



SUMMARY REPORT

Beyond the death of a child

Social impacts and economic costs of the death of a child

Jon Stebbins and Trevor Batrouney • The Compassionate Friends Victoria Inc

Funded by The William Buckland Foundation



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Foreword

Beyond the death of a child is ground breaking. The study expands our understanding of the effects of a child's death well beyond the scope of the previous scholarly and clinical literature about bereaved parents and their families. Because the study is so well done, the recommendations its authors make deserve the close attention of the audiences to which they are directed.

The study is sponsored by The Compassionate Friends Victoria Inc (TCF), a self-help group of parents whose children have died. The early scholarly work on self-help groups stressed that self-help is based on experiential knowledge, which is very different from professional and scholarly knowledge. 'Experiential knowledge is truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others' (Borkman, 1976, p. 446). Professional knowledge, on the other hand, can only be developed within strictly limited research procedures and transmitted within certifying education programs. This study uses solid scholarly research methods to make TCF's experiential knowledge clear to outsiders.

It is difficult to overstate how much the professional literature has ignored what bereaved parents themselves know about their lives. The stresses of grief have been defined largely in psychological terms, as stages or tasks that lead to restoration of life as it was before the death. Indeed, one strong movement in the current psychological research is to define 'complex bereavement' as a diagnosis to be included in the next edition of the DSM (see Maciejewski et al., 2007). Studies of the bereaved very rarely include self-help. Of the few that do, most just ask the surface question, 'Attended self-help or support group: yes/no?'

Bereaved parents know that they don't have just a psychological problem. True, many report depression, hallucinations, bizarre behaviour and suicidal thoughts, so they think they are going crazy. But in TCF meetings they learn that many, perhaps most, members have felt that way. They are not crazy; they are bereaved parents. When a parent dies, we lose a part of our past. When a child dies, we lose a part of our future, and that takes some getting used to. It is not a psychological syndrome. It is a life to be reorganised in light of the new and terrible reality.

The parents also know that much of their stress comes from the disconnect between their grief-filled world and the outer world. Friends don't know what to say, so they act as if the death did not happen, or they say unhelpful things. 'It was God's will' makes it hard to look to God for comfort during long sleepless nights. Veteran TCF members know it takes most bereaved parents at least a couple of years to make a new life for themselves, but after six months, most people expect them to be 'over it'.

The work world cuts grieving parents very little slack. I remember a salesman who was expected to entertain clients in the company's box at sporting events. After his child died he could not be his old funny self. His clients were uncomfortable around him, so, perhaps unconsciously, they took their business elsewhere. His productivity dropped and he was fired. He had a hard time finding another job, but he knew he had to shut off his feelings in order to keep the new job. His wife's employer was more understanding and moved her to a less stressful position. Still, the wife interpreted her husband's keeping his grief at arm's length as his not caring. He must not, she thought, have loved their son as much as she did. It was not the death of their child that brought that marriage close to breaking point. The problem was how the business world responded.

Beyond the death of a child presents the full impact of a child's death on the parents' whole world. I know of no study that comes even close to this one in its scope or is as pointed in its findings. True to its roots in the bereaved parents' experiential knowledge, the recommendations in this study are practical. No matter where we are in the parents' world, we can do something to soften the impact of the child's death. Whether we are in their workplace, in their schools, in their neighbourhood, in their families, in the professions, or in government, we can find ways to support them, or at least not to harm them, as they rebuild their lives.

Like the help parents give each other in TCF meetings, the recommendations in this report don't tell us exactly what to do. They are not templates of protocols and procedures. Rather, the report gives us information and direction that helps each of us to find the right way to do what we can, and what we hope would be done for us if ever we found ourselves in their place.

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Parental Grief: Solace & Resolution
Continuing Bonds: New Understandings of Grief

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Acknowledgments

This research into the social impacts and economic costs of the death of a child would not have been possible without the contributions of a number of individuals and groups from within the bereavement community and beyond.

First, our deepest thanks go to those 103 parents who shared their experiences and perceptions by conscientiously answering a long and detailed questionnaire. This proved to be a demanding and painful exercise for many parents. From within this group we are particularly indebted to those 17 parents and siblings whom we had the privilege to personally interview and who told us their stories in intimate and often poignant detail.

We acknowledge the William Buckland Foundation, which provided the funds over a two-year period to enable this substantial research project to be conducted and the findings published.

Special thanks go to all those at The Compassionate Friends Victoria Inc (TCF) centre who contributed to the project. These include the Board of Management, which approved this study as the first large-scale research project undertaken at TCF, and offered continual encouragement and support. Anne Wicking, the Chief Executive Officer, proposed the idea of the research project, gained the necessary funding and provided invaluable support throughout the life of the project. The other staff and volunteers at TCF not only provided assistance where necessary, but also showed unfailing interest in the conduct and outcomes of the project.

We owe a debt of gratitude to the members of the Reference Group, who oversaw all aspects of the project and approved the final report. In particular, we thank them for their willingness to read and comment on drafts of chapters – often at short notice.

We thank the Human Research Ethics Committee of the Victorian Department of Human Services, who carefully considered the ethical dimensions of the research and granted ethics approval.

In the early stages of the project, the members of two focus groups were of particular assistance: one consisting of bereaved parents and the other of professionals in the bereavement field. We thank them for their frank and open comments, which alerted us to many dimensions of the topic and issues related to research in this field.

Rhonda Gordon-Brown from the Australian Centre for Grief and Bereavement provided expert and invaluable assistance in questionnaire development, data analysis and presentation. The final report owes much to her skills in these areas.

We are very appreciative of the encouragement and support we received from Dr Dennis Klass and Dr Robert Neimeyer, whose own contributions to bereavement knowledge and research is immense.

We are particularly indebted to Dr Klass. Firstly we thank him for the thoughtful and challenging Foreword he so generously provided. Secondly we thank him for his thorough reading of the report and for his invaluable suggestions concerning its presentation.

Finally, we acknowledge with great affection the understanding of our families in supporting a project that turned out to be larger and more involving than we anticipated.

The conduct of this study gave us valuable insights into the economic costs and social impacts following the death of a child. Our hope is that through our recording and interpretation of these matters we have been able to share these insights and develop recommendations that will be of future benefit to those who have lost a child and to the bereaved community as a whole.

Jon Stebbins and Trevor Batrouney

Executive Summary

This study conducted both quantitative and qualitative research on the topic *the social impacts and economic costs of the death of a child on the family during the first three years following the death*. Two major research instruments were used: an extensive questionnaire to 103 bereaved families and 17 in-depth interviews with members of seven families.

The research project was approved by the Board of Management of The Compassionate Friends Victoria Inc (TCF) and funds were obtained from the William Buckland Foundation in September 2004.

This study provides bereaved parents, governments, community agencies and business organisations with findings on the impact on families of the death of a child and recommendations directed to greater understanding and improved support services by these bodies.

Families and the deaths of children

Two-thirds of the bereaved families lived in metropolitan Melbourne and one-third in regional Victoria. The majority of parents whose children had died were in their thirties and forties, that is, in mid-life and mid-career. The major causes of death were vehicular accidents, other accidents, suicide, SIDS, still-birth or miscarriage, cancer and other chronic illnesses.

Economic costs

As a partner on a dairy farm I was unable to do any activities physically for 6 months and then mentally/emotionally lost all interest in farm business for one year.

(Father of Michael aged 20 years)

Almost half (46 per cent) of the respondents indicated that members of their family had incurred out-of-pocket medical, hospital and other health-related expenses which they believed were directly linked to the death of their child.

Of these, over 70 per cent experienced moderate to extreme difficulty in meeting such expenses. The situation was even worse for those families who also incurred substantial costs caused by illnesses preceding the death of their child.

The more significant out-of-pocket medical and health-related expenses were in the areas of mental and psychological health and more general medical expenses provided by general practitioners and specialists.

Nearly 80 per cent of families incurred out-of-pocket funeral and burial expenses and almost half of these experienced considerable difficulty in meeting such expenses.



The substantial financial costs following the death of a child included a loss of income from employment and the negative impact on work of family members. This arose from premature retirement, premature resignation, voluntary or involuntary demotion, leave without pay, absences, selling or leaving a business, loss of entitlements and inability to do weekend or shift work. Of these, the most common impact involved parents taking leave without pay, often after exhausting other forms of leave.

As many as three-quarters of respondents saw the impact on their work performance as very or extremely significant. Parents cited lack of concentration, lack of motivation, depression and other emotional responses as being the major ways in which their work performance was affected.

Alongside the measurable costs related to employment changes were less easily measurable impacts related to diminished self-worth and personal satisfaction.

Most parent-respondents indicated that the death of their child exerted a negative impact on their work around the house. The major response was a lack of interest in, and motivation to undertake, household chores.

Social impacts

Relationships

We [parents] were totally unable to support each other during the first year, each locked in our own grief pain – resentment grew, inability to cope etc. Both grieved differently – caused disharmony and arguments. (Mother of Sarah aged 12 years)

The strongest impact of the death of a child is felt on the relationships between the parents and between parents and children.

In general, relations between parents, in terms of mutual support and closeness, decreased during the three years after the death when compared to the period before the death. Nearly 50 per cent of respondents reported that they experienced less support and closeness over the three years following the death of their child.

Relations between parents and children reflected little significant change in level of support and closeness over the two periods, with one exception: the other children in the

family were perceived as being more supportive of their parents after the death of their sibling than before.

Relationships with extended families were not subject to significant change over the two periods, suggesting that the nature of the relationships established with extended families before the death of the child tend to continue after the death.

In terms of the relationships between parents and friends, the overall result was less closeness to their original friendship network.

Social activities

I still find it difficult to engage in social things. I do hope this will improve ... I feel uncomfortable, incomplete and out of sorts around the other kinder/school parents. Everyone has moved on from where I'm at. I do try and get into things but I always find an excuse to avoid activities I once really enjoyed. (Mother of Fiona aged 12 months)

There was a dramatic decrease in both the frequency and importance of social activities (social contacts, sports, hobbies and other interests) in the lives of both parents and children following the death of the child.

Support for bereaved families

[the support organisation] were lifesavers... wonderful ... we both got into counselling ... we still have a lot to learn ... but it reconnected us ... helped us see that while things were wounded and broken there was still connection ... still a basic underlying love. (Mother of Jeffrey aged two years four months)

In general, parents felt they needed more support during the earlier period (first days and weeks after the death) than during the later period (up to three years after the death).

Around half of the parents received essentially the practical, organisational, emotional, professional and spiritual help they needed over both periods.

However, substantial numbers of parents received less support than they perceived they needed in all support categories over the two

periods. In most categories, the gap between assistance needed and that received by parents actually increased over the two periods.

Over the two periods, bereaved parents perceived their most significant support as coming from within their immediate family. Then came extended family and friends, followed by bereavement organisations and support groups.

In the early days of their grief, parents looked for practical and general emotional support from extended family and friends. Three years later their needs were more specific – to be listened to about their dead child, to have anniversaries acknowledged and more contact with bereavement organisations.

The actions parents found least beneficial over both periods were the inappropriate comments of others, variously described as thoughtless, insensitive and/or uninformed.

In both the early and later periods, most parents perceived that their other children received essentially the level of support they needed. However, this still left significant numbers of children who were considered to have received less support than they needed and this deficit extended over both periods.

The actions parents perceived to be beneficial for their other children related to maintaining the integrity and unity of the family, and the support of bereavement organisations and support groups.

The least beneficial actions for children were inappropriate comments, echoing those experienced by parents.

Bereaved families: Case studies

The various elements outlined above are brought together in Chapter 8, which contains seven case studies of bereaved families. These stories covered a range of family types, structures and socio-cultural differences. They illustrate that the impact of the death on each family involves more than just the death of the child, and hence is both complex and unique. At the same time some common themes emerged such as the significance of family cultures and gender in grieving and the various ways in which parents seek to make meaning following the death of their child.

Recommendations

The Report frames a number of recommendations directed to providing more appropriate and enriched support for families experiencing the impact of the death of a child.

The recommendations are directed to government and non-government bodies and cover the following areas: bereavement support programs, economic costs, employment, education and research.

Bereavement support programs

Recommendation 1

That organisations which currently provide bereavement support programs evaluate and, where necessary, modify their programs to take account of the following:

- the range of support needs and priorities over time of different family members
- the range of support needs and priorities over time of family members in relation to different types of deaths
- the uniqueness and complexity of both individual and 'family' bereavement
- the need for flexibility in the type, timing and the length of support programs
- the fact that many families and individuals will require long-term support, where 'long-term' is measured in years, not weeks or months.

Recommendation 2

As there is no one public body concerned with the planning of bereavement services in Victoria, the State Government set up an interdepartmental task force to examine the current matrix of support programs for bereaved families, to determine whether they currently cater for the range of individual, family and cultural needs and expectations for support.

Recommendation 3

That the task force examine the matrix of information and training programs on loss, grief and bereavement support to determine whether they provide appropriate knowledge and skills to all potential support personnel, including:

- members of the immediate family
- members of the extended family and friends
- professionals including general practitioners, psychologists, psychiatrists, counsellors, social workers, youth workers, clergy, teachers and other school personnel, funeral personnel, Coroner's Court personnel and Occupational Health & Safety (OH&S) personnel
- employers and employer bodies, managers, supervisors, union leaders and employee bodies
- community organisations supporting bereavement.

Recommendation 4

That organisations which offer support programs evaluate the extent to which they provide for:

- all age groups
- both city and country families
- home-based support including child care for home-based parents.

Recommendation 5

That organisations which offer existing support programs be requested to establish 'bridging' support programs for families of terminally ill children, covering both pre-death and post-death periods.

Recommendation 6

That state and local governments, as appropriate, expand the program of Home Help to enable more readily available and affordable access to bereaved families.

Recommendation 7

That the State Government make provision for subsidised grief and bereavement counselling similar to that provided by Transport Accident Commission and WorkCare for families whose children dies from other causes.

Economic costs

Recommendation 8

That organisations such as the Australian Centre for Grief and Bereavement and The Compassionate Friends Victoria Inc be requested to include and funded to provide grief-related financial counselling as part of their suite of programs.

Recommendation 9

That organisations such as the Australian Centre for Grief and Bereavement and The Compassionate Friends Victoria Inc provide advice and guidance to financial counsellors in organisations such as community health centres on matters related to grief and bereavement.

Recommendation 10

That the State Government initiate a community awareness program targeted at appropriate bodies such as banks, insurance companies and funeral homes to encourage families to make provision for future funeral and burial expenses, by either pre-paying, putting aside savings, or insuring against death in the family.

Recommendation 11

That the Commonwealth Government make provision for financial grants or low-cost loans for families when a child dies; that such grants or loans take into account the added burden when the death follows a long-term chronic illness.

Recommendation 12

That bereavement organisations consider raising funds to provide immediate financial support for bereaved families.

Employment

Recommendation 13

That the State Government initiate an information program on the debilitating impact of the death of a child on paid and domestic employment, together with measures to mitigate the impact; the program to be targeted at employers, employer organisations, unions, OH&S personnel and government agencies such as WorkSafe and CentreLink, and include:

- information literature
- information programs
- support-training programs.

Recommendation 14

That CentreLink initiate special occupational programs offered by grief-related trained personnel to assist bereaved family members over the transition hurdles of returning to work, changing employment or seeking new employment.

Recommendation 15

That employer and union bodies support the expansion of OH&S policies and programs in work places to provide greater support for bereaved family members, including through the provision of extended compassionate leave.

Education

Recommendation 16

That existing bereavement support programs in government and non-government schools be expanded to include three levels of grief support:

- programs directly supporting bereaved children
- information and training programs on bereavement support for students
- information and training programs on bereavement support for school staff (teaching, administration and maintenance).

Research

Recommendation 17

That the Productivity Commission be requested to fund research into the economics of bereavement with a particular focus on the cost to industry and the community.

Recommendation 18

That the Australian Institute of Family Studies be requested to include questions related to the impact of the death of family members on children in the Longitudinal Study of Australian Children and in other research projects, as appropriate.

Recommendation 19

That the *National Statement on Ethical Conduct in Research Involving Humans*, published by the National Health and Medical Research Council, designate and fund a Human Research Ethics Committee in each state to consider applications for ethics approval from individuals and small organisations which do not have their own ethics committees.

Recommendation 20

That the Australia Research Council be requested to designate bereavement research a priority in the next funding round.

Families and the Death of Their Children

Chapter 3 of the Report is summarised below:

The bereaved families included those who had been contacted through TCF (around 60 per cent) and those who had been contacted through other bereavement organisations (around 40 per cent).

Two-thirds of these families lived in metropolitan Melbourne and one-third in regional Victoria.

The majority of parents whose children had died were in their thirties and forties, that is, in mid-life and mid-career.

Three-quarters of the parent-respondents were mothers, and the average length of time since the death of their children was 5.6 years.

Over one-third of the deaths of these children occurred up to the age of five years and around one-fifth took place in each of the age groups of 15–19 years and 20–24 years.

Around one-third of the children who died had been studying and some 30 per cent were working at the time of their death.

While two-thirds of the children who died came from Christian backgrounds, less than a quarter regularly attended religious services.

The chapter concludes with an analysis of parental accounts of the types and circumstances of the following deaths: vehicular accidents, other accidents, suicide, SIDS, still-birth or miscarriage, cancer and other chronic illnesses.



Economic Costs of the Death of a Child

Chapter 4 of the Report is summarised as follows:

Of the out-of-pocket medical and health-related expenses, the more significant were in the areas of mental and psychological health, at an average of around \$2100 per family, and more general medical expenses provided by general practitioners and specialists, at an average of \$1060 per family.

The one-off costs associated with funeral expenses amounted to a substantial figure of \$3800 per family, while legal expenses were incurred by a small number of families, amounting to around \$1900 per family.

The financial costs following the death of a child included a loss of income from employment and a negative impact on employment of family members. This arose from premature retirement, premature

resignation, voluntary or involuntary demotion, leave without pay, absences, selling or leaving a business, loss of entitlements and inability to do weekend or shift work.

As many as three-quarters of respondents saw the impact on their work performance as very or extremely significant. Parent-respondents cited lack of concentration, lack of motivation, depression and other emotional responses as being the major ways in which their work performance was affected.

The most common impact of the death of their child on employment involved parents taking leave without pay, often after exhausting other forms of leave. The periods of leave taken varied from a low of two weeks to a high of two years and eight months, with an average period of leave without pay of 15.5 weeks that cost family members around \$8000 on average.

A second impact was to be found among those parents who chose, or were forced, to resign from their employment following the death of their child. The amount of employment time lost as a result of their 'resignation' or 'forced resignation' or 'premature retirement' averaged 30 months. Parents' estimates of their lost income varied from a low of \$2500 to a high of \$600,000 with an average of \$59,500.

Most parent-respondents indicated that the death of their child exerted a negative impact on the work around the house of family members. The major response was a lack of interest in and motivation to undertake household chores. This seemed to be even more significant than with paid employment, possibly because of a greater discretionary element about work around the house.



As a partner on dairy farm I was unable to do any activities physically for 6 months and then mentally/emotionally lost all interest in farm business for one year.
(Father of Michael aged 20 years)

No motivation, sense of uselessness, lack of pride in myself therefore no reason to 'keep house'. I didn't want to move anything trying to preserve Richard's memory. Overwhelming despair replaced all motivation for maintaining house. When given the option, away from our home became a preferred [option].
(Mother of Richard aged six weeks)

Social Impacts of the Death of a Child

As indicated in Chapter 5 of the Report, in general terms, relations between parents, in terms of mutual support and closeness, decreased during the three years after the death when compared to the period before the death.

Relations between parents and children present a different overall picture, with no significant change in perceived level of support and closeness over the two periods. However, the other children in the family are perceived as being more supportive of their parents after the death of their sibling than before.

There was no significant overall change in the perceived levels of support and closeness between children in the immediate family over the periods before and after the death of their sibling.

Relationships with extended families were not subject to significant change over the two periods, which suggests that the quality of relationships that have been established with extended families before the death of the child tends to continue after the death.

In terms of the relationships between parents and friends, there was no significant change in the perceived level of support from friends in general but, on the other hand, friends were perceived as less close to parents after the death. An important impact on some families has been the changing network of friends following the death of the child.

The impacts of the child's death on the social activities (such as recreational, sporting, charitable and hobbies) of parents and children were similar, in that they led to a decrease in frequency of social activities for both groups.

Furthermore, both parents and children rated social activities as less important after the death of the child than before the death. This, together with other evidence, suggests the notion of a collective family response to the death of the child.

We were totally unable to support each other during the first year, each locked in our own grief pain – resentment grew, inability to cope etc. Both grieved differently – caused disharmony and arguments.
(Mother of Gemima aged seven years)

A few friends (one or two) were 'golden' and knew instinctively how to deal with us. To some we became somehow tainted. Our circle of friends shrank, but those who are left are somehow more trusted, more honest.
(Father of Allan aged 20 years)



Support for Bereaved Families

Chapter 6 of the Report examines the extent and type of support that the parents perceived they and their remaining children needed and received – and who provided that support – across two periods: immediately following the death of their child and during the three years that followed. The following is a summary of the findings.

Parents were asked which actions were most and least beneficial to them and to their remaining children over those two periods.

The complex reactions of grieving parents to the support they received following the death of their child is explained by high expectations, low personal resources, fragile vulnerability and extreme sensitivity to the reactions of others.

Around half of the parents received essentially the practical, organisational, emotional, professional and spiritual help they needed over both periods.

However, substantial numbers of parents received less support than they perceived they needed over the two periods. This particularly applied to emotional support.

Although parents felt they needed less support during the latter period, in general the gap between assistance needed and that received by parents actually increased over the two periods.

Over the two periods, bereaved parents perceived their most significant support as coming from within their immediate family – from their partners and other children.

The next source of support was extended family and friends, followed by bereavement organisations and support groups.

The actions parents perceived as most beneficial for them over the two periods related to emotional support: in the early days, being listened to about their loss and grief generally, and three years later being more explicitly listened to about their dead child.

Practical support was more appreciated during the early days after the death.

Actions parents found most beneficial included those designed to recognise, legitimise, normalise their grief, and memorialise their loss.

Actions parents found least beneficial were inappropriate comments and actions, described variously as thoughtless, insensitive and/or uninformed.

In relation to their other children, although many parents perceived their children received essentially the level of support they needed, substantial numbers still considered their children received less support than they needed.

The most significant support for their other children came from within their immediate family – from parents and other siblings, followed by extended family and friends.

Core actions perceived to be beneficial for their other children related to providing emotional and physical security, especially related to family unity.

The least beneficial actions for children were inappropriate comments, reflecting the experience of the parents.

Finally, a number of children specifically experienced disenfranchisement of their grief by others.



When we got back on that Saturday our table was covered with food, the fridge was full and there was stuff in the freezer ... people were so generous ... We didn't know where it came from ... but people in a practical way looked after us ... (Case study: Tonia and Terry)

My dad is very much an old fashioned kind of guy who would prefer to forget about those things, just leave it ... And yet when it came to making a special box to store some of Claire's things, it was dad who did it. (Case study: Liz and Andrew)

Case Studies of Bereaved Families

The case studies are based on detailed interviews with the parents and (where available) siblings, supplemented by information from the questionnaires. The families were selected to cover a range of family types, structures and socio-cultural differences.

The deaths of the children in the seven families cover the major types of deaths (post-natal, congenital, accident, transport, suicide) and age ranges from infant to young adult. Each of these deaths was accompanied by its own set of pressures, derived from the particular circumstances of the deaths, the nature of the families and the pressure of keeping a relatively normal family life going, mainly for the sake of the other children.

The seven deaths studied are:

- The first is that of Liz and Andrew's twin, Claire, who died at the age of only 11 days from brain damage after failing to breathe after birth.
- The next-youngest death was that of Jeffrey, the son of Jenny and Gary, who died of a rare degenerative nerve disorder at the age of two years and four months.
- Trudy and James were living and working in Singapore when their seven-year-old daughter, Carrie, an asthmatic, collapsed and drowned in 15 centimetres of bath water.
- Lena, the daughter of Kylie and Paul, died at the age of 13 years after suffering from a rare congenital bowel disorder for all of her short life.
- Kira, the 18-year-old daughter of Merle and Piero, died in a car accident while she was driving not far from her home at two o'clock one morning.
- A car accident also took the life of Sandra, the 21-year-old daughter of Tonia and Terry. Sandra was on her way to a church function after work and apparently lost control of her car, resulting in a fatal accident.
- The one suicide in the group was that of Allan, the 21-year-old son of Kevin and his estranged wife Maggie. The tragic circumstances surrounding the death included drug-taking and violence, which culminated in Allan attacking a 14-year-old boy and then, believing that he had killed him, taking his own life by hanging himself.

The following table provides a summary of the families interviewed; all names are pseudonyms.

FAMILY NAME	NAMES OF INTERVIEWED MEMBERS	AGE AT DEATH OF CHILD	RELAT. TO CHILD WHO DIED	NAME OF CHILD WHO DIED	AGE OF CHILD WHO DIED	TYPE OF DEATH	FAMILY STRUCTURE AT TIME OF DEATH	YEAR OF DEATH	OTHERS IN FAMILY REFERRED TO
Ryan	Kevin [1] Alana Patrick	49 23 14	Father Sister Brother	Allan	21 years	Suicide	FMDSS	1999	Maggie
Harris-McCann	Kylie Paul [2]	40 52	Mother Father	Lena	13 years	Long illness	MFSSDS	1998	Owen
Marrik	Merle Piero	44 49	Mother Father	Kira	18 years	Motor accident	MFSD	2000	Lew
Tarrent	Gary Jenny Sandy Abbie	44 42 12 6	Father Mother Sister Sister	Jeffrey	2 years	Terminal illness	FMSDDDS	1995	David Kath
Lee-Yam	Trudy [3] James	38 37	Mother Father	Carrie	7 years	Drowning	MFDD	2000	Ajana
West	Liz Andrew	25 25	Mother Father	Claire	11 days	Unknown illness	FMDD[4]D[5]	2004	Linda [4] Jessica [5] Mandy
Rivers	Tonia Terry	37 41	Mother Father	Sandra	21 years	Motor accident	MFDDSSSD	1996	Juliette Brian Benjamen Sean Lara

F=Father; M=Mother; D=Daughter; S=Son

[1] Kevin and Maggie (parents) separated three years before Allan's death

[2] Paul previously married; two sons by previous marriage (SS)

[3] Trudy and James are Singaporean Chinese – Carrie died in Singapore

[4] Claire's twin sister Linda

[5] Jessica born after Claire's death

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Appendix 1: Members of Expert Consultants' Group

The following members of the Expert Consultants' Group have provided advice and assistance during the course of the research project:

Professor Robert Neimeyer, PhD
Director of Psychotherapy
& Psychopathology Research Area
Department of Psychology
The University of Memphis
Tennessee
USA

Dr Dennis Klass
Professor Emeritus
Webster University
St Louis, MO
USA

Appendix 2: Members of Reference Group

NAME	POSITION
Mr Chris Hall (Chair)	Director Australian Centre for Grief and Bereavement
Dr Gerry Healy	Australian Jesuit Delegate for Education Assistant to Principal Xavier College Methods Lecturer Faculty of Education University of Melbourne
Dr Alan Hope	(Formerly) Associate Professor of Economics Deakin University
Ms Joan Hamilton-Roberts	Bereavement-Coordinator Manager, Family Support Team Very Special Kids Counselling Psychologist
Ms Dorothy Ford	(Formerly) Manager Program Development SIDS and Kids, Australia
Dr Elizabeth Bruce	Emotional Health Centre
Dr Jon Stebbins	Consultant researcher
Dr Trevor Batrouney	Consultant researcher
Ms Anne Wicking	CEO The Compassionate Friends Victoria, Inc.
Mrs Pat Burns	Vice-President The Compassionate Friends Victoria, Inc.

Appendix 3: The Compassionate Friends Victoria Inc

The Compassionate Friends Victoria Inc (TCF) was established in Victoria in 1978 by bereaved parents to offer compassionate understanding and support to any parent, brother or sister, or grandparent following the death of a son or daughter. TCF mutual assistance/self help offers the special understanding that comes from talking to someone who knows how it really feels when a child dies and how hard it is over the years that follow.

A voluntary Board of Management, all of whom are bereaved parents or siblings, governs TCF. In addition the organisation depends on the work of at least 100 trained volunteer bereaved parents/siblings who contribute unpaid work, on average more than 6,000 hours per year, to every aspect of TCF work. This includes one on one support, telephone support, support group facilitation, editing the TCF Bereaved Parent Magazine and Sibling Newsletter and contributing to the overall governance and running of the organisation. TCF employs five part time staff, consisting of a CEO, two Volunteer Coordinators, a Community Education & Service Co-ordinator and an Administration/Accounts Officer.

TCF helps by providing:

- assistance to bereaved families in the rebuilding of their lives following the death of their child or sibling and to support families' efforts to achieve physical, emotional and mental health.
- Information and education about bereaved parents and siblings, to raise public awareness of the need for support and to help those in the community, including family members, friends, employers, co-workers and professionals, to support the bereaved.

TCF Bereaved Parents Support & Information Centre in Canterbury, a converted terrace house, is a place where bereaved parents are welcomed to attend support groups, spend time in the library, come to meet one on one with other

bereaved parents & siblings, attend seminars and workshops or simply drop in. It is also the administrative centre. In the twelve years since 1994/95 TCF, on average, has had first contacts from 340 families per year, following the death of a child. Their children, brother or sister have died as a result of accidents, suicide, drowning, transport related death, drug overdose, illness, murder/manslaughter, stillbirth, neonatal death and sudden infant death. Bereaved people hear about the service from a variety of sources – TCF members, professionals, friends and family, and via the media.

The impact of the death of a child is perhaps the worst crisis that parents can experience: the impact is devastating.

The following specific support services are provided by TCF:

- The Bereaved Parent Support & Information Centre
- 24-hour telephone support, including a freecall 1800 number for Country Victoria
- Monthly Grief support groups and special interest groups held state-wide
- Seminars and workshops
- Easily read literature for the bereaved
- Literature available to clergy, teachers, counsellors, doctors, nurses and employers
- Free lending library
- Parent Magazine & Sibling Newsletter published six times a year and mailed to over 1,200 families
- Training programs for volunteers and grief support
- Community education
- Website
- Compassionate Employer Recognition Awards
- Research into grief and bereavement.

The statewide telephone support and network of support groups provides friendship and mutual support and assistance to bereaved parents and siblings. Support groups are lead by trained bereaved parents/siblings and work on the basis of mutual support which refers to the positive effects of people with similar experiences, working together in order to support each other. This may involve people identifying and sharing their knowledge and experiences about the impact of the death of their child on their lives that contributes to the overall understanding of the issues for themselves, their families and friends and the broader community.

'TCF has provided wonderful support during my bereavement and healing period. It's been comforting to come across kindred spirits that really do understand – without judgement. Every year, the anniversary card is a reminder that TCF hasn't forgotten my loved one – unlike many others.'

Bereaved parent.

TCF magazine and personal hand written anniversary cards are sent to all bereaved parents and siblings who choose to remain on the TCF mailing list.

'TCF was a 'light in the darkness' for about 5 years after my son's death. I used to 'devour' the magazine – it was wonderful to find something I could relate to at this terrible time in my life.'

Bereaved parent

Bereavement resource brochures available from TCF have been developed in collaboration with bereaved parents (both in Australia and overseas). Family members find these helpful in understanding and coping with the trauma and grief that they are facing, both in the early period following the death and in the years that follow.





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