



# Prolonged Illness

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We see her put through the torture of test procedures over and over again.

We see her arms pierced repeatedly for blood work.

We hear him moan as they probe his body.

We see him cry each time a white coated person walks into his room.

We see him retching and vomiting from a strong medication.

We see her hair fall out after chemotherapy.

We see her slowly waste away to a mere shadow of what she once was.

We watch her succumb to the awful disease that claims her body.

Finally that dreaded day comes when he can no longer fight the terrible illness ravaging his body. And he dies,

The word "prolonged" gets at the very heart of this type of loss.

The fact that your child was sick for a long time is devastating.

The illness went on and on as you stood helpless at your child's bedside praying for a miracle that you knew would never happen.

If your child's death came as a result of a prolonged illness, you may battle many questions.

"Did I do enough?"

"Did I do too much?"

"If I had let them do that last treatment, would she still be alive today?"

"If I hadn't allowed that treatment would he have hurt less?"

"Would another doctor have had the answer?"

"Was the hospital the best one?"

Over and over you questions what you did or didn't do.

Along with this are the "If only's."

"If only I had seen the symptoms sooner."

"If only I had taken her to a different doctor."

"If only, if only \_\_\_\_\_."

You fill in the blanks!

Sometimes a child dies from a disease that he inherited from you or your spouse.

This can devastate the parent he inherited it from.

If not faced and dealt with, it is possible that the resultant guilt and blame could seriously threaten your marriage.

You may feel guilt if there were times you couldn't be with your child because of work or demands of your other children, or because there were times you simply needed to get away from your child's sick bed.

If you were not there at the moment of death you are almost certain to be convinced that you let your child down at the time she needed you the most.

Something that may surprise you is a sense of relief when your child dies.

It may be hard to admit to yourself or others for fear that it will be misinterpreted. But, this feeling is a valid one that many parents feel.

The child's illness may have lasted

months or even years, during which time there was a constant roller coaster of remissions and relapses, hope and disappointments. You spent long hours at your child's bedside feeling helpless and frustrated at not being able to make her better or alleviate her pain.

It is natural to feel relief when the long hours of worry and doubt and dashed hopes are over.

Probably you were worn out with the constant running back and forth from the hospital, all the while trying to work or keep the home in some kind of order.

You worried about the other children, "Did they think we loved her more than them?" "Did they feel neglected?" "Do they fear that they too, might come down with their sibling's illness?"

And your spouse!

You probably had little time for each other. Fatigue and worry may have caused you to be sharp with each other.

The almost constant demands on your time by your sick child can be a strain on even a good relationship.

Some parents have reported that after their child died they experience some of the child's symptoms themselves.

This could be an unconscious way of denying the reality of their child's death.

It is as though your subconscious says: "See, the symptoms are still here, so the child must still be here."



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# Prolonged Illness

*Just as each type of death carries its own special problems in grief, so too does the loss of a child to a prolonged illness.*

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Similar to this is the belief, again unconscious, that your child can still be hurt.

This is a deeply psychological mix up where the parent believes that a pain which is being inflicted on himself, as being inflicted on the dead child.

For example, my daughter's child died after an illness that lasted over six weeks.

She deeply regretted the many times she had allowed the doctors and nurses to stick and probe her daughter.

Three months after Emily died, my daughter had blood drawn for a minor illness.

She became almost hysterical, all out of proportions, at this simple procedure.

After her blood was drawn my daughter kept crying: "Emily, I'm so sorry, I'm so sorry."

It was not hard for me to see that she was associating having her blood drawn with the many times they drew Emily's blood.

I pointed this out to her, and later when this procedure was repeated, my daughter was not upset at all.

She was now clearly able to see that this was being done to herself, not to Emily.

You have probably seen your child go through many painful procedures and horrifying experiences in her illness.

You may relive some of these experiences over and over.

While your tendency may be to attempt to push them away and not allow them to replay: Don't!

As difficult and painful as it may be, it is more helpful to allow yourself to rehash these experiences.

This will eventually desensitize you to them and they will come into your mind less frequently.

Whatever thoughts or emotions you experience, especially guilt, it is helpful to examine them carefully.

It's important to understand as clearly as possible, what this thought or emotion is about and where it is coming from.

Certainly, your grief can not be dealt with by logic, but much of the guilt can.

Understanding can be healing. The question to ask yourself is: "With the knowledge and resources I had at the time, did I know to do it differently?"

This will help you see that you did your best.

There is a thought by some that when a child dies from an illness that happens over months, or even years, that we begin our grief before our child dies.

It even has a name "preparatory" grief.

Personally, I doubt that this is true.

We might grieve the fact that our child is not the vibrant, happy child he once was, or we might grieve some of the other losses that come with an illness, but we

can't grieve the loss of our child until he dies.

Just as each type of death carries its own special problems in grief, so too does the loss of a child to a prolonged illness.

Yes, you may have had time to say "good-bye", but that is little comfort.

The prolonged experience of watching your child die slowly causes deep feelings of helplessness, frustration and powerlessness.

Deal with these feelings by talking them out with a non-judgmental listener, and/or in a meeting of the Bereaved Parents of the USA.

Healing can happen if you allow yourself to experience and express these thoughts and emotions.

