

When a Child Dies

A Survey of Bereaved Parents
Conducted by Directions Research, Inc.
for
The Compassionate Friends, Inc.

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WHEN A CHILD DIES

2006 Survey

BACKGROUND/OBJECTIVES

The mission of The Compassionate Friends is to assist families toward the positive resolution of grief following the death of a child of any age and to provide information to help others be supportive.

Government statistics show that the job of The Compassionate Friends (TCF) and other support organizations that help bereaved families following the death of a child is massive. Based on the latest available government statistics, approximately 150,000 children and young adults can be expected to die in the United States this year.¹ And these statistics do not include miscarriages, stillbirths, or the deaths of older adults (age 40+) whose parent or parents survive them.

There were approximately 980,000 stillbirths and miscarriages in the United States in 1996, the last year for which government agencies have provided statistics and trends related to these deaths.² A modest continuing drop is expected in miscarriages, based upon the government's report. However, total deaths from pre-birth through young adults is still likely to approach at least a million annually, leaving nearly two million bereaved parents every year. In a 1999 survey, TCF established that 19% of the adult population have experienced the death of a child and 22% the death of a sibling.³

The Compassionate Friends, with nearly 600 U.S. chapters, has found it important from time to time to gain insight into those it serves and those whom the bereaved turn to when a child dies. With this in mind, TCF authorized a new survey to ascertain support available, public awareness of this support, and actual use of this support by bereaved parents.

The objectives of the 2006 TCF survey were to specifically understand:

1. Sources of support that were perceived by parents as most helpful and most unhelpful in their grief journey.
2. Awareness and usage of support organizations such as The Compassionate Friends.
3. The relationship between parental grief and divorce.

¹ Centers for Disease Control: Deaths, Final Data Worktable GMWK310_2003.

² National Center for Health Statistics: *Highlights of Trends in Pregnancies and Pregnancy Rates*. Vol. 47, No. 29. 12. pp. (PHS) 2000-1120.

³ The Compassionate Friends: "The Death of a Child," released June 1999, conducted independently on behalf of TCF.

4. Support within the workplace for employees who have experienced the death of a child.

In addition, a limited survey, conducted separately from the main survey, examined public awareness of The Compassionate Friends among the general population.

Both 2006 surveys were conducted by E-Rewards Internet Panel under supervision of Directions Research and were conducted in March–April 2006. Methodology of the study is discussed at the end of the report.

KEY FINDINGS

Support Following the Death of a Child

To ascertain how support was given to bereaved parents, four main questions were asked regarding support available through normal channels.

When asked to name sources found to be helpful or not helpful, **parents perceived as the most helpful and providing the most information** friends (82.3%) and family (80.3%), followed by physicians (58%), coworkers (44.8%), and the clergy and hospitals (39.5% each). Websites were found helpful by 20.5%, therapists/counselors by 19%, online chats/message boards/forums by 13.3%, and general grief/bereavement support groups and support groups specifically for bereaved parents were both found helpful by 12%. It is obvious that these results indicate bereaved parents found support from many sources during their grief journey.

Perceived as not helpful by the greatest numbers were hospitals (29.5%), physicians (23%), funeral homes/directors (18%), and coworkers (12.3%). Support groups specifically for bereaved parents were rated lowest at 4.5%. This indicates that support groups specifically for bereaved parents were most likely of all to be perceived as helpful.

When asked to name the **one source most helpful** in providing emotional support and information, family fared best at 44.9%, followed by friends at 21.7% and clergy at 6.9%.

When asked to name the **one source least helpful** in providing emotional support, hospitals were first at 17.9%, physicians at 13.5%, funeral homes/directors at 9.2%, and coworkers at 8.4%. Listed as least helpful by the lowest number were therapists/counselors at 1.5%, support groups specifically for bereaved parents at 1.3%, and general grief/bereavement support groups at 1.0%.

Support Groups

Of the 400 persons surveyed, 89 indicated they had used a support group of some type. Of that 89, 48.3% attended a church/religious organization support group, 31.5% an organized support group dedicated to grief support, and 25.8 percent a support group from a hospital or hospice.

Awareness of The Compassionate Friends Among Bereaved Parents

Of bereaved parents surveyed, **22.3% were aware of The Compassionate Friends**. This included 4.5% who had heard of and used TCF and 17.8% who had heard of but never used TCF. The percentage of bereaved parents who had heard of TCF increased by approximately 4 percentage points from the 1999 survey.

To indicate an understanding of awareness by bereaved parents of specific organizations related to the death of a child, the survey showed awareness as follows:

Mothers Against Drunk Drivers (MADD) 96.8%
The SIDS Alliance 52.8%
Survivors of Suicide (SOS) 29%
Parents of Murdered Children (POMC) 31.8%
The Compassionate Friends (TCF) 22.3%
SHARE pregnancy and infant loss support 22%

In the seven-year period since the last survey, these organizations changed as follows in awareness by bereaved parents (1999 survey figures were not carried out beyond whole percentages):

MADD (-1.2%)
The SIDS Alliance (+9.8%)
SOS (+3.0%)
POMC (-4.2%)
TCF (+4.3%)
SHARE (+8%)

Awareness of The Compassionate Friends Among the General Public

A separate, limited survey of the general population was taken to indicate an awareness of specific organizations related to the death of a child. The survey showed awareness as follows:

Mothers Against Drunk Driving (MADD) 85%
The SIDS Alliance 22%
Parents of Murdered Children 12%

Survivors of Suicide 11%
The Compassionate Friends (TCF) 7%
SHARE Pregnancy and Infant Loss Support 6%

There were 13% who said they were unfamiliar with any of these organizations. The 106 persons who responded that they were familiar with The Compassionate Friends were then asked to indicate **all places where they had seen or heard about The Compassionate Friends**. “Word of mouth” was highest at 57% and newspapers second at 29%. Magazines followed at 21%, the Internet at 20%, and radio/television at 18%. “Other” was by 7% and “do not remember” by 21%.

The two surveys were integrated in an attempt to determine what portion of the general public is aware of The Compassionate Friends, beyond those who are bereaved parents and aware of TCF. Of the 7% of the general population familiar with The Compassionate Friends, 4% are estimated to be bereaved parents aware of TCF, leaving 3% of the general public (including bereaved siblings and grandparents served by TCF) who are not bereaved parents, but still aware of The Compassionate Friends. This indicates that much work remains in making the general public, as well as bereaved parents, aware of TCF.

Grief and Divorce

Despite a widespread belief that the death of a child and the divorce of the parents are virtual cause and effect, **this survey strongly suggests this to be a myth**, confirming the results of the 1999 survey of The Compassionate Friends, as well as another study released the same year by two University of Montana professors.⁴

In the current study, the survey group members were queried about their marital status at the time of the death of their child, and those who were married were then asked their marital status today. Of 400 participating in the study, 306 were married at the time of the death of their child (of those who had only one child who died) or of any of their children (if they had more than one child who died).

Of the 306 who were married, 57 (18.6%) responded that they were no longer married to the same person. Of that 57, eight were widowed, yielding a divorce rate of 16%, far below the national divorce rate of approximately 50%.⁵ Of those who divorced, less than half, only 40.8% felt the impact of their child’s death contributed to the divorce. An interesting observation is that of 67 persons surveyed in the 18–34 age-group, 66 were still married to the same person, a 1.5% divorce rate. In the age-groups of 35–49 and 50+, divorce rate incidence

⁴ Survey, “Bereaved Parents and Divorce,” by Dr. Mark Hardt and Dannette Caroll of Billings, MT, as reported in *Bereavement Magazine*, Sept./Oct. 1999.

⁵ National Center for Health Statistics for 2004, *Births, Marriages, Divorces, and Deaths: Provisional Data for 2004*, Table A.

was higher at a combined 20% (76.6% still remain married to their spouse with 3.4% widowed).

This survey and the 1999 TCF survey, which showed a divorce rate among bereaved parents of only 12%, suggests that the 70%, 80%, and 90% divorce rates often quoted as fact by professionals and in the media are completely inaccurate. ***The figures indicate that the death of a child actually appears to draw bereaved parents together as they travel life's grief journey.***

Grief and the Employer

The Compassionate Friends has worked over the past years to increase public awareness of the need for employers to be compassionate when an employee's child has died. In this survey, employers fared well in this aspect, according to respondents. Of the 400 persons in the survey group, 82.5% were working at the time of the death of their child. Of those working, one quarter, 25.2%, reported their employer was extremely helpful following the death of their child. Another 25.8% said their employer was somewhat helpful. Of the remainder, 8.8% said their employer was either somewhat or extremely unhelpful. By group, 40.3% said their employer was neither helpful nor unhelpful.

Without including the 50.9% who reported their employer as extremely or somewhat helpful, the remainder were given a choice of ways in which their employer could have been more helpful following the death of their child. The greatest need, as cited by 47.5%, was for employers to give time off/more time off. Other high responses were: Be more compassionate/ understanding (27.8%); provide more work schedule flexibility (25.3%); be more flexible with normal bereavement policy (25.3%); and be more patient with me (24.1%). Ten to 15% of respondents said their employer should: have a formal bereavement policy; send a card/flowers; be available to listen to me when I need to talk; provide information on support groups.

These findings do indicate that a majority of employers fared well in helping their employees following the death of a child. However, that figure (51%) was considerably lower than the 1999 TCF survey, where 69% said their employer was "very" or "somewhat" helpful. The good news is that in the current survey, only 8.8% cited their employer as "somewhat" or "extremely" unhelpful while in the 1999 survey, 12 percent cited employers as being "somewhat" or "very" unhelpful.

Other Findings of the Survey

Bereaved parents who answered that they were familiar with The Compassionate Friends (22.3%) received the follow-up question: How did you first learn about The Compassionate Friends? “Word of mouth” was highest at 16.9 percent, with newspapers close behind at 14.6%. The clergy/church was next at 9%, counselor/therapist at 7.9%, and magazines at 6.7%. Responding that they “did not remember” were 21.3%.

In response to a question asking bereaved parents who were familiar with TCF to name all the ways in which they had heard of the organization, 12.4% said they had received a call, mail, or some type of direct contact from The Compassionate Friends. Thus, among the full sample of 400 bereaved parents taking part in the survey, only 2.8% had been personally contacted by a TCF representative in some manner.

CONCLUSION

What Can Be Learned from the Survey?

1. Support organizations have a long way to go if they wish to truly service the bereaved parent population. Increased awareness within the bereavement community and within the general public can help in this mission.
2. Divorces among bereaved parents are far rarer than most people, including many professionals, believe. If this misinformation about the divorce rate is ever to be eliminated, it is imperative that the high divorce rate generality be challenged and refuted wherever it appears.
3. While employers generally are doing a good job of supporting employees after the death of a child, there’s still a long way to go. Providing compassion toward employees who have had a child die, and adjusting work hours, can give those workers an improved view of the company for which they work. It follows that, in the short and long term, improved work performance will be the result of additional understanding and compassion.

Where Are We Compared to the 1999 TCF “Death of a Child” Survey?

Though the transition from telephone to Internet data collection does not make the two studies directly trendable, there are a few comparisons worth noting.

1. TCF has increased its awareness among bereaved parents from 18% to 22.3%, an improvement of approximately 24% from 1999.

2. The divorce rate remains low among bereaved parents. The 1999 survey found that only 12% of marriages had ended in divorce. The 2006 survey found the rate higher at 16%.

3. Employer approval rating by bereaved parents following the death of a child remains good, but has decreased from 69% to 50.9%. This may be the result of smaller companies being absorbed by larger companies, generally perceived as less caring of individual employees, and market pressures causing companies to demand higher performance from every person on the job.

METHODOLOGY

Both 2006 surveys were conducted through the Internet, while the 1999 TCF survey was conducted by telephone. Internet surveys reportedly have several advantages. They are less expensive, believed more accurate because of greater anonymity, and faster to administer.

Both surveys were conducted by E-Rewards Internet Panel under supervision of Directions Research and were conducted in March–April 2006.

E-Rewards was directed, for the main bereaved parent portion, to survey 200 adult males and 200 adult females from the United States in a demographically dispersed method applying to both location and age. The 400 surveyed came from 45 states, plus Washington, D.C., with higher numbers from states with greater populations. Of the 400, 124 (42 male and 82 female) were age 18–34, 131 (66 male and 65 female) were age 35–49, and 145 (92 males and 53 females) were age 50+. The margin of error was $\pm 4.3\%$ with a 90% confidence level.

Of the 400 bereaved parents surveyed, 298 had experienced the death of one child and 102 had experienced the death of more than one child. This included 24 who had three children die, and 9 who reported they had experienced the death of more than three children.

The short general population survey was administered in an omnibus survey where a limited number of questions are posed by several companies in an attempt to provide specific, but limited, information in a cost-effective manner.

The general population survey was completed by 1,528 persons from across the United States, which included 810 males and 718 females. Ages were as follows: 18–24, 236; 25–34, 284; 35–49, 481; 50–64, 280; and 65+, 247. The margin of error was $\pm 2.2\%$ with a 90% confidence level.

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LIMITS AND FUTURE DIRECTIONS

In this section, we discuss some of the limitations of our research and specify reasons why our findings should be interpreted cautiously. Because this research employs a cross-sectional survey, it is difficult to make definitive claims based on the findings. The results are based upon a specific point in time, not taking into account extraneous variables such as respondent attention, memory of past events, confusion related to questions in the survey, or potential bias. These factors or limitations are inherent to any perception-to-perception methodology and specifically the use of a self-administered survey. Because we rely on perceptual data measured with a series of questionnaire items, our results may also be affected by the way in which questions were posed or perceived.

Both 2006 surveys were conducted through the Internet, using Internet panelists from E-Rewards Internet Panel under the supervision of Directions Research (conducted in March-April 2006). Although Internet surveys are advantageous in many ways (less expensive; believed more accurate because of greater anonymity; and faster to administer), there is risk associated with using a panel of consumers simply because the panel population is limited and may not be fully representative of the greater population.

E-Rewards was directed, for the main bereaved parent portion, to survey 200 adult males and 200 adult females from the United States in a demographically dispersed method applying both to location and age. The 400 surveyed came from 45 states, plus Washington D.C., with higher numbers from states with greater populations. The margin of error was +/-4.3% with a 90% confidence level.

The short general population survey was administered in an omnibus survey where a limited number of questions are posed by several companies in an attempt to provide specific, but limited, information in a cost effective manner. On the short general population survey, 1528 persons from across the United States responded, which included 810 males and 718 females. The margin of error was +/-2.2% with a 90% confidence level.

Future studies may address some of these issues by utilizing a stratified sample that mirrors the United States population on all factors such as (but not limited to) geography, age, gender, ethnicity, and income. Although this will require a much more robust sample size, it would allow for a more in-depth analysis of all respondent groups in the United States. Care could also be given to more thoroughly questioning respondents about the death of the child(ren) and what impact it had on them and their family members.