Symptom Management

Breathing difficulties
The first breath begins life – the last ends it.

The quality of life and the ease of death are closely bound up with the ability to breathe easily.

Many parents are frightened by the idea that their child will gasp for air and they will be helpless. Most children have less breathing difficulties than adults. Their lungs are healthier. But it is still important to consider this worry. Some children will have changes in their breathing. There are things that we can do to help the child feel comfortable.

The risk of breathing difficulties increases when the child:
- has a disease that affects the lungs or has had many chest infections leaving scars in the lung tissues
- has infection;
- is less able to clear fluids that collect in the lung and around the heart;
- has problems with coughing or swallowing so that stomach contents or mucus accidentally get into the lungs;
- is panicky (causes rapid breathing);
- has pain (often affects breathing);
- has anemia (there are too few red blood cells to carry oxygen);
- is unconscious (there may be a pause of several seconds between breaths).

Watch for these signs of breathing difficulty
- shortness of breath;
- dizziness or light-headedness may lead to fainting;
- less energy;
- change in pulse, blood pressure or breathing pattern;
- a feeling of not getting enough air (air hunger);
- blueness around mouth or nail beds;
- headaches in the morning;
- chest pain;
- noisy or wet sounding breaths;
- coughing – wet or dry;
- fast breathing.

"Breathing easy" is our language for feeling well and stress free.
Preventing breathing and circulation difficulties

- Give your child cardiac or other prescribed medications regularly.
  Use the medication that gives relief of “attacks” of shortness of breath and reduces the anxiety.

- Consider slowing down
  If an enjoyable activity causes breathing difficulty, think about a way to slow it down. Think through the plan for the day and try not to rush from one thing to the next.

- Create more calm
  Lower the noise level and limit the number of people with the child at one time. If fear and panic affects breathing, try to teach your child some self-calming strategies. (See “Emotional Distress” in the handout called Parenting a Dying Child.)

- Check that pain is under control
  Pain can be a factor in breathing difficulty.

  Parent voice:
  *We used to do lots of suctioning and chest physio - we did it several times a day. I’m glad we stopped that when we did. It was causing Ron so much discomfort and it did little to improve things. We saved our precious time for other things. We relied on meds., positioning and cuddles - simple comforts - to help breathing.*

Managing breathing and circulation difficulties

A general plan includes some of these ideas:

- Put your child in the position that brings most relief
  Try different positions - sitting up, leaning forward, lying down, arms above head.

- Give oxygen if you have it
  Take your cue from the child. Some children find the mask annoying. You can give oxygen through nasal prongs (small tubes that fit into the nostrils) or a tube held close to the nose and mouth.

- Remove tight clothing

Sometimes the breathing difficulties are related to problems with the heart and blood circulation.

Have a plan in place for managing breathlessness.
• **Remain calm.**
  Your panic can increase your child’s fear.
  Reassure and repeat calming messages: “You are going to be O.K. I’m here with you. Let’s breathe deeper and slowly....”

• **Give prescribed medications**
  There are medications that control feelings of panic, breathlessness. Ask your doctor about them. Keep them with you at all times.

• **Open a window or put on a fan.**
  The movement of air often helps the child feel less breathless.

  Note: Discuss whether there is any benefit to giving a blood transfusion to boost the oxygen carrying blood cells. (Refer to your decisions about quality of life. See the handout Critical choices about blood transfusions.)

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**Getting professional help when appropriate**

Call your nurse or doctor **during the day if:**

• the plan to manage shortness of breath is no longer working
• there is an increase in any of the signs of breathlessness

If you have not already decided on a plan, call your doctor **immediately** if your child has:

• choking (call 911 for help)
• gasping and distress

When you call, give your child’s name, age, and diagnosis.

Be ready with this information:

1. Is this a sudden change in breathing?
2. What have you already tried?
3. Is the breathing very slow or very fast?
4. Does he have pain?
5. What medications is he taking?
6. What therapies/treatments has she had recently?
End note:
In the last hours of life breathing will change. This is a normal part of dying. As the time gets closer, prepare yourself. Read over the section about what to expect in the hours before death. The greatest comfort for your child will be hearing your own steady breathing and heartbeat close to hers. Practise using your own breathing as a calming strategy. It will support all of those present at that awesome moment.

The plan to manage breathing difficulties:

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