Parenting a Dying Child

Loss of movement

Some children are able to move around without help to the very end. Others lose muscle strength slowly but surely and need more and more help with things like feeding, getting on and off the toilet, or walking. Movement can also be affected by dizziness, fatigue, or paralysis caused by some conditions. It may also change the way your child is able to play and interact with others. Children can get very frustrated by these losses.

The team will do its best to find ways to support your child so that he can help himself for as long as possible.

Signs that your child may be losing the ability to move

- slumps over often;
- trips often;
- needs support to keep balance;
- gives up quickly on activities like combing hair or brushing teeth;
- chooses to spend more and more time in bed.

Consider how to respond to your child's loss of movement

From your child's point of view, the loss is one of independence – what she could do before without your help she can no longer do. It may feel like being a baby. Losing what it means to be "grown up." We will all try to manage this with sensitivity.

Ask family and friends to be helpful without commenting on the support they are giving. For example put drinks where they are easy to reach. Put telephone into the hand. Take the child's arm when walking.

Your child might ask questions about why he can't move like he used to. You can use these questions to try and find out what your child is thinking and feeling. (Refer to the handout "Emotional distress.")

Parent voice:
For us the hardest was the day Jon could not stand for long enough to get from bed to chair. His knees seemed to give out and he crumpled up and fell. It was hardest because it was this that drove home to him that he was not getting better. He told us he felt like a baby that had to be carried. Other changes were less clear to him even though we could see them. Because he couldn't notice them, somehow they had less impact.

Parent voice:
I did not want to feed Jonah when he had been feeding himself for at least 2 years. I would bring the food already cut up, but arrange it as if this is how it was meant to be. This way I did not have to cut it up in front of him. I served soup in a small cup so he did not have to lift spoon after spoon."

Parent voice:
Someone asked us what he could get Peter, our teenager. We suggested a speaker phone. Peter loved getting calls from his friends but he really could not hold the phone at his ear. This allowed him to speak in private. He loved that bit of independence.

- ### Consider what kind of help would make it easier to get around

  As changes occur, your health care professionals can help you get equipment that will make moving easier and safer for your child. They can refer your child to an occupational therapist (OT). An OT can meet your child and advise on ways to make the most of the strength and movement your child has. Some examples of helpful equipment are a hospital bed, a wheelchair with head and neck support, bars installed near the toilet or shower/bath, or lifting equipment.

- ### Consider how to protect your own back and muscles while helping your child

  - If you need to give your child a great deal of support when moving from bed to chair or toilet, make sure you know how to do these transfers without hurting yourself. An occupational therapist or nurse can teach you the safe ways to move your child.
  - Ask for help when you can't manage safely on your own. Hurting your own knees or back is a danger you can avoid!

- ### Consider ways to keep your child in on your family's activities

  - Some families move their child's bed into the living or dining room.
  - Find things that the family can do that involve less moving around - watch movies, do a giant jigsaw, read books or listen to music together
  - Have an inside picnic.
  - Have a manicure night. Paint everyone's nails!

Parent voice:
We rented a wheelchair as soon as it got hard to take walks. Pele enjoyed being out. The wheelchair made it possible for us to go on taking our evening stroll on the beach.

End note:

Movement is a very obvious sign of life - hurrying, moving about, doing. When we talk about things slowing down, we think about the pace of life changing as it moves to the end point of stillness.

This pamphlet is the result of a collaboration between
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