

Parenting a Dying Child

Sleep

We can't do without sleep. Enough sleep is as much a concern for the caregiver as it is for the sick child. It is foolish to think that you can deprive yourself of sleep and continue to be the best you can for your child. Parents find that their sleep is linked to their child's sleep pattern. It is hard to be asleep when the child is awake. Keep in mind that other members of your family can take turns to be with your child so you have sleep time.

Sleep patterns change

Your child's sleep patterns will likely change. This is normal at the end of life.

- * **Sleep times may get shifted from night to day**

Some children fear the night and being alone while asleep. They fight sleep until they see the light of day, then relax into it. Some children nap for short periods at a time rather than having one long sleep. After the nap the child may have a time when he is very alert.

- * **Some children sleep much less**

They are afraid that they won't wake up, or that you will leave once they are asleep. Some children are not afraid, but use the time to think, come to terms and "ready themselves."

- * **Sleep may be more disturbed and restless**

- ◆ It may be filled with vivid dreams. Some dreams bring feelings of peace, others of terror.
- ◆ Night sweats or pain may wake the child.

- * **Most children will sleep more as death comes closer**

The child may be drowsy much of the time and have to work to stay awake, even for fun times. Some children will move into states of "waking sleep." They will seem neither fully awake nor truly asleep but are difficult to arouse. At the end, the child may slip from this into unconsciousness.

Consider how to respond to your child's changed sleep patterns

* If your child is not able to sleep or sleep is disturbed

Ask your child what might help:

- ◆ a night light and an open door;
- ◆ a bell beside the bed that she can ring if she wakes;
- ◆ moving his bed into a room closer to the centre of family activities;
- ◆ a massage, warm bath, or shower before bed;
- ◆ distractions like music, stories or videos;
- ◆ a hot water bottle inside a furry cover;
- ◆ someone resting on a bed beside him all night.
(Take turns with other family members.)

If the sleeplessness is distressing to your child, contact your health care professional to explore sleep medications, and other ideas.

Consider whether pain, night sweats or other physical discomfort may play a part in disturbed sleep. Ask for help with this from the health professionals.

* Make sure your child is safe in her bed so you can sleep restfully

- ◆ If he is in a hospital bed, keep the side rails up.
- ◆ If he is in a regular bed, install side rails if he is restless or confused. They are available at toy stores and pharmacies. They are easy to set up. You can also put the mattress on the floor.
- ◆ Pin or tie a small bell to your child's bed sheet. If he becomes restless or tries to get out of bed while you are resting, you will hear him.

* If your child is sleeping most of the time with very few alert times

- ◆ Try to gear family time around your child's waking and alert moments.
- ◆ Ask the doctor or nurse to review the medication to allow your child to be as present as possible for as long as possible.
- ◆ Respect the natural process of death.

Try to sleep when your child sleeps. Allow close friends, family or volunteers to help you with chores like laundry, cooking, etc.

Fear may disturb sleep. Talk with your child about his fears. Be honest so that your child is truly free to share his fear. If you will not talk about death to your child, your child will carry his fear alone. (See the handout on Talking to the dying child and the "Emotional distress" section in this handout.)

Parent voice:

We really struggled to find a balance between staying connected in our usual way to Enrico and allowing him to fall into the long sleeps. All of us really wanted him to stay present with us. When he slept we felt we were losing out on our time together. Also, we didn't want him to feel we had given up on him as a member of the family. The other kids found it hard to know what to do if he was sleeping.

We suggested that they say good morning and good night and hello and goodbye in the usual way whether he was sleeping or not. We would still read a story and play music each day. We would tell him about friends and family who had called. But we gave up on the constant chatter and attempts to get his attention. We left him undisturbed by words and did more humming and handholding. It felt right but who really knows?

End note:

People say that we turn inward to our spiritual self, away from the activities of life, to prepare for death. We call this turning inward drowsiness, but perhaps it is a different state. Perhaps it is not one we can know until we come to the end of life. It is important to respect this state and not try to pull the child out of it. Perhaps this is the entranceway to peace?

This pamphlet is the result of a collaboration between
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