

# *When a Child Dies*



**THE  
COMPASSIONATE  
FRIENDS**  
Supporting Family After a Child Dies

A Survey of Bereaved Parents  
Conducted by NFO Research, Inc.  
on Behalf of  
The Compassionate Friends, Inc.  
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## FOLLOW-UP CONTACTS:

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## BACKGROUND/OBJECTIVES

Government statistics estimate that each year 228,000 children and young adults die in the United States – and these statistics do not include miscarriages, stillbirths, or the deaths of older adults (age 40+) whose parent or parents survive them.

Since the mission of The Compassionate Friends (TCF) is to provide support and understanding to families following the death of a child, regardless of the age of the child or the cause of the death, TCF commissioned a survey in order to gain insight on the true scope of its mission.

The objectives of this study were to better understand:

1. The percentage of the adult population that has experienced the death of a child, at what age, and from what causes
2. Sources of support which were most helpful and unhelpful in parents' grief journey
3. Awareness of and use of support organizations such as The Compassionate Friends, and
4. The relationship between parental grief and divorce

Complete methodology is described at the end of the report.

## KEY FINDINGS

### The Magnitude of the Issue

The scope of the TCF mission is quite broad. Including all child deaths from miscarriage through death of an adult child, 19% of the adult population has experienced the death of a child, and 22% the death of a sibling. Taking into account people who have lost both a child and a sibling, 36% of the adult population has suffered the death of a child, a sibling, or both a child and a sibling.

Miscarriage is the most prevalent cause of death (43%), followed by illness (27%), accident (13%), and stillbirth (11%). The majority of deaths by illness occur in children over age 21, while accidents are most likely in the teen/adult years. Organizations providing support to bereaved parents must be sensitive to the needs of older parents, as children over age 30 accounted for 29% of deaths in children who survived past birth.

### Support Following the Death of a Child

An encouraging finding is that most bereaved parents found support through their family and community. Over 80% of parents said that family and friends were helpful to them following their child's death.

Other sources frequently sought out for support were co-workers (62% of employed parents turned to co-workers for support), clergy (60%), and funeral homes (45%). In most cases, these sources were helpful.

Women were more likely than men to seek understanding through books, while men were more likely than women to reach out to funeral homes/directors. Older parents were more likely to turn to clergy and funeral homes, while younger parents were more likely to seek assistance from books. Very few parents sought help from therapists (10% used), parental support groups (7%), other support groups (3%), or the Internet (2%).

Parents were also asked which one source they used was MOST helpful to them, and which one source was LEAST helpful. By far, family members were the most helpful source (66% said most helpful, vs. only 9% saying least helpful). Clergy was also likely to have been the most helpful (12% vs. 9% saying least helpful).

Most often cited as least helpful were friends (26% least helpful vs. 11% most helpful), co-workers (20% least helpful vs. 2% most), and funeral homes (20% least helpful vs. 2% most), suggesting the need for more education regarding how people around bereaved parents can be more supportive.

### Grief and the Employer

The learning from the workplace was also encouraging. When parents were asked specifically about their employer's helpfulness following the child's death, 69% said their employer was "Very" or "Somewhat" helpful.

Employees who did NOT find their employer helpful cited as opportunities for improvement: more flexibility in work hours/time off, stronger acknowledgement and understanding (verbally and through cards, flowers, etc.) and referrals to support organizations. Both supervisors and Human Resources departments can play key roles in conveying compassion on behalf of a parent's employer.

### Support Organizations

All grief support organizations have an opportunity to increase awareness of their services. Overall, only 46% of parents said that they were aware of any organizations that existed to provide support and understanding to families following the death of a child. Organizations most often named by parents who said they were aware of such groups included church organizations (10%), The Compassionate Friends (6%), hospice groups (6%), and hospitals (5%).

To understand awareness of specific organizations, the survey asked parents if they had ever heard of each of several organizations. Even among people who are a key focus of these groups—bereaved parents—total awareness (unaided from above + aided) of support organizations was low. Awareness was generally higher among women:

% Ever Hearing of:	Total	Men	Women
MADD	98%	99%	97%
SIDS Alliance	43	33	53
Parents of Murdered Children	36	29	42
Survivors of Suicide	26	23	28
The Compassionate Friends	18	12	24
SHARE Pregnancy & Infant Loss	14	13	14

Awareness of The Compassionate Friends came most often via newspapers (35%) and word of mouth (32%). Very few referrals came through the professional community.

### Grief and Divorce

Newly bereaved parents frequently read or hear disturbing statistics about a high divorce rate (often claimed to be 80-90%) among couples following the death of a child; however, TCF has never found reliable statistics concerning divorce rates following the death of a child.

To confirm or refute these claims, the survey included a series of questions regarding marital status. Based on the results, it is clear that the divorce rates quoted so often are erroneous. Overall, 72% of parents who were married at the time of their child's death are still married to the same person. The remaining 28% of marriages include 16% in which one spouse had died, and only 12% of marriages that ended in divorce.

While this percent may be slightly understated due to sample composition, the undoubted conclusion is that the divorce rate among bereaved parents is significantly below the often-cited numbers, and may in fact be lower than the level in the population in general. Furthermore, even among the 12% of parents whose marriages ended in divorce, only one out of four of them felt that the impact of the death of their child contributed to their divorce.

### IMPLICATIONS

- Community outreach is critical! Less than half the population which could benefit from parental grief support organizations even know that such organizations exist. It is important for these organizations to build community and national visibility, and to maintain it so that the newly bereaved know that support sources are there for them. Likewise, professionals who interact with bereaved families could be more aware of services available locally and could provide valuable referral services.
- Grief touches all ages. The death of a child is devastating, whether it's a young mother with a stillborn child, or an 80-year old father mourning the cancer death of his 50-year

old son. Miscarriages, stillbirths, and deaths of children over age 30 account for around two-thirds of all child deaths. Organizations and professionals who provide support must remember to be inclusive of and sensitive to the needs of all parents, regardless of the age of the child or the cause of the death.

- Bereaved parents generally feel supported by those around them, but there is an opportunity for even stronger community support. Grieving families received the most support from other family members, and most found their employer to be helpful. Though generally satisfied, parents see an opportunity for friends, co-workers, and funeral homes to be more helpful to grieving families, suggesting the need for further education on how to be helpful to bereaved families.
- Stop talking about divorce risk. Divorce in our society is a reality, but stories of even higher divorce rates among bereaved parents are a myth that must end. While it is beneficial for newly bereaved couples to understand the importance of communication and the fact that each family member will grieve differently, it is NOT beneficial to create an expectation that their marriage is doomed.

## METHODOLOGY

### SURVEY #1: THE SCOPE OF THE COMPASSIONATE FRIENDS' MISSION

In order to learn the number of people impacted by the death of a child, sibling, or grandchild—from miscarriage to the death of an adult child--TCF secured the services of NFO Research, Inc., to ask this question of 20,000 adults across the country. Respondents were selected randomly from NFO's national panel of 250,000 households, balanced to match the U.S. Census on geographic region, and within region on age, income, market size and household size. NFO included this question at no charge in a national multi-topic mail survey conducted in November, 1998. A total of 14,852 surveys were returned.

### SURVEY #2: HOW TO BE HELPFUL TO BEREAVED PARENTS

From the nearly 3,000 bereaved parents' names obtained in the first survey, a random sample of 290 men and 304 women was contacted via telephone by NFO Research, Inc. in February, 1999. (Overall cooperation rate was 33%. No significant demographic skews were seen relative to the total contacts. However, sample of 300 men was more difficult to obtain than a sample of 300 women. Thus, once the female quota of 300 was filled, remaining interviews were conducted with the male head of each household that was contacted.) These bereaved parents were asked a series of questions about their child's death. If they had experienced multiple deaths, they were asked to think about the most recent death. Sometimes the most recent death was a multiple death; this results in some columns summing to more than 100%. Information collected in this survey included:

- age of child, type of death
- how long since the death
- who/what was helpful, not helpful to them in the resolution of their grief
- awareness of TCF
- marital status then and now
- demographics of parent

Statistical variation in results depends on the sample sizes for the percentages being compared; for the total sample, percentages are accurate +/- 3.4%. Funding and analysis of the survey were made possible through a private grant made to TCF.