



Medicines in the last days of life



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This information sheet explains when and why medicines are used at the end of life for babies, children and adolescents. Not all people will need all the medicines discussed here.

When a child is in the last days of life, their body functions and vital organs slow down and will eventually stop. During this time a dying child may become less awake and go into a coma-like state. This is an expected part of the dying process. The goal at this time is to provide comfort and support to the child and also to you and other family members. One important part of comfort care is to provide medicines that will prevent or relieve pain, discomfort and suffering that may be caused as a result of the child's medical condition/s or slowing body function.

Some parents/carers want to be in control of their child's medicines and care when they are in hospital, whereas others would prefer not to be so involved. If this is important to you, please ask the nurses and doctors caring for your child what medicine/s they are given, what the medicines do and how you can be involved in ways to make your child more comfortable.

If your child is at home, your Care Team will have explained what medicines should be used and why. You may also have a role in giving these medicines to your child.

You and your child's Care Team will work together to make sure your child is comfortable by watching for signs of discomfort or distress. While your child's Care Team is experienced in caring for patients, they cannot have the deep understanding of your child that you do. *So, if you think or feel that your child is feeling pain, is uncomfortable or is distressed, please let them know.* These symptoms may be shown by:

- Facial signs, such as grimacing or wincing
- Groaning
- Stiffening or resisting body movement when being moved into a different position
- Restlessness or agitation
- Bloating tummy (which was not there before)
- Dry heaving, vomiting or repeated burping
- For some children, being very quiet or still when they are awake can be a sign that they are not comfortable

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How is medicine given in the last days of life?

It is likely some or all of your child's usual medicines may not be needed at the end of their life or they may not be able to still take their medicines in their usual way. The most common way to give medicine to children (including very small babies) in their last hours or days of life is through a small very thin tube that goes under the skin. The medical name for this is a *subcutaneous catheter*.

The outside part of the subcutaneous catheter will be taped to the skin. It will have a "bung" where medicines can be given without using a needle. It will also be able to be connected to a machine called a *syringe driver (or syringe pump)*. This is a machine that is able to deliver very small amounts of medicines continuously.

Most children will not be able to swallow medicines in the last days/hours of life and medicines can instead be given via the subcutaneous catheter. Medicine given this way works very well to help prevent and manage your child's symptoms. The subcutaneous catheter can stay in place for a number of days before needing to be replaced.

If your child has an intravenous catheter, a port or a central line, these may be used to give their medicines.

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Medicine for pain and breathlessness

Morphine (and other pain medicine such as oxycodone, fentanyl, hydromorphone)

Morphine or similar medicines are an important part of comfort care management. Some dying children or babies may experience feelings of pain or breathlessness (feeling like you cannot catch your breath) in their last hours/days of life.

Giving regular or continuous amounts of morphine or similar medicines works very well to keep dying children comfortable by easing their pain and helping them to breathe more easily.

Morphine and similar medicines are safe and are used by many people every day. Morphine and similar medicines that are given when a child is dying, do not shorten their life. People are only given the amount of morphine or similar medicines that they need to keep their pain controlled and to be able to breathe comfortably.

If you think that your child is in pain or finding it hard to catch their breath, please let the nursing or medical staff know. It is better to start treatment earlier rather than later.

Medicine for restlessness or confusion

Haloperidol or midazolam

Confusion or restlessness may occur in the last days of life. The medical word for this is *agitation* or *delirium*. Your child may be hallucinating – talking to people who are not there; become difficult to reason with or maybe angry with family/carers and friends, even though there is nothing that has caused their anger. Often it is not possible to settle them down because they are responding to what is happening in their thoughts. They do not understand that what they are thinking isn't really happening.

Two common medicines used for settling agitation are called *haloperidol* and *midazolam*. These medications can be given through the subcutaneous syringe driver or as a subcutaneous injection.

Medicine that is given to manage confusion and restlessness has a relaxing and calming effect on your child. You may find that they are more settled and do not wake up as easily. They may only open their eyes or nod occasionally rather than talk to you. Sometimes they may stay asleep even when you talk to or touch them.

Please let the nurses or doctors know if you are worried that your child is restless or confused. It is more comfortable for your child if we can manage this restlessness or confusion earlier rather than later.

Medicines to control nausea and vomiting

Ondansetron, haloperidol, and metoclopramide

Not everyone will feel sick or vomit at the end of life. But if your child has been vomiting or if they have felt sick in recent days, please let your Care Team know. If your child has been started on morphine and it has in the past made them feel sick with nausea and/or vomiting,

it is important to tell your Care Team so they can give medicines to prevent this from happening again.

Medicines for noisy or rattly breathing

Glycopyrronium (glycopyrrolate), hyoscine butylbromide, hyoscine hydrobromide

In the last hours of life, a person may begin to make a noisy, 'rattle' sound when they breathe. The noisy rattle comes from a build-up of spit (saliva) and mucous that they are no longer able to swallow or spit out. Changes in breathing and the rattly sound are not usually distressing to the child who is dying.

Medicine may be given to dry the mouth and reduce saliva so that fluid does not build up in the mouth. These medicines work best if they are given as soon as the noisy breathing begins. The medicines can be given through a subcutaneous catheter, either as needed or via a continuous syringe driver.

Please be aware that these medicines may not completely stop the noise.

Increasing doses of medicines

Medication doses will be increased only to make sure your child is kept comfortable. Sometimes your child will seem more sleepy but this is usually the effects of the disease or illness and not related to the increase in medication.

What should I do with their medicines after my child dies?

It is important that any medicines prescribed for your child are safely disposed of when they are no longer needed. This includes regular medicines that may have been stopped (including tablets, liquids, inhalers and eye drops) as well as the injection medicines used in the last days of life.

What to do:

Take any medicines that were prescribed for your child to your local community pharmacy and ask the pharmacist to safely dispose of the medications for you.

What not to do:

- Do not flush medicines down the toilet
- Do not pour medicines down the sink
- Do not throw medicines into the garbage

(Adopted from the Return Unwanted Medicines (RUM) Project)

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PPC6523/0720



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