

Parenting a dying child

Precious Time

You will not regret the time you have spent focussing on your child rather than the disease or the “battle.” This is true whether your child survives or dies. Regrets often focus on time lost to the “battle.”

Parent voice:

Weeks after Sal died I was still stuck with ‘what ifs’. What if I had insisted on another transfusion? Maybe if we had tried pushing the diet and vitamin supplements Jan told us about we would have had another year? When I would go on and on about this, my good friend used to remind me about how carefully I made each decision for my child, how hard I worked at thinking through what was best for Sal. She always helped me to focus again on why I made the decisions I did.

Parenting a child through life is the most important and the hardest work most of us will do. Many manuals have been written offering advice and still we struggle. Parenting a child through dying is overwhelming. It is hard to find helpful guidance.

Many people talk about “finding meaning” or making the experience “meaningful.” It is challenging to know what this means, let alone how to do it. How can the loss of a child ever make sense? So what are these people trying to tell you? They are not trying to get you to make sense of your child’s condition or to find comfort in some philosophy. They are encouraging you to make the time special, to be mindful of how you are connecting to your child. It means thinking about what your child gives you and what you give your child.

In our experience so many parents miss the very best chances for joy and closeness. This is because they remain focussed on a “fight for the cure” no matter how improbable, during those months when the child still has the energy to invest in life. They may choose to push nourishment rather than the pleasure of food when the child still has an appetite. They may forgo a birthday party for a blood transfusion. Consider what is being lost with an ongoing battle for the cure. Try not to leave it too long to start focussing on quality above cure. Perhaps today is the day to start.

A parent framed his regret about how he had used his time this way: *“I have journals filled with every lab test result, with blood counts, pain measurements, calories eaten. Why did I keep all these records and no record of the cute things he said?”*

The guiding principle must surely be to use every chance you can to create pleasure and joy. And when this is no longer possible, to move toward an inner peace for you and your child.

Love lives in the space between people who are reaching out to one another.

Precious time can be lost as easily as gained

We can lose precious time when we don't recognize or seize the moments. The moments may be a good day, a good morning, a good 10 minutes. A moment may be a child's question or comment which serves as an opening for an intimate talk. A moment may be a storybook or a song that opens the door to a memory. A moment may be a good laugh. A moment may be a chance to express love, quiet fear, or make a new discovery.

Consider how you can add precious time to your child's life – and yours.

- * **Use the opportunity that comes with a good day, a good morning, a good 10 minutes. Forget chores in favour of fun at these times.**

Ideas:

- ♦ Make an "I wish I could ...list." Pick something from the list to do when your child has energy to do it.
- ♦ Take a trip to the mall/town and invite your child to buy a gift for anyone he chooses. (Set a dollar limit!) Suggest he write or dictate a card to go with it. This is not just a fun activity. It gives a chance for your child to express love.
- ♦ Invite your child's best friend for a visit. Take a photo of the two of them together.
- ♦ Sit under a tree in the garden with your child on your lap.

- * **Pick up on a child's question or comment**

Examples:

"I just love puppies". Maybe there is some special outing you can make around puppies - like a pet shop visit or borrowing a puppy to take for a walk. Find a breeder with a new litter. Chat about where each puppy might go when it leaves.

"How come I can't see the moon tonight?" This can be a rich moment. You can talk about how one can know that something is there even if you can't see it.

"I wonder what Jamie is doing now." If the time is right, this can lead to a meaningful talk: *"Isn't it strange how people come into our minds. We think about them even when they are not there in the room with us."*

Adding precious time to life may be adding an extra day. It can also be using a given day well.

* Use the power of stories and songs

Read stories together. If your child chooses the same book or story often, consider why this is special. Is there a message in it? You can make that book a precious thing. Perhaps write a special message in it for your child. Perhaps ask your child for a special message to write for the family. Write it into the book and have your child sign her name. Record a sibling reading a story to your non-verbal child. Try to comment, as she reads, on her sibling's smiles and responses. This can become a memory treasure.

Make your own storybook or scrapbook together. This can be a way to reflect on your child's life. It can include lists of best times, things I am good at, holidays, remember whens and so on. Type it up, leave space for photos and drawings. (Keep a tape recorder handy.) Older children may have a pop song they sing often. Ask your child to teach you that song. Record the two of you singing it together.

* Do some family art projects

- ◆ Many children (and adults) find it hard to express feelings or ideas with words. Crafts can be a different way. Ideas:
- ◆ Have a playtime when everyone makes a card for each other.
- ◆ Do family handprints.
- ◆ Cut up old family photos and magazines to make an album of funny people from them.
- ◆ Make pictures and reflect on them.

* Create a chance for a good laugh

- ◆ Nothing brings down the tension level like a laugh or silly time! It is a relief for everyone to laugh together. Watch for chances to be silly.
- ◆ Help your child play a joke on the doctor, dad, or visitor.
- ◆ Get a funny movie and laugh together.
- ◆ Remember funny family events. Replay funny videos of the family if you have them. If you don't, maybe make a few. You can include everyone if you use props rather than words to create the fun. For example, how about making a video of everyone modeling a hat or costume.
- ◆ Make up funny words to a tune you know well.

Parent voice:

Nicholas's brothers and sisters often started to do silly kidstuff with Nicholas - make rude noises, bounce on the bed and so on. It drove me crazy. I wish now I had encouraged it. Sibling time is very precious time. Grown ups can't be kids and kids don't really want to be grown up all the time.

* **Take every chance to express love or quiet fear.**

- ◆ Cuddle up together as often as possible.
- ◆ Allow your tears when they come. Use them as a precious moment in which you can say, “I’m crying because I love you so much.” “I’m crying because I wish this moment could last forever.”
- ◆ If your child is crying, see that as a chance to talk about feelings and what makes us cry. Cry with your child if it comes naturally.
- ◆ Not all feelings are as comfortable as tears. Outbursts of anger can also be turned into a healing moment. (See the next section on “Emotional distress.”)
- ◆ Put up a board with photos of everyone who loves your child. Take photos of them with your child when they visit. Add them to the board so it fills up with love.

* **Discover new things about each other**

- ◆ Tell your child about the sweet things he did as a baby that you remember now and always will. Make a list of the cute words he used.
- ◆ Tell your child stories about you as a child. What kinds of mischief did you get up to?
- ◆ Play a game where you tell each other “something you don’t know about me.”

End note:

Good times together are rich in themselves. If these times have drawn you close and created memories, they will be the precious times. These are the times of no regrets and “sadness that is sweet.”

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CHILDREN'S HOSPICE

Parent voice:

We learned so much about each other in the last few weeks of Amir's life. One of the best hours we had was when I described how it felt to have him in my belly. I told him about all the stories his father and I made up about what he was like. I told him about how we gave him many funny names. He loved it! Funny - I have never done that with my other children.

Parent voice:

We needed to be reminded to make emotional and physical space for our child. We were so intent on making every moment count. We wanted someone with him all the time. We had his room crowded with stuff - there was nowhere for friends to be when they came. We took things in hand. We moved Matt into the family room - it was a bigger room. We went through each item on the wall of the bedroom and asked if he wanted it up again or in a drawer. Then, we made sure there was time for him to be on his own each day. When he didn't want alone time he let us know!