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Recovering

Changes, Activities, and Support Groups

"I am a different person from the young woman I was just before my child died. I don't feel changed in a radical sense, but I am changed. It's sometimes difficult to relate to that person: to the youth, invincibility, and near simplicity. Sometimes I have difficulty remembering that young woman who was the mother of two children. . . . It was a good time, laced with all the happiness and minor dissensions that are part of living.

"And in one hellish moment, all of that changed. Changed as swiftly as if a bomb had been dropped into the core of our lives. Changed on a bright, sunny summer morning when I picked up the rigid, lifeless, distorted body of our young son."

Carolyn Szybist wrote these thoughts after her three-month-old son died of Sudden Infant Death Syndrome. Life changes for most couples after the baby they wished for dies, whether before or soon after birth. Tragedies jolt people into taking a deeper look at their lives, their beliefs, their feelings. For many parents there is a new appreciation of life and of the family they have. They say:

My values changed. I have a different feeling about what is important. I don't care as much about material things.

I'm less selfish now, more aware of other people's suffering.

For the first time I understand the feelings of people who can't have children.

Although they may welcome these new insights, they wonder if a tragedy is the only way to gain different perspectives.

Some people become embittered and toughened by the experience. They no longer believe in a just God, or they are angry at the whole world. They feel unfairly marked for suffering.

For almost all parents there are heightened fears that something else might happen, that they are jinxed now. An example is the comment made by the mother of a stillborn daughter:

I kept having this premonition that my husband would die suddenly just as the baby had. Every time he was a minute late coming home from work, I would go crazy. I was sure that he had had a car accident or a heart attack.

Usually these fears subside over time. Yet the confidence, even innocence, of earlier days can never be entirely recaptured.

Emotional changes are only a part of what happens to families after the loss of their baby. In many cases there are changes in life-style as well. For the mother especially, the failure of pregnancy may dramatically alter the life she had expected. The woman who has given up her career or other involvements, in anticipation of becoming a mother for the first time, must make the biggest readjustment. Without either her career or baby she is faced with important decisions at a time of great distress. She is likely to be unsure about what to do next. Should she return to her former job or try something entirely different? Should she get pregnant again? Her ideas may change completely from one day to the next. One woman described her confusion after her stillbirth:

I couldn't bear facing new people, asking for a job, going to all those interviews, and then being turned down. I just didn't have the strength or the confidence. And the work seemed so meaningless to me. I wanted to get pregnant soon, so I also did not want to start something new, only to quit again. Since I couldn't decide, I didn't do anything. All I remember about that time is watching a lot of television. It was pretty depressing.

In coping with this emptiness, some women find that it helps to pamper themselves. They buy new clothes, redecorate the

house, join a pool or health club, buy the pet they always wanted, go on vacation. All of these are attempts to restore some sense of well-being, to erase the feelings of shabbiness and failure.

Almost any activity that contributes to greater self-confidence, no matter how trivial it may seem, can help the parents in recovering from the terrible blow that they have been dealt. In time, as they gradually feel ready to become involved in new activities, they may look for more substantial changes. This presents an unexpected opportunity for some parents to rethink their goals, to reorganize their priorities, and to move in new directions. It takes time and patience; the healing process is slow.

Sometimes the tragic experience itself becomes the source of a variety of creative outlets. Some individuals organize support groups or seek training in counseling in order to help others. Some become involved in environmental and political activism related to the causes of their loss. Others write stories and poems; a number of outstanding women authors such as Mary Shelley, Anaïs Nin, and Harriet Beecher Stowe all created great literature out of their experiences with infant loss.

In the past decade, a wide variety of books, seminars, and counseling services has become available to women seeking career changes or reentry into the labor force. Adult education courses have also expanded to offer them greater opportunities to obtain or complete a degree. And a multitude of organizations, consumer groups, political coalitions, and charitable or religious institutions eagerly seek committed volunteers.

A woman who took a maternity leave from her job or who is still working, or who already has other children at home to take care of, has the option of continuing what she was doing before her pregnancy. Women in this situation feel fortunate that they have something to keep them busy, just as do most men who continue with their work.

Nevertheless, it is difficult at first for both men and women to concentrate on their work or their other children at a time when

they are still grieving for the baby they lost. Friends or relatives may try to distract them, but sometimes they wish they could withdraw and be alone to cry or to think. Parents who are busy with work, child care, or housekeeping responsibilities do not always have the opportunity they need for grieving. One man whose son died two days after birth commented:

I work in a large room surrounded by people. Everyone knew the baby died, and I felt really awkward since I knew they were watching me to see if I was all right. I just wanted a chance to be left alone to deal with my own feelings.

How do people gather up the pieces and go on? How do they get over the nagging memories and begin to concentrate on other activities? Sometimes supportive friends and family or personal strength just aren't enough. For some, a social worker or psychologist is needed to help them to put their lives back together.

Even when professional counseling is not necessary, discussions with others who have also experienced the loss of an infant can help tremendously in the recovery. Organized support groups can put such parents in touch with each other.

The number of support groups—or self-help groups—has grown rapidly throughout the United States in the last decade. Professionals such as physicians, social workers, and clergy have been instrumental in organizing these groups, where individuals meet with others who understand their troubles from personal experience. Often it is only by sharing their emotions with those in the same situation that they can believe their own reactions are normal, that they are not going crazy.

Only in the last few years have families who have undergone a tragic pregnancy had an opportunity to meet and share their feelings. Some groups now in existence were organized by maternity nurses, social workers, and clergy. They often have the most immediate contact with bereaved parents in the hospital, so they can encourage them to meet with others soon after the infant's death in order to help them through the early stages of grieving.

In contrast, groups have been organized and run by parents outside of the hospital setting. Compassionate Friends is one such group for families who have lost a child at any age. There are local chapters in many parts of the United States. Although most of the parents grieve for a son or daughter whose death came at a later age, the parents of infants are also welcome.

AMEND (Aiding a Mother Experiencing Neonatal Death) was one of the first organizations that responded to the specific needs of families after infant death. In addition to group meetings, parents who have lost their infants in the past are trained to speak with and counsel the newly bereaved. These counselors meet regularly for lectures and discussions. Groups are being organized throughout the country, and their numbers are growing steadily. (See Appendix A for names and addresses.)

Probably the most active organization nationally for helping parents with all types of pregnancy loss is SHARE, based at St. Elizabeth's Hospital in Belleville, Illinois. Started by a remarkable woman, Sister Jane Marie Lamb, as a local support group, SHARE has grown to be the center of a network of hundreds of groups in the United States. It is an excellent source of information about available resources and of assistance in starting a new group.

These support groups are usually most helpful for parents going through the normal grief process. They do not offer intensive therapy but rather provide a setting where feelings can be expressed and will be understood. On occasion, they also present speakers who provide information on a variety of subjects that are important to the family. Some groups are more formal and organized than others. Some have a public meeting place, newsletter, and leaders who plan the meetings. In others, parents meet informally to discuss their feelings. In all groups, the atmosphere is one of acceptance, of allowing people to speak or simply to observe as they wish.

Many families find that they are not yet ready to become involved; they are reluctant to expose their open wounds so quickly to others. Fathers especially are less likely to participate

in groups, perhaps because many of them prefer to keep their feelings to themselves.

For some parents, it may be frightening at first to attend a meeting. They do not know what to expect. One mother talked about this feeling:

I had a name to call for Compassionate Friends, yet picking up the phone was very difficult. What would I say? Could I talk comfortably to someone I didn't even know? It took a few months of thinking about it and needing someone to talk to before I could bring myself to call her.

When parents do eventually decide to participate, it may be months after the event. Sometimes friends or relatives discourage involvement. Perhaps they are afraid that talking to others will revive the intense grief of the first days and weeks. But it is precisely at the time when others may be tired of listening and think that the mourning period should be over that the parents may need a sympathetic ear the most.

If there is no group available in the area, some individuals may wish to form their own. They should contact existing groups in other areas for suggestions on how to get started. Professionals in local hospitals may be able to provide contacts with other families and even meeting space and program ideas.

For Carolyn Szybist, whose son died of crib death, the support group she organized three years later was the key to her coming to terms with the tragedy. A magazine article about crib death led her to contact other people who had experiences similar to her own. She found that by talking to them—even though they were strangers—she could express her long-hidden feelings about the event:

... the release inside of me of so many locked up feelings can only be described as nearly exhilarating. It was a strange blend of hearing other people say what I had been feeling, and feeling along with them what I was hearing them say. When we all finally met as a group, it can only be described as a warm reunion of very old friends.

This feeling, that only someone else who has been through a similar experience can truly understand, has made support groups an important part of the recovery process for many parents. It is one way in which they can begin to overcome the terrible isolation of their personal grief.