

CHAPTER 10

Communicating with Each Other

When a child or sibling has a serious brain disorder, episodes of illness AND periods of clarity manifest. These periods of clarity which I refer to as “Windows of Opportunity,” offer us a chance to communicate with our relative during illness. These “Windows” are recognized by every family member I have talked to.



Communication work when done inclusively with all of those players who will be affected may take a little longer to create, but generally works out better for everyone in the long run. When I asked my brother, “What’s the difference between you and all those other people on the ward who are still there?” He answered, “We (the family) could all sit down at the table and talk, and nobody would get mad and leave.” This “sitting down at the table” and “nobody leaving” is one example of the family working together as a team.

When our child or sibling has a serious brain disorder, they experience episodes of illness AND periods of clarity. These periods of clarity which I refer to as “Windows of Opportunity” offer us a chance to communicate with our relative during illness. These “Windows” are recognized by every family member I have talked to. We can all remember times when our relative is feeling calm and we can discuss a problem clearly and succinctly. It is never going to be perfect. Talking with any ill person requires compassion and respect. We need to communicate clearly so that the person hears us. We need to listen thoughtfully so we can hear what they are saying.

It is helpful to bring only one subject up at a time. About a month after my brother was released from the hospital, I traveled to visit him and to arrange housing for him. Naturally I had concerns about his ability to maintain his own fragile stability in new housing. I chose a time after dinner when we were both happy and relaxed. I remember we were sitting beside each other on a couch while another sister washed dishes in the kitchen. The warm feeling resembled many Sunday evenings in our parents’ living room. I decided that the time was right. We had a short and good talk about two important issues. It probably lasted about three or four minutes. My brother agreed to take his medication and he also agreed to call me if he had a problem that he needed help solving.



In my own experience four things made our conversation successful:

1. Become familiar with what a “window of opportunity” looks like.
2. Know what you want to say and say it clearly.
3. Do not philosophize: communicate in a concrete manner.
4. Make it brief.

To be able to communicate again with my brother is a gift. I cherish and respect it. During bouts of illness, do not attempt too much. Just like anyone of us when we are very ill, relatives of ours feel better and safer when life around them is simple and not too much is asked of them. Remember during ill periods they may find it extremely difficult to get up in the morning.

