribe.

A longer acting benzodiazepine may be required

With specialist advice other useful medications may be required

Document actions and effect of sedation.

Contact paediatric palliative care team if further support is required.

**Associated Documents**

CR8873 - End of Life Care Plan

ADHB Policy - Allow Natural Death

**References**


