

Nightmare that Come in the Day Time

Some events come into our lives that fall under the heading “Our worse nightmares”. They are experiences from which we wish we could wake up, but we can’t. They are our “Daytime nightmares”

One of these events is the diagnosis of a serious and life threatening illness for one of our children. There are a number of such illnesses. They are all devastating. They all turn our lives upside down. They all test us as parents, as couples, as friends.

If you have been involved with a serious childhood illness either as a child, a parents, a family member or a friend then you understand what I am describing. There are a wave of shocks to which you respond and a series of reactions which you experience. Research shows us that as humans we have similar reactions and responses even though for each of us they are unique.

Like the person in the jungle cutting through the under bush we can only see what is immediately in front of us. This limited vision and lack of experience fills us with fear.

Those attempting to guide us are like the tribesmen of the jungle who have climbed high up the tree to give us directions from their vantage point. They have a better view of the directions we need to follow and the breaks in the jungle. However, it is hard to trust them and believe them from our overwhelming location.

As parents caring for and supporting a seriously ill child we enter into a new world of medical personal, medical treatments, disease and procedure education and knowledge. We and our family become part of a different culture. A culture of medical personnel, medical tests, hospital stays, treatments and reactions, new friends with shared experiences.

It is a world which we never wanted to enter and about which we become too familiar. It is a world in which fear, anxiety, panic, desperation, pain and hope dance through our days and nights in no defined pattern. We live two lives; the upbeat, smiling positive one for family, friends and our children and the terrified, out of control, sensations we carry inside.

How do we survive this trauma and help our children and families survive, also? How do we maintain our balance and sanity while living this daytime nightmare?

In humble sensitivity we offer the following observations and suggestions for we know that each person and each family must find their own way through the jungle.

- 1) While shock, denial, anger and sadness are call competing emotions especially during the first year, bargaining seems to be the most prevalent emotional reaction. Parents

and families seek to find solutions, both conventional and alternative, in every location and venue. This is a necessary process as they educate themselves and seek to obtain some type of control in a very out of control situation.

- 2) Supporting the basic needs of all family members is essential. This includes healthy eating, regular exercise, systematic sleep patterns and maintaining regular schedules. No one can be supportive of others if they do not care first for themselves.
- 3) Establishing and continuing good communication with family and close friends provides outlets to share fears and successes. This helps the family keep the situation in perspective. Good listeners are essential in helping all family members process the experience.
- 4) Allowing for regular enjoyable activities for all members of the family, especially the ill child and his immediate care givers, provides balance and helps the body restore itself.
- 5) Accepting that fighting severe childhood illness is a long term process helps everyone involved pace themselves both emotionally and physically for the “distance” This provides more realistic expectations at each stage of the process.
- 6) Acknowledging that everyone involved will be changed by the experience helps the child, family and friends develop a “New reality” in time. This will guide the long term and permanent adjustments as a result of the illness.
- 7) Keeping a record through journaling, letters, e-mails, etc provides everyone involved an opportunity to share and record the progress made through this devastating experience. Out of all struggles comes triumph.

It is far easier to write suggestions than to implement them during a traumatic situation. The “Guides” in the tree; Medical staff, Family members, friends and others on the same journey are essential to the child and family in providing them with love, faith, support, humor, experience and balance.

The journey will unfold as it is ordained. Everyone will be different at its conclusion. The changes and memories created will shape and define us as we move forward in our lives. In time the nightmare will come to a conclusion.