

Symptom Management

Confusion and other changes in the mind

Some children show signs of mental confusion and other changes in the mind as their condition gets worse. These states of mind may come about slowly or quite suddenly. They may last for a very short time or they may last for hours or days. When a person is in a different reality than ours, it can be frightening for those around. It is a fear of the unknown. What does it mean when our child sees something we cannot? What do we do when sister does not seem to know brother? Will my child no longer respond to me? Express your fears to your child's doctor and nurse. They can help you understand and manage your child's specific symptoms.

The risk of confusion or changes in the mind increases when the child:

- * has more pressure in the brain;
- * is taking some kinds of medication that has side effects on mood and the nervous system;
- * is in great emotional distress;
- * has a condition that is affecting more and more of the body;
- * moves closer to death.

Watch for these signs of mental changes

- * mood swings from high to low;
- * insists rigidly on a certain activity or routine (obsessive)
- * confuses time, place or people;
- * fails to respond to what is happening around him;
- * restless or repetitive actions like pulling or picking at the bed or the air;
- * talks about things that do not relate to here and now;
- * "sees" or responds to people that are not present for others;
- * vivid dreams that may comfort or frighten;
- * responds with emotions that don't fit (crying at a funny movie).

You can expect some mental change along with physical change as part of dying.

Parent voice:

I've always been so much better at dealing with physical illness than anything to do with the mind. I'm frightened by thoughts of "losing my mind". The first time James became confused and had visions I was beside myself. Then I just made up my mind that he was not going anywhere on his own – I had promised him that. So I stopped trying to bring him back to my reality. I just went along with his vision. I told myself I was along for the ride – a mind trip, a fantasy, a place I would never go on my own. All I had to do was "change my mind".

Preventing mental changes

- * **Review medications with your doctor to reduce the risk of side effects**

Deal with emotional concerns (refer to the handout [Emotional Distress](#)).

Keep surroundings and routines as familiar as possible.

Managing changes in the mind

- * **Help a confused child come back into the reality**

Say in a soft clear voice who you are and introduce others before you start to interact.

Explain what and when: *“David is here to say hello. He has come home from school. It is lunch time.”*

Always tell your child briefly but honestly what you are going to do before you touch *“I am going to give you your medication”*.

- * **Figure out what is most comfortable when your child is withdrawn and less responsive**

Some children prefer the calm of a quiet room away from things. Others seem more comfortable where the action of the family is happening. In that case maybe you can have the child’s bed in the living area or near a window where she can see outside.

- * **Don’t try to hold down a child who is restless or picking at things unless he is in danger**

For example, trying to get out of bed and has poor balance.

- * **Accept what your child claims to see and hear**

Try not to correct or explain away your child’s experience. It is more comforting to be reassuring about them. *“I see you are smiling. Something is making you happy.” Do not try to find out more about it.*

If your child is **frightened** by the “vision” or a dream shake him gently and reassure him. *“It’s ok, you are in your bed, in your room. Mommy is here and you are safe with me.”* Leave a low light on at night if this is a comfort.

Keep what you say short and simple when you are moving your child out of confusion.

Unless your child shows signs of stress, keep speaking, stroking, kissing, reading, or playing music even if she is not responding.

Just because others cannot see or hear something does not mean that it’s not real to your child.

Remember that brothers and sisters will need help understanding and knowing how to respond to what seems “weird” or “spooky” to them.

* **Use medications if this is part of your comfort plan.**

Discuss this with your health professional. If your child seems terrified and anxious much of the time, medication that calms may be a great relief. If your child is afraid to go to sleep because of bad dreams, medication may help her get some rest.

Getting professional help when appropriate

If you have not already decided on a plan, call your doctor or nurse during the day if your child:

- * seems afraid about what is happening
- * has odd behaviours that trouble you
- * is withdrawn for most of the time.

When you call, give your child’s name, age, and diagnosis. Be ready with this information:

- * What is happening and when?
- * What medications is your child taking?
- * Does your child have a temperature? (Explain if taking a temperature is not part of your plan.)
- * What drugs/therapies has your child had?

End note:

A lot is asked of you as you go as far as you can with your child. Will it help to think of going with your child into these altered times and places, where only she can lead you, because only she sees the way? Strange places – yes. But, all great explorers have had to be brave.

The plan to manage confusion:

This pamphlet is the result of a collaboration between
 British Columbia’s Children’s Hospital
 and Canuck Place Children’s Hospice

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BCCH - 1028

