

Symptom Management

Fatigue

Fatigue is a loss of energy. A fatigued person feels physical changes such as heavy, weak limbs and a need for sleep. A fatigued person also feels emotional changes such as restlessness, loss of interest, and irritability.

Our common sense tells us that as the organs of the body become weaker they will work less well. They will also need more of the available energy to keep going. Fatigue is part of feeling unwell. It is almost always an aspect of the months and weeks before death.

The risk of fatigue increases when the child:

- * has a condition such as anemia that affects the red blood cells;
- * has a condition that affects the heart or lungs;
- * is not able to eat a healthy diet;
- * has many infections;
- * is taking some kinds of medication or other therapy that make him tired or drowsy;
- * is depressed;
- * has changes in body chemistry eg blood sugar or salts that are too high or low, hormones that are not at normal levels;
- * is not sleeping well;
- * has chronic pain;
- * is getting sicker.

Watch for these signs of fatigue

- * loss of interest in activities;
- * withdrawn from people;
- * less alert;
- * cranky and impatient;
- * rests and sleeps more than usual;
- * feels weak;
- * cannot “stay with” an activity.

Preventing fatigue

- * **Make sure your child gets enough restful sleep**
Put a bedtime routine in place that includes a quiet time together.

If sleep is often disturbed then ask about a sleeping pill to help ensure a good pattern of sleep.

There are many ways to describe the feeling of fatigue: tired, weak, weary, drowsy, loss of interest in life.

For many families it is the fatigue that interferes most with their efforts to make the best of these precious weeks. Because of this, we will all work towards reducing its impact on quality time.

Body energy needs calories and oxygen in the cells of the body. Anything that limits the amount of either of these increases fatigue.

* **Try out different rest or nap times during the day**

- ◆ Some children do best with a fixed time and others prefer to lie down only when they need this.
- ◆ A rest time does not have to mean sleep. A rest time can be a story or quiet music time.

* **Get some exercise, in each day, for as long as this is possible**

Caution: Be very sensitive to changes in levels of fatigue. You don't want to insist on exercise beyond the point when it is helpful.

* **Plan the activities of the day to avoid rush and stress**

- ◆ Slow the pace when possible. That means leaving earlier, starting sooner, putting less into the day so your child can enjoy it more.
- ◆ Balance out active and restful activities. When you plan, consider that eating a meal, getting dressed, taking a shower all use just as much energy as work or play.
- ◆ Try to space out visitors so that each can be enjoyed.

* **Conserve energy for what counts**

- ◆ Some things may be very important for your child. Limit other activities on the days or in the weeks when these events happen. If a party or outing is something your child is eager to attend then don't add other things into that day or week.
- ◆ Give the child some choice: "Do you want a bath now or should we take our puppy into the garden to play?"

Managing fatigue

If your child wants to be active and involved but is frustrated by fatigue discuss some options with your health care team.

* **Treat the underlying cause**

Talk with your doctor and nurse about whether there are benefits in treating the cause of the fatigue during this phase of your child's life. Depending on the cause, the doctor may suggest blood transfusions, food and or mineral supplements, changes to medication or oxygen.

- ◆ Use medications to give a boost of energy for a short period or special event.

Ask your doctor about this.

The key to rest is a period in a peaceful place with less noise, light, colour and activity. Lower the lights, close the door, turn music down or off.

Strange as it may seem, light exercise "works up" energy. It also promotes restful sleep.

Parent voice:

We involved Caitlin in planning activities for the week and day. As a teenager she needed some sense of being in control of her own life. We talked about her 'energy bank'. 'How much is in there today? What shall we spend it on? Shall we save it up for the hockey game tomorrow?' "

* Sometimes treating the emotional stress factors like depression and fear relieves fatigue

- ♦ Medication is useful at some times.
- ♦ Consider asking for a psychologist or play therapist for your child.

Getting professional help when appropriate

Call your doctor or nurse during the day if you:

- * see any of the signs/symptoms listed above and need some ideas on how to manage increasing fatigue.

If you have not already decided on a plan, call your doctor or nurse as soon as you can if:

- * fatigue or weakness comes on quite suddenly – in minutes or a few hours.
- * drowsiness is so deep that you cannot rouse the child.

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

1. When did the fatigue start?
2. When and what treatments/medications/blood work has your child had?
3. Has this happened before? What did the doctor do then?

End note:

As your child moves into the final weeks of life, it is likely that he will retreat into more sleep and quiet, inward time. Although it is very difficult to allow this to happen – it is so clearly a slipping away from life – it is an act of great love to take this part of the journey at your child’s slowed pace.

The plan to manage fatigue is:

Follow your personal plan before these suggestions.

Fatigue is a part of the dying process. Rather than trying to energize, move toward more times of holding and breathing together, quiet story-telling and remembering.

This pamphlet is the result of a collaboration between

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