



# The Compassionate Friends

Offering friendship and understanding to bereaved parents

## A PARENT'S PERSPECTIVE FOR CAREGIVERS

There is little anyone can say or do to help ease the pain of losing a child.

It is a time no parent ever forgets, a time of unbearable anguish and sorrow. And yet, experience has shown that what happens in the hospital while a child is dying can have lifelong repercussions. It can affect the severity and length of parental grieving as well as the ability of parents to resume a normal life.

The following suggestions were compiled by people whose children died in a hospital or other health care setting. It contains their suggestions as to what was and was not helpful to them in their interactions with caregivers.

### WHAT YOU CAN DO FOR PARENTS WHEN THEIR CHILD IS DYING

Let parents "parent." They need to participate in the care of their sick child as much as possible AND to be with their child.

Prepare parents (and siblings) for what they will see before they see it. Explain the machines, tubes, needles and other equipment. Try to avoid complicated terminology without "talking down" to families.

If parents really want to be at the bedside during procedures, let them see what you are doing with their child. Let them lead in that decision.

### HONESTY

Always tell the truth. Tell parents everything you know about their child's condition. Be honest about what you don't know. Tell them the numbers – blood pressure, temperature, pulse, and so forth.

### EXPRESSING EMOTIONS

Give parents permission to talk about their feelings, to be extremely tired, to cry. Cry with them if you are truly sad. Don't hide your feelings to protect them. You are in a position of authority and your permission (and modelling) gives their feelings validity. Some parents may not be able to accept bad news and may cope by denying it. DO be patient with parents as denial is a form of emotional protection which will disappear when an individual is ready. Everyone is on a different timetable.

### SENSITIVITY TO PARENTS' NEEDS

Refer to the child by name - especially after death. Reassure families that everything possible is being done. They won't automatically know or assume that. Keep on reassuring them that no measure will be left untried in the attempt to save their child's life.

Recognize that sometimes there is a need to repeat the same explanation or information several different times. Parents under stress may only absorb a little of what you have explained. Allow enough time for parents to ask questions.

Make every effort to arrange for parents to be with their child at the moment of death if they wish to be. Please don't "protect" parents from this opportunity. Treat parents equally in giving information and breaking news. Mothers need information and fathers need support, too.

## **WHAT YOU CAN DO FOR PARENTS AFTER THEIR CHILD HAS DIED**

### **UNDERSTANDING GRIEF AND MOURNING**

Allow parents as much time as they need to be with their child (alone if they wish) after death. This time is vital in their healing process. In the case of a child who was hospitalized for some time, there is often a vast amount of personal possessions to be packed up and taken home. Allow the parents to do this for themselves if they wish, but do ensure that they are not left to find their own way out of the hospital premises. If you cannot accompany them yourself, arrange for a senior (and familiar) member of staff to escort them.

Take pictures of newborns who die and put them in the infant's file in case parents want them in future weeks or months. (Sometimes, a baby dies before the mother is discharged from the hospital or before she has seen her baby.) Taking a footprint or saving a lock of hair also may have special meaning for parents. These things are tangible proof that their child lived.

### **SHOW PARENTS YOU CARE**

Touching is our most basic form of comfort and communication. Don't hold back if you want to put your hand on a parent's arm or your arm around a parent's shoulder, or if you want to say, "I'm sorry." Don't "hit and run." If you must break sad news, try not to rush away immediately.

At the time of informing parents that their child has died, tell them what steps to take next. They are in shock, disbelief, and will be confused and need direction and guidance. There is no such thing as an "expected" death.

Most parents appreciate being asked about organ transplants. Sometimes, parents who aren't asked feel left out or even insulted. However, parents also need reassurances that their child's body will be treated with respect and dignity.

If possible, go to the funeral and/or visit the parents at home. It means more than you can imagine. A brief letter written to the family expressing sympathy reassures them that their child was not 'just another number' and that his/her death mattered very much. They will really appreciate your showing you care.

### **SUDDEN DEATH**

If your only contact with parents is in an emergency room, be sure to allow them plenty of time to absorb what has happened. Many parents want detailed information about the circumstances surrounding the death. (Was she in pain? Did he say anything?)

Be available to answer questions and let family members know they can call you if more questions surface later.

## **WHAT YOU CAN DO TO UNDERSTAND BEREAVEMENT AND TO HELP THE FAMILIES OF CHILDREN WHO HAVE DIED**

Learn about bereavement and how it affects family members. Symptoms of grief may include:

- feelings of sadness and body distress (lump in throat, sleeplessness, loss of appetite, exhaustion).
- preoccupation with the one who has died;
- guilt/search for causality (How could I have prevented this from happening?);
- anger/hostility;
- change in social patterns (isolation, inability to do daily living skills, vulnerability to physical illness).

Understand that parents do not wish to hear rationalizations about their child's death. Never tell a parent such things as: "Your child would have been a burden to you as he was", "She just would have suffered if she had lived" or "It's for the best".

Talking - expressing shock, pain and grief – helps parents adjust to the death of their child. Be available to listen, knowing that it will take years to adjust to what many people consider the worst loss of all.

Not all anger with the hospital or doctors and nurses is displaced. Some of it may be, but some is probably justified and may need to be examined.

Bereaved people know they need to have something to do, but they may be extraordinarily tired for a long time, and whatever they do needs to have meaning and importance. Don't suggest "busy work" as grief therapy.

### **WHAT YOU CAN DO FOR YOURSELF**

Many caregivers have expressed feelings of failure, sadness and frustration when a child they are caring for dies.

Be aware of your feelings and find a safe outlet for them. Your honesty and genuine expression of emotion will allow you to be more sensitive to those in your care. Acknowledging these feelings may also enhance your emotional well-being.

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