

# men grieve too

stories of loss, grief and remembrance

by bereaved fathers



# acknowledgements

This publication is a project of Hope Bereavement Care, which was originally part of a Community Education project conducted in 2002 – 2003. At that time Hope Bereavement Care was known as Barwon Paediatric Bereavement Programme Inc. The name was changed with the purpose of having a more community friendly name for the service that reflects the nature of the work undertaken.

Hope Bereavement Care is a joint project of Barwon Bereavement Services Inc and SIDS & Kids Victoria, that provides community-based outreach support and education service for families and others affected by the sudden and unexpected death of an infant, young child or adolescent. The service office is located in and supported by Barwon Health at The Geelong Hospital.

The original publication was funded by the Geelong Community Foundation Ltd. Without the foundation's generous donation, the project would not have been possible.

Hope Bereavement Care, SIDS & Kids Victoria and Barwon Bereavement Services would like to thank the individual contributors and their families for participating in this project, and recognition is extended to our own Committees and Boards of Management for their invaluable support and contribution to the project.

## **PUBLICATION CREDITS:**

Contributors:	Bas Baskaran Mark Butcher Greg Roberts Andrew Shell Dion Ware Aaran Adair Craig Mulder
Writer/Editor:	Dion Teasdale (Original Project) Greg Roberts (Additions and Edits to 2 <sup>nd</sup> Edition)
Designer/Typesetter:	Caz Brown
Proofreader:	Matthew Barbetti
Bereavement Support Worker at time of Original Project:	Leona Daniel
Ex Officio:	Nerida Mulvey
Community Education Project Worker:	Dion Teasdale
Administrative Assistance to Original Version:	Maggie Verigos (Barwon Health) Denis Sheard (SIDS Victoria)

## **THANK YOU:**

Nathan Baird, Dr Katrina McKerran, Dr Alex Clinch, Stephan Faubel, Leona Daniel, Andrew McNess, Michael Taylor and David Dandos.

© COPYRIGHT 2002 & 2008 (2<sup>nd</sup> Edition) - BARWON BEREAVEMENT SERVICES INC.

Trading As 'HOPE BEREAVEMENT CARE'.

**THIS BOOK IS SUBJECT OF COPYRIGHT. APART FROM ANY FAIR DEALING FOR THE PURPOSES OF STUDY, RESEARCH, CRITICISM OR REVIEW AS PERMITTED. UNDER THE COPYRIGHT ACT, NO PART MAYBE REPRODUCED, STORED IN A RETRIEVAL SYSTEM OR TRANSMITTED, IN ANY FORM OR BY ANY MEANS ELECTRONIC, MECHANICAL, PHOTOCOPYING, RECORDING OR OTHERWISE WITHOUT THE PRIOR WRITTEN PERMISSION OF BARWON BEREAVEMENT SERVICES INC, THE OWNERS OF THE COPYRIGHT.**

# foreword

Death is part of life. To embrace life and death with respect, appreciation and dignity is to experience the truth and meaning of living. Family and community are the meaning for living. Death is not an ending but rather a change of context for those left behind. A marker of the success of a society is human kindness and how we care for each other.

These values have been the hallmark and impetus behind the development in 2006 of Hope Bereavement Care (Barwon Bereavement Services Inc), the offspring of Barwon Paediatric Bereavement Programme Inc (BPBP) which was established first in 1985, and launch in 1992. Over the years, the Geelong community has quite appropriately earned a reputation for being very caring. This programme arose from the concerns by professionals and community representatives, who worked with children and families, that there was no co-ordinated support for the bereaved. They did not leave their concerns at that; rather they did something about it.

This community driven journey has encompassed the work of many remarkably generous and caring volunteers, professionals and counsellors. The story of the development of BPBP and then Hope is one of a struggle for existence, at a time of limitations and other priorities for health and welfare resources. It is a story of commitment by a community to fulfil a vision and a dream, and to provide core funding through its community chest United Way. It is also a story of how SIDS and Kids Victoria and BPBP then Hope, two professional organizations with similar wills and philosophy, through sharing expertise, mutual respect and goodwill, created a special partnership.

We have learned another level of appreciation of life and death from those who experienced the tragic, sudden and unexpected loss of their child. Sharing the emotion, the story, the humanity, and redirecting the energy with others is healing for many people. It is an acknowledgement and a celebration of the privilege of the existence of the child who has died. We are very proud to present this book that epitomizes these ideals.

**Dr. Bernard M. Jenner**

**Chairperson – Barwon Bereavement Services Inc**

**MBBS, FRACP, Dip. Child Psychiatry, Grad Dip. Family Therapy**

**Consultant Paediatrician**

**Family Therapist**

# introduction

In September 2002 I was engaged by the Barwon Paediatric Bereavement Programme Inc. (BPBP) to develop a range of resources to be used by professionals and community groups to assist bereaved families, as part of the programme's Community Education Project.

The central aim of the Community Education Project was the production of resources to support the education and training of families, support workers and parts of the community directly involved with children experiencing grief, young people affected by the death of someone close to them and bereaved fathers.

At the core of the project was a desire to assist the members of each of BPBP's support groups to communicate their experiences of loss and grief, to record their personal stories and present them in a written format as an educational resource.

To achieve the desired outcomes, I worked closely with members of the BPBP Children's Grief Support Group known as 'The Seven Steps', with members of the BPBP Young People's Grief Support Group known as 'Going There', and with members of a Men's Grief Support Group conjointly run by BPBP and Bethany Family Services, known as 'Men and The Death of a Child'.

Initially I attended group support meetings to familiarise myself with group members and to engage them in discussions about the projects. Group members were asked to contribute their ideas for the projects and were invited to contribute individually outside of the support group environment.

The members of the Men's Grief Support Group were most interested in participating in an individual interview process. I met with group members on a one-on-one basis and conducted and recorded a structured interview. Each interview was divided into three distinct sections. Interviewees were firstly invited to recount their experience of the death of their child. Secondly, interviewees were asked a range of questions about their experiences of grief since the death of their child. Finally, interviewees were asked to reflect on the nature of their relationship with the deceased and to comment on their overall outlook on life since the death occurred. The edited transcripts from these interviews have become each participant's contribution to the group's publication.

The stories collected in this book are deeply personal accounts of loss and grief told by bereaved fathers wishing to share their experiences. While the stories stand as testimonies of the experiences of these men and their families, they are also an invaluable resource for other bereaved men and their families. The men who have contributed to this publication believe strongly that reading other people's stories of loss and grief can be a compelling and enlightening educational experience. It has been their wish that this publication offer insight into the different ways men experience bereavement while at the same time encouraging readers to connect with the similarities from their own experiences.

It has been a tremendous privilege to meet and work with the contributors and their families. I would like to offer my gratitude to them for openly welcoming me into their lives and for courageously and honestly sharing their painful yet profound stories with me. I trust you will find them as touching and as informative as I have.

**Dion Teasdale**  
**Community Education Project Worker**  
**December 2002**

# notes to second edition

It's now been six years since five fathers sat down with Dion Teasdale (Project Worker) and told their stories. Back then I was one of those five Dads and I know we all hoped that this little booklet would offer something to other bereaved Dads who might be struggling to understand and live life after having a child die. We knew at the time that there was very little printed material available to bereaved fathers that spoke about the lived experience of other men who had experienced the death of a child.

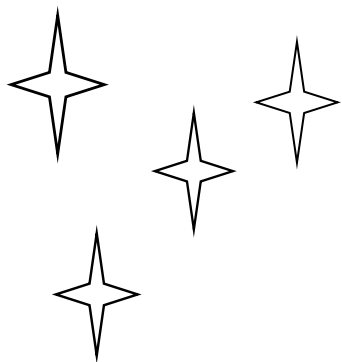
Since that time, this little book has been welcomed by bereaved parents (yes mums as well as dads), not only around Geelong, but across the state of Victoria and around Australia. Obviously, the book must be offering what we had all originally hoped it might – a connection to other people who are grappling with one of life's most awful events and continuing to live their lives as best they can, while not forgetting the children who are not physically with us. We have been overwhelmed with requests for this booklet and while it is always a struggle to fund the printing and distribution, HOPE Bereavement Care is committed to ensuring that this book will be available to bereaved fathers anywhere.

We have already re-printed the original booklet once and when it came time to do another re-print, we decided that we would update the information and add two more stories that to expand on the range of experiences that people encounter in their lives. Thank you to Craig Mulder and Aaran Adair for writing and offering their stories for inclusion in this second edition.

We have had suggestions that we might like to include a professional perspective from counsellors or researchers about grief and loss. In the end we have decided against this because the booklet is simply what it is – Bereaved dads sharing their stories with those who are trying to understand their own story. Within their own individual stories each father is claiming their place as an 'expert in their own grief'. While not claiming to be experts in anyone else's grief, the dad's in this booklet hope that some of the content in their personal stories will resonate with and speak to, other bereaved dads, so that they too can find a path to also becoming experts in their own grief. In the words of another bereaved dad - Art Peterson – "There is no expert to make the pain go away". I would add though that sometimes we all need someone, who understands our situation, to share what they know, while allowing us to find our own way along the path of life. That someone may be a professional counsellor or just another human being.

So this booklet is not intended to necessarily reduce the terrible pain that can come with the death of a child, it is simply seven dads 'telling it like it is and was for them'. It is about honouring the lives of our children and families. It is about letting other dads know that "Men Grieve Too" and it can be okay to tell your story.

**Greg Roberts, Counsellor/Educator**  
**HOPE Bereavement Care/SIDS & Kids Victoria**  
**September 2008**



**in memory  
of our children**

# contents

## flying blind

**Andrew Shell** .....7

Isobel - 20 weeks gestation and  
Patrick (twin of Jackson) 28 weeks gestation – 1 day old

## it does not go away

**Dion Ware** .....14

Emily – 40 weeks gestation and 5 days

## love lives on forever

**Bas Baskaran** .....18

Nishkalan – 38 weeks gestation; and Sharyaka – 18 months old

## the day my world changed forever

**Mark Butcher** .....25

Izak – 20 weeks gestation

## madeleine lived for 25 days

**Greg Roberts** .....34

Madeleine – 25 days old

## why so young?

**Craig Mulder** .....42

Andrew – 11 months and 8 days old

## small but mighty

**Arran Adair** .....45

Finn – 7 months and 7 days old

# flying blind

ANDREW SHELL

My wife Sharon and I have had two of our children die. In 1995 our first daughter, Isobel, died in the womb about 20 weeks into the pregnancy. Isobel had a hernia and her stomach had moved up into her chest. The doctors said there was nothing we could do. We had no choice. Isobel would be seven years old now, if she had survived.

We had only been married for a couple of years and had moved into a new house when we made the decision to have a baby. When Sharon found out she was pregnant we were on top of the world. Life was looking pretty rosy.

Sometime into the pregnancy we decided to go on holidays for a couple of weeks in Queensland with Sharon's parents. We were going to fly up and meet them there. A couple of days before we were to leave, we had an ultrasound. We went to the hospital and one-minute we were on cloud nine, and the next we had the wind knocked out of us. Basically, the doctors said, 'You're going to have to give this baby up.'

We had no idea that something like that could happen. Nothing like this had ever happened to anybody we knew.

I went into shock. It was like nothing I had ever experienced before. I had known people who had died, I'd had friends and cousins and relatives die, but when I found out our baby was not going to live it was like being sent into another world. I can remember walking through town and not knowing what to do or where to go. I was absolutely shattered. I was on top of the world and then I was told, 'It isn't going to happen.'

It was the worst feeling I've ever had. We were devastated.

A couple of days after we found out, Sharon had to go into hospital. We rang her parents and got them to come back from Queensland. Sharon was in labour for a long time. They had to induce the baby. Finally, Sharon gave birth to a little girl.

I was flying blind. All of this was new to me. There I was, up at the hospital, standing around while my wife was doubled over in pain. I didn't like seeing Sharon in that sort of pain.

You look back and wonder how you coped. We didn't have time to prepare for what was about to happen, which was probably a good thing. We didn't have time to dwell on feeling bad. We had to act quickly. It was like, 'This baby has to come out now.'

After Isobel was born we got to spend time with her. When we were told that the baby had to be delivered early, I didn't know what to expect. I didn't know if the baby was going to come out whole, but she was fully formed; a little miniature baby with nails and toes and everything. I got to hold her and a woman from the hospital came and took photos. The nurses put ink on Isobel's hands and feet and gave us an unofficial birth certificate. It doesn't sound like much, but it meant a lot to us. You go in to hospital to have a baby and you expect to walk out with something.





Sharon was in hospital for a few days after she gave birth. I slept on a foldout bed next to her. She had been through a really hard time. She went through hell to give birth to Isobel and there wasn't much I could do expect be there with her.

While I was at the hospital I ran into some friends of mine and they had just had a baby boy at the same time. They were 'as happy as Larry' and they started asking questions. 'What are you doing here? How's Sharon and the baby?'

I didn't feel like talking about it after everything we'd just been through. I said, 'We had a baby girl,' which we did, but I didn't say anything else. That was very hard.

When we left the hospital we saw other people walking out with their babies, putting them in car capsules and driving off home. It was like someone had stuck a knife through me. I'll never forget that. Your wife has just been through hell and you walk out the front door and other people have got what you should have. I don't wish anything bad against other people, its just that it was such a terrible feeling.

When we got home we both felt so empty. Everything was doom and gloom. Neither Sharon nor I had any motivation to do anything. It was like our will to live had been taken away. I had no zest. I didn't want to do anything. I walked around as if in a dream. I didn't know what was going on. I think that's why I went back to work pretty quickly. I wanted to get going again. I thought, 'If I can just get back into the swing of things, then I might feel better'.

I went back to work two weeks after Isobel's birth. I was on holidays (we were meant to be in Queensland) and when they were up I thought, 'I've had two weeks to dwell on this and its time to get back and face reality'. It was good having the two weeks at home because it helped settle things down. It gave Sharon and I a bit of time together to get used to what had happened. I thought going back to work would help make things more normal for me.

The following few months were really difficult. Its hard coming home at night to find your wife crying. I'd walk in the door and see that she was very upset and that she had been crying for a long time. That was really hard. I felt stuck sometimes. I didn't know if I should stay home with Sharon or if it was better for me not to be there. Our parents stepped in and helped us both. Sharon's mother was at our place a fair bit and she kept a close eye on Sharon for me.

I was doing shift work at that stage and when I did the afternoon shift I had a lot of time to myself. Being on my own was good for me. I was able to get things organised in my head a little bit. While I was working I was thinking, and whenever I had a spare ten or fifteen minutes I'd sit down and reassess things in my mind. I tried to put things in perspective. Sharon had been saying, 'We shouldn't have done it. We shouldn't have done it,' and I was going over it in my mind, thinking, 'We had no choice. The doctors are the experts. The ultrasound showed us that things weren't right.'

When the doctors say, 'You have no hope,' then you have no hope. I was able to sort it out in my mind. I was one hundred percent sure we did the right thing.

Sometimes, when I was at work, when there was a quiet moment and I was thinking about Isobel, I would cry.



After Isobel, Sharon and I had two more daughters, and about 18 months ago Sharon gave birth to our twin boys, Jackson and Patrick. Everything was fine with the birth of the girls, but it wasn't smooth sailing with the boys. As if it wasn't bad enough losing Isobel, Patrick died as well.

It took us a while to accept what had happened to Isobel, but as time went on, things got a little bit easier. A couple of years later, Sharon wanted to try for another baby, but I was very hesitant. I didn't want to go through it all again. I was wary of going down that road. I had told Sharon, 'Look, I don't want any more. Something might happen.'

She had to talk me into it.

When Sharon did get pregnant again, I was very worried. I couldn't shake the feeling that something was going to happen again. I remember going to the first ultrasound when Sharon was pregnant for the first time after Isobel, and praying that there wasn't another hernia. There are hundreds of things that can go wrong and I was hoping nothing would show up. I felt like I went in there with my eyes open wide. I wasn't blind to what could go wrong any more. Thankfully though, we had two perfectly healthy, normal girls.

Even though we had the two girls without any problems, I was still hesitant when Sharon told me she was pregnant with the boys. In the back of mind there was a voice saying, 'Its happened once. Its going to happen again.'

And it did. I couldn't believe it.



Sharon did a pregnancy test on herself and said, 'I'm pregnant.'

I said, 'Oh yeah? Good.'

She went to the doctor and I jokingly said to her, 'Don't come back if there's more than one.'

I don't know why I said that. Our daughter Lauren started out as a twin too, but between 12 weeks and 16 weeks something had happened. The other twin didn't make it. When we went to the first ultrasound for that pregnancy, there was only one heartbeat and that was Lauren. Perhaps that experience triggered an alarm with me.

Sharon came home giggling that afternoon, after being at the doctor's, and said, 'We're having twins.'

I thought, 'Oh no. You're joking.'

I was happy and joking with her, but I was also thinking, 'I hope it isn't like last time.'

I even said to Sharon, 'I hope one of them doesn't disappear like last time,' and she said, 'No way. The doctor said its completely different.'

So, after that I was very excited. It had always been my dream to have twin boys. A friend of mine had twin boys about ten years ago and I had thought, 'Jeez, that would be good.'

Ever since then I've thought I would like that to happen to me. I thought the chances of having twin boys were pretty slim, but I thought it would be really good.



Sharon was only 28 weeks pregnant when the boys were born. Everything had been going well up until about the 20 week mark when Sharon had another ultrasound and the doctors discovered a problem. The boys were in separate sacks and had separate blood supplies. There wasn't enough fluid in one of the sacks. There was a tear in Patrick's sack and fluid was leaking out. It was like a bucket of water with a crack half way up and when the fluid built up, it would leak out. The other little boy, Jackson, was perfect.

I was very worried, but I had to hold up hope. The doctors said that there was a chance things might work out and that one of the babies was doing okay. Sharon and I were determined to

keep fighting for both of the babies, but we were worried that the one that wasn't doing well would affect the other. The doctors mentioned they were worried about infection setting in and harming both babies, as well as Sharon.

For a month before the boys were born, Sharon was in hospital. The doctors kept a close eye on her in the Geelong Hospital for a couple of weeks and then they thought it was best if she went to Melbourne. At that stage it was a day to day prospect. Everyday that went by was a bonus. If the boys had been born at 24 weeks, they would not have lived. It was like sitting on a time bomb. Every day, every hour that went passed meant that the babies would be better off. We hadn't given up on either of the babies. We were still thinking they could both be okay. The doctors had said the one without the leak had more of a chance.

I kept going to work during this time because I thought it was important to keep some sense of normal life going and I thought it would help me to stay positive. I went to work everyday hoping that when I got home there would be good news. Sharon's parents moved into our house to take care of the girls and each night I'd go up to the hospital and make sure Sharon was doing all right. I felt okay because I knew that if anything was going to happen, that Sharon was in the best place.

When Sharon was moved up to the Mercy Hospital in Melbourne, I went up to visit a couple of nights a week and on weekends. I kept working full time because I knew that I would need to take time off when the babies arrived. I tried to focus on good thoughts. I counted the days and hours knowing that the longer the babies stayed in the womb, the better our chances would be. We were told that if we got to 28 weeks there would be a ninety- percent chance of the babies surviving. At 27 weeks, that percentage was halved. Our percentage was going up every minute.



I was at work on the day it all happened and at 11.00am I got a phone call. 'You better get up the Melbourne. Things are happening,' I was told. I flew home in a mess. I don't even remember how I got home. I was thinking, 'Gee, its not even 28 weeks. I'm gonna lose all three of them here.' I howled my eyes out all the way home. Things had been going so well, but then I got that phone call. I thought, 'I'm not gonna go through this again. It can't be happening'. I got home and my father-in-law was waiting for me. We got in his truck and off we went.

When we got to the hospital, Sharon was in a dressing gown and she said, 'Looks like the babies have got to come. Its time.' We sat up at the hospital all day and then the doctor's said, 'No, don't worry about it. Things look all right now.' It was like a roller coaster ride. Up and then down. Then, an hour or two later, they said, 'Don't go too far away just yet'. I remember thinking, 'I can't go through this any more'. I was up and down and up and down.

The doctors finally made a decision. They said, 'At 8.30pm you're going into surgery and having an emergency Caesarean'. The medical staff were very positive at that stage. They were very supportive and said, 'There is still a chance. It's not all doom and gloom.'

Patrick was the first boy out and he cried like a normal baby. He looked healthy and when they held him up he was kicking. The doctor said, 'Here's your first boy'. I thought, 'This must be the good one'. Then they lifted out the second boy and the doctor said, 'Things aren't looking too bad'. I thought they both looked really well. Both the boys were crying. I thought, 'You never know, things might be all right'.

A little later on I found out that Patrick, the baby from the leaking sack, had bad lungs. They hadn't fully developed and he wasn't able to breath properly. When I left the hospital later that night, I was told, 'Its not looking too bad, but its an hour to hour thing'. As the night

went on, Patrick got worse. His lungs couldn't cope. I got a phone call early the next morning saying, 'Things aren't looking too good'. I went back to the hospital, spent all my time with Patrick and was I praying that Jackson would be all right. I sort of knew, in my own mind, that I wouldn't have long with Patrick.

Patrick died at about 10.00pm that night. The doctors said, 'He isn't going to make it', and then they took him off the respirator. The only things keeping him going were the machines and we felt that he'd fought long and hard enough. It would have been cruel keeping him alive any longer. We took him off the respirator and Sharon held him. Patrick lived a day and a bit.



A few weeks later we had a funeral for Patrick. It was very hard. We hadn't had one for Isobel. The lady at the funeral home was very good. She obviously knew what she was doing. She got the kids to do some drawings to put in the coffin and asked us what we'd like to put in the coffin with Patrick. I put a few items in. I put a Don Bradman medal, which I had gotten from the Herald Sun newspaper, in one of Patrick's hands. It was a hard time.

The kids went through a lot too. They didn't know what was going on. They had been without their mother for months and they didn't always know what was happening. It definitely affected them. They lost a brother. They got to hold him, cuddle him, give him a kiss goodbye. Its very hard for them too.

Sharon stayed in hospital in Melbourne for months after the boys were born. We'd lost Patrick, but Jackson was still going and he was only 28 weeks old. He was now fighting for his life. He was in a humidity crib and connected to monitors. He still had a fight on his hands. On one hand we were grieving for Patrick, but on the other we had to keep going for Jackson.



When Isobel died we were made aware of the different types of support groups there are. Sharon attended meetings at SANDS and got involved with a few other different groups. I wasn't really into anything like that. I went to one or two different functions. I think I went to a Christmas party and a memorial service run by one of the groups Sharon was involved with, but as for sitting down and talking about how I was feeling or anything like that, I wasn't interested. I didn't feel like I needed counselling. I was upset, but I was happy dealing with it myself. I didn't want to deal with it in a group. I knew Sharon wanted to get involved in group counselling and I fully supported her doing that. I said, 'You go for it', and I could see how it helped her when she did. At that stage, counselling wasn't for me. Everybody is different and looking back I don't think I would have done it any other way.

It's only recently that I've started attending a grief support group for men and I've really enjoyed it. Talking about my experiences has really helped, so maybe it would have been good to do something like that back when Isobel died, but back then I didn't think I needed help. I think I'm better off the way I have done it. I can see the benefit of going to a men's group now whereas in the past I couldn't. I can talk about things now in a way I wasn't able to before. I might only go for six months, but the time is right for me to go now.

I didn't know what to expect before I went to a men's group. I wasn't sure if there would be people there to pick our brains. I didn't know what it would involve and that's probably half the reason I didn't want to go earlier on. I thought there might be somebody there firing questions at me and I wasn't sure I would be able to come up with answers.

When I went to the first men's group meeting I really liked having the chance to talk about my feelings and what Sharon and I have been through. Many of the men there are guys I have met through other support groups our wives are involved with, and they have almost become close friends because they are not strangers to the experience of the death of a child.

It's good to talk to other guys who have some idea of what you've been through because they've experienced something similar. Everybody in the group I have been going to has experienced the same sort of loss and grief. Whether your 16-week-old baby has died or whether you're eighteen year-old son has died, you've all been in the same situation at some point. It helps to share your experiences and if what I've been through helps another guy understand what he's going through, then that's even better. After I attend one of the men's support groups I feel a little better.

Looking back I probably should have let go of my emotions a little more when Isobel and Patrick died. I was a bit reserved when Isobel was born. I didn't breakdown or anything like that. I did cry but I wasn't a wreck. I thought, 'Well, I have to be a bit strong for my wife'. She was in a bad way and needed me. It is a man's job to support his wife, but there's no shame in crying or showing some emotion.



At work, nothing has really ever been said. I haven't really sat down with anyone from work and told them about my experiences, and no one has come up to me and said, 'I've been through the same thing. Do you wanna have a talk?'. As far as I know, no one at work has been through what we've been through. When we lost Isobel, the company I work for sent flowers, but the topic was never brought up. With Patrick, the boss called me into his office and said, 'Do you want to have a talk?' He wanted to know what was going on. He asked me if I wanted any time off and asked me if I needed any help. That was good. I preferred that to nothing being said at all.



I think the world of Sharon. She's such a strong person to go through what she has. She is unbelievable. I remember what it was like when she was giving birth to the boys. She was lying on a table and the doctors were cutting her open. I was holding her hand and she didn't know what was going on. She vomited everywhere and she was shaking like a leaf. I thought, 'Bloody hell. What's going on here'. I'd never seen her like that. It looked like she had no blood left in her face. She was white and trembling uncontrollably. She was drifting in and out and didn't know where she was. It was a bloody nightmare. Sharon is the strongest person I know. I have a lot of admiration for Sharon as a person and as a mother.

Sharon would probably say that I haven't really come to terms with the things that have happened. I suspect, with Isabell, she would say I haven't opened up enough, but we do talk a fair bit about it. As time goes along I'm getting better. We go to the cemetery as a family, as often as we can. There's a plaque at the cemetery for Isabell and a grave for little Patty. That helps a little bit.

On birthdays and at Christmas I look at Jackson and think, 'He's here. His best friend should be here too'. I get through those occasions, but I always spare a thought for Isobel and Patrick. In the back of my mind I think, 'There should be another little girl and little boy here'. It bugs me. I think, 'Why did it happen? Why didn't they make it?'. Sharon wonders about that too. She wonders if there was something she did, but the doctors and I have told here it was nothing to do with her. It was just bad luck. Nobody did anything wrong.

The way I look at it, no matter what happens, you have to look for the positive things. After everything that's happened to us, we've still got Jackson and the two girls. In a perfect world we would have the other two with us, but it wasn't meant to be. You can't look backwards all the time. You have to keep moving forward. You can't go back and change things. Death is a part of life and you can't do anything about it. What we've been through has been pretty bad, but there are other people a lot worse off.



If you are a father whose child has died then I'd say get in contact with support groups when you feel like it would be useful, whether it is twelve months after the death of your child or three years. It doesn't matter when it is, as long as you feel ready when you do seek help. Some guys might want to go straight after the death, whereas others might be a bit hesitant at the start and seek out help later on down the track. I'd also say definitely go to a support group, no matter how much you think, 'No I don't want to do it. It's not for me.' Just give it a chance. You probably don't not know how much it can help. Don't just say, 'Nah it won't help me. There's nothing they can do for me. I know what I'm doing. I don't have to talk to anybody about it.' Even if you feel like that, just go. Go for one night or two nights, just to see what its all about. You might be surprised to see how much it can help.

If any of my friends were in the same position that I have been in, I would have no hesitation in saying, 'Look, you're not on your own. People like you go through this everyday. Don't think you're the only one. If you wanna have a talk to me, talk to me. If you wanna come to a group, come along. You don't have to be embarrassed.'

Everybody cries. Nobody is going to give you funny looks or think you are weak if you cry. You wouldn't be human if you didn't cry. It might do you good to have a bit of a cry. Its a good way for a bloke to get his emotions out. A cry can make you feel better. You've got to let your emotions go, but that's not easy for some blokes. I think a lot of men don't like to show there emotions. They keep things bottled up.

It's not that men don't grieve as much as women, its just that they don't want to be seen to be upset or weak. I don't think men grieve as openly as women. Perhaps men play through things in their mind a bit more. I think many men think things through and keep things to themselves, but I think men need some sort of release. It might not be on the day of a death, or even within the first year, but I think most men get to a point where they need to let it go. That's what happened to me. It built up inside and then I just let go. I don't think women work like that. They don't built up as much. I think they are better at letting things go. You don't see men showing there emotions as much as women, but just because they don't show it visually doesn't mean they are not as upset. Just because you can't see it doesn't mean it isn't there.

I thought it was best to deal with things myself because I didn't know what I could get out of talking about it with other people. When you are ready, when you feel like having a talk, go to a group. You've got nothing to lose.



# it does not go away

DION WARE

We still don't know what went wrong when we lost Emily. What I do know is that the night before, everything was okay. I remember Chrissie saying, 'Come here and feel the baby kicking', and I laughed as I felt her tummy moving. That was about 7.30pm. Chrissie was five days past being 40 weeks pregnant.

At around one or two o'clock in the morning Chrissie woke me to say she was in labour. I asked her, 'Do you want to go to the hospital?'

She said, 'No, I'm okay at the moment.'

Later she rang her Mum and asked her to come around as she had more of an idea of what to do to ease labour pains than I did. I went back to sleep when her Mum arrived.

At 7.00am I was woken by Chrissie saying, 'Something is wrong.'

She said she had breakfast and the baby didn't move around like it normally did after she ate. We rang the hospital and they said to come straight in. We got there at 7.30am and they could not find a heartbeat.

The midwife said, 'The sound device might be faulty.'

They got another machine but it was the same. No heartbeat. At that stage both Chrissie and I knew the worst, but we could not say anything. I felt sick to the core.

A doctor came to do an ultrasound. When we looked at the monitor there was no heartbeat and no movement.

The head obstetrician came in soon after and said 'Your baby is dead.'

That was absolutely the worst feeling I have ever experienced. I can't speak for Chrissie and how she felt, but for me the world stopped at 8.30am that morning.

The feelings I experienced that morning are difficult to put into words, but I suppose if someone ripped your guts out and smacked you in the head with them, then you might have an idea of what it was like.

The worst part was that Emily, our daughter, was not delivered until 11.30pm that evening, so trying to support Chrissie throughout that entire day was very hard. The doctors thought she had an infection and were pumping her full of antibiotics and other crap. I don't know what they were giving her, but she had so many drips in her it was scary.

I was a zombie. I was running on autopilot. I have trouble remembering exactly what I was doing during that day.



The funeral we had for Emily was fantastic, if there is such a thing. The woman who married us conducted the service. We told her our story and our hopes and dreams for Emily, and left the details to her. She arranged for a naming ceremony with Emily's hand and footprints that we had taken up at the hospital. That was special for us. It made us, and our friends, aware that Emily was real. Then, we moved to Emily's coffin which was surrounded by teddy bears, and the celebrant spoke on our behalf.

I really have trouble remembering what was said during the service, but I do know it was very sad and everyone was crying. It was very hard to be there, but I am glad we did it now. At the time I did not want to be there.



I don't know how we got through the first few weeks after Emily died. I honestly cannot remember much from that period of time apart from our family and friends being there if we needed them. My best friend's wife is a chef and she cooked us about two weeks' worth of food so we did not have to worry about chores like that. We were lucky because our friends understood what we were going through and accepted our grief as natural.

I didn't handle my emotions too well. There is no textbook or set of rules to tell you what the correct thing is to do. I basically fell into a heap. Although I could talk about what had happened, I couldn't accept it. I spoke in third person, as if it wasn't happening to me. This was wrong. I know now that I should have tried to accept it more, and talk about it as if it was happening to me.

After Emily died I didn't take any time off work and to this day I carry the scars emotionally. Nothing is as important as your wife and yourself. Don't make the same mistake I did. I thought I could forget about what had happened by going back to work, but it does not go away. All I can say to anyone who find themselves in a similar situation to me is, 'Take time off work'.

Being back at work was a nightmare. I could not function properly and I really didn't care about what I was doing. My boss was one of those blokes who reckon it all goes away if you ignore it. That's bullshit. It doesn't go away. It comes up and smacks you down. I suggest you take as long as you want off work and don't worry about what others think. It is happening to you, not them. Screw what anyone else thinks you should be doing. Do what you feel is best for you.

I quit my job as a panel beater after 16 years in the industry. I went on sickness benefits for a while because I was suffering depression. Now I work for Foxtel. It is like 'before life' and 'afterlife' to me. Before I was a panel beater and was only ever concerned about things related to that. Now I see that as a waste of my life. Now it is time for something new. It is hard to describe, but starting again at something new helps. I think changing careers has helped give me a new direction in life.

One of the things I've found the hardest to cope with is that all my friends had just had their first or second child around the same time we lost Emily. Seeing them now shows us where she would be at if Emily had lived and that is very hard. Don't get me wrong. I am glad their children are healthy, but you do get a little jealous and think, 'Why us and not them?'. Its a horrible way to think, but its the truth.



The support Chrissie and I got after Emily's death was fantastic. It started with the midwives and staff at the hospital. Then a counsellor from Barwon Paediatric Bereavement Program called in on us and offered support and understanding. After that we found that SIDS and SANDS were great, and then recently I've been attending the Men's Support Groups at Bethany.

I honestly thought counselling would be about everyone sitting around drinking herbal tea and smelling incense. I imagined there would be some stupid person with a soft annoying voice saying strange things. I thought, 'That's not for me.'



Now I realise, after attending group counselling, that it is okay to go there. It's just people in the same situation as me talking and sharing their experiences.

I have found it enormously helpful attending support groups. They've helped me to realise that what I have felt and was going through was normal and that it was okay to cry and be sad and to go at my own pace. All blokes in my situation should think about going to some kind of support group. I was hesitant at first, but now I go when I can.

After Emily died I found there wasn't much information about grief for men to read. There was nothing to say how to go to a funeral directors and what to do when you go back to work. There was nothing out there to say it was normal to feel like shit. There was nothing around to let you know that it was okay to leave your job. There was nothing about support groups for men and no information about what you could expect to find at a support group if you did go. I think it would have helped me to read about what other men have been through.

As someone who is experiencing grief for a child right now I can tell you that, as a man, it doesn't help you to be macho. Be sad. Cry. Scream if you have to. Then, when you are ready, seek help from support groups. Believe me, you are not alone in this.



'How do I cope?'

My answer is, 'I just do.'

There is not a second that goes by that I don't think of Emily. Sometimes, for no reason at all, I get really sad and all choked up. It is only ten months since Emily died and it is still very fresh in my mind. It is easier now, but not any better. Chrissie is still finding it hard. She is coping much better but I don't think the grieving will ever stop completely. Some people in my family think a bit differently about grief. They think we should be over it by now. I tell them, 'No way'.

Our friends are supportive and understanding, but there have been times when they've been hesitant to tell us things. My best mate and his wife got pregnant not long after we lost Emily and they found it hard to tell us. They did not know how we would react to the news. They have had a healthy daughter now and we see them often. We are happy for them and our relationship with them is fine.



Life is like a roller coaster ride. One minute you have no problems and the next thing you can't think straight. I know now that I am a more emotional person. I get upset at sad things now, like when other babies or children die, but I think I am also more cynical of others and what they think is hard or difficult in life. I don't think I have ever been angry about Emily's death. If anything, I am more mellow. I have been very lucky. My relationship with Chrissie has been made stronger by losing our daughter.

I still love Emily as if she is here right now, and I will always remember her as the most beautiful, perfect thing I have ever seen. I hope the grief gets easier. I can see from other father's I've spoken to that it does get easier as time goes by, but I also know it will never go away. In a way I hope it doesn't go away because I will always want to remember Emily.

*For Emily Jordan Ware*

*December 30, 2001*

*The journey continues*  
*December 2008 - Post Script*

When I wrote what you have read above, it was very early days for me after Emily had died. As time passed and I re-read my story I realised how angry I was and that really comes across in what I've written, I was in a very bad space back then. But now, seven years later, I want other Dads to know that things do change and the anger isn't there like it was back then and I'm coping with things much better. The other thing that perhaps made my story seem different to the other Dads in this book was that I didn't sit down and talk in-person because at the time I wasn't up to talking to people openly about Emily. What I did though was provide my story to Dion Teesdale by writing him an email and I guess I can see now that maybe doing that changed the tone of what I said a bit. I sort of regret not talking to Dion in person to tell my story, but that's just what I needed to do at the time.

For those men who have only recently had a child die, I would say things can and do get better over time, even though I would never have believed that was possible myself. I remember being told it gets better and I thought what a load of shit, but now I'd say it never goes away, but it does get better. You don't really notice it getting better, it's gradual and you find you can take an interest in other things bit by bit. That's pretty much where I'm at now.

It's seven years since Emily died and Chrissie and I now have twin boys – Aiden and Ryan, who are five and a half years old. There was some stress when we went for the ultra-sound with the boys pregnancy (we didn't know we were having twins at the time), when the technician seemed unsure about something. Instantly I started to think 'oh no here we go', but then they moved the instrument around and I could see a second baby and said 'holy shit it's twins'. When they were born we kept such a close eye on them, checking them when they were asleep to make sure they were OK.

There are still things that are a no-go zone for me, like looking at the photos of me holding Emily, I don't know if I will always be like that. I'm a bit more cynical now about things in life, although you do get back your sense of humour. I'm now back involved with a local motor sport club that I hadn't been back to since Emily died, because I just didn't have the energy for it. But now I take the boys along to some of the events and it's good. Having the boys helps us focus on the future. Now, the boys certainly keep us busy, but we always remember Emily. At Christmas time the boys put a ball on the tree for Emily and we buy a gift for the local wishing tree charity, by picking out a gift for a girl and that's how we remember Emily at that time of year. Emily will always be a part of our lives, we talk about her, perhaps the boys don't quite understand, but they know she's part of the family. We wouldn't want it any other way. But the main message I want to get across is that things do change and it does get better over time, even though it's always there.



# love lives on forever

**BAS BASKARAN**

My daughter, Sharyaka, died when she was eighteen months old. She was born on February 28<sup>th</sup> 2000 and she was a wonderful child with a beautiful personality who was known by many people in Geelong. When she was about nine months old, my wife, Gayatri, and I took her and our eldest daughter, Harshini, on a seven-week holiday to Sri Lanka, so our parents could meet their newest grandchild. We travelled around to many places and had a wonderful time as a family. It was the longest holiday I have ever had. We came back to Geelong in the first week of January, 2001, and picked up our usual life of full time work and childcare.

In February 2001, Sharyaka had a round of immunisations, as most children do when they are twelve months old, and she had a reaction to them. She contracted a mild form of Measles. Harshini had the same problem when she was the same age and she was fine after a few days. Sharyaka got better quickly too, so we didn't think much of it.

Some time in August, Harshini developed a rash after one of her swimming lessons. Both Harshini and Sharyaka had been having swimming lessons since they were one year old. The rash was all over Harshini's body and we thought it might have been something to do with the Chlorine in the pool. We put some lotions on her skin and the rash cleared up in about a week. Then, a few days later, one of her ankles became swollen and she couldn't walk on it. We had some tests done and the doctors seemed to think that it was caused by some sort of rheumatic problem. At the same time, Sharyaka had a bad cold and was running a high temperature. When we took her to the doctor, she was put on Ventalin to prevent Asthma, but everything turned out to be okay at that stage.

Another few days later I was at home and I decided to take both of the girls to the doctor for another check-up. I can still remember Sharyaka running around the doctor's surgery while the doctor had a good look at Harshini and her ankle. Sharyaka was such a notoriously inquisitive child. The doctor decided to do some more blood tests on Harshini, so I called my wife to come and get Sharyaka and I took Harshini off to have the blood tests.

That night Sharyaka had a very high temperature, which we thought was probably a result of her cold. We gave her Panadol every few hours to try and bring her temperature down. We decided that if the temperature didn't come down, we would take Sharyaka to the doctor in the morning. In the morning her temperature had come down. She was very lethargic and drowsy, but she hadn't slept much during the night so we thought she was just tired.

The doctor called me that morning, told me he had the results of the blood test and that it would be a good idea to take Harshini to see a Paediatrician. We went and saw a Paediatrician that morning and he called in another Paediatrician for a second opinion. They both agreed that Harshini needed to be admitted to hospital and given some antibiotics. They said, 'It looks like there is some sort of infection on the bone'. I told the doctors that I was concerned about Sharyaka as well, because she had been sick too. They said, 'Bring her in and we'll have a look at her'.

On the way to the hospital Sharyaka was very lethargic and quiet, but we were mostly concerned with how Harshini was doing at that point. When we got to the hospital, the doctor spent about two hours with Harshini. He had a look at Sharyaka and did a thorough examination of everything, but he didn't think there was any sign of the infection they had

detected in Harshini. He thought, like we did, that she was unwell due to the cold she had developed.

In the evening, when all of the tests had been completed on Harshini, the doctor came back to check on Sharyaka and he said, 'Well you're going to be in here for Harshini, so we may as well keep Sharyaka in so you can all be together.'

He said that it looked like Sharyaka was finding it difficult to breathe and that it might be necessary to give her some oxygen to keep her Asthma under control.

A little while later, at around 6.30pm, Sharyaka's blood pressure dropped dramatically and the doctors decided to call in another specialist. From that point on, everything started working on an emergency basis. They decided to do blood tests and within about half an hour we were told that there was an infection in Sharyaka's blood too. At 7.30pm Sharyaka had a Cardiac Arrest but the Intensive Care Unit staff were able to revive her.

At around that time our doctor, who we had seen us one day earlier, rang the hospital to find out how Harshini was doing and when I told him what had happened to Sharyaka, he couldn't believe it. He had seen her the previous day in his surgery and I think it was hard for him to make sense of what was going on.

In the middle of the night an air ambulance was arranged to take Sharyaka to the Royal Children's Hospital in Melbourne. Luckily, one of our friends from work came to the hospital with his wife. I had told them we were taking the girls to the hospital and they came to check in on us. They took Gayatri to Melbourne to be with Sharyaka and I stayed at the Geelong Hospital with Harshini.

Our friend has a daughter who is a doctor at the Austin Hospital. My friend called his daughter at 2.00am in the morning and asked her to give us some support. She was waiting at the Royal Children's Hospital when Gayatri and Sharyaka arrived.

One of the hardest things was having to tell Harshini what had happened when she woke up in the morning. She had gone to sleep in Geelong the previous night and she didn't know anything about what had been happening to Sharyaka. I didn't want to hide anything from her, but it was difficult trying to explain the situation.

The doctors in Geelong thought it was a good idea to transfer Harshini to Melbourne, so we could all be in the one place and so the girls were getting the same treatment. However, we were going to have to wait four or five hours for an ambulance and I didn't want to be apart from Gayatri and Sharyaka for that much time. I said, 'We haven't got time for that. I'll drive Harshini in my car.'

When I look back now I realise that was one of the stupidest things I could ever have done because I hadn't slept the entire night. I got in the car and I drove Harshini up the highway to Melbourne. It was a pretty tough drive, but I had time to fill Harshini in on everything that had been happening and I had time to answer her questions.

When we arrived at the Royal Children's Hospital, Harshini was under the impression that Sharyaka was going to be okay because the hospital was so big. I had a different perception. I knew something was very wrong. I knew it was a touch and go situation.

I was trying to admit Harshini to the hospital when one of my cousins, who had come to the hospital to meet us, said, 'No you don't have time for this. You have to come upstairs. You are needed up there straight away.'

When I got upstairs I saw that Sharyaka had deteriorated. She was bloated. The fluid in her body was bleeding and her skin had changed colour.

At that point the doctors told us it was only a matter of time. Harshini was very upset so I took her to another room and when we got there she said she did not want to go back into the same room as Sharyaka. I then had a battle on my hands because Harshini did not want me to leave her. She said, 'I don't want you to go.'

She wanted me to stay with her and Gayatri to stay with Sharyaka. I wasn't sure what to do. I was torn.

I stayed with Harshini in the other room for a bit and a Social Worker from the hospital kept coming in and saying to me, 'Look, its only a matter of minutes now. You should come, otherwise you'll miss seeing your daughter alive. You'd better come and be with her.'

Harshini was crying, she refused to let me go and she did not want to be left with anyone else. So, at that time, I had to make a decision.

The Social Worker said, 'You can leave the child here.'

I said, 'No, that's fine. I'm going to stay here with Harshini.'

The Social Worker didn't understand the situation. Harshini was still quite sick, clinging to my lap, and I wasn't going to leave her alone. It was as very hard decision to make.

It wasn't long after that Sharyaka died with Gayatri at her side.



The thing that got me through those few days, and the days that followed, was the fact that there were things that needed doing and somebody had to do them. I felt that I had to do them. I didn't think that I could afford to let myself fall apart. I thought that if I didn't keep everything running then everything would fall apart. I felt like I had the ability to get things done and I wanted to take care of certain matters so that Gayatri wouldn't have to worry. I became very task oriented, which was my way of coping. I knew I couldn't change what had happened, but I knew that I could delay everything else that was going to happen.

My first task was to make sure Harshini was okay so that Gayatri could focus on Sharyaka. We knew that the infection Harshini had at that stage wasn't life threatening, but we were concerned that the infection might spread to her bones. I thought it was important to stay focussed on Harshini and the antibiotics she needed to get better. There was a time factor to all of this. Harshini was having intravenous antibiotics on an hourly basis. I had to give Harshini one injection at the Royal Children's Hospital while everything else was happening. I had to convince Harshini that she had to have the injection. I had to manage Harshini's health.

I didn't see the point in admitting Harshini to the Royal Children's hospital at that stage. I wanted to take her back to Geelong. I rang the Hospital in Geelong, told them what had happened and asked them to keep a room for Harshini. When we got back to Geelong Harshini was admitted to hospital and then people around me wanted to know what I wanted to do next. I told them that I would refuse to do anything about a funeral for Sharyaka until Harshini was out of hospital. I said, 'It can wait. It has happened. Nothing can be changed.'

One of the things I found around the really critical time, in the few days after Sharyaka's death, was that there were many people around me saying, 'Do this, do that, do this.'

People only wanted to help, but you can get a bit confused about what you need to do and what you should do. I think it's important that you decide what you want to do and do things your own way. Handle things the way you want to handle things, and take your time doing them. It would have been good to have someone around to tell me that what I was doing wasn't wrong.

I think part of my ability to deal with everything that was happening around me came from the experience of losing our first child Nishkalan back in 1995. Nishkalan was still born at 38 weeks and we still don't know why he died. There were no clear medical reasons, so it was out of our control. I was much more mature and able to cope with Sharyaka's death than I was when Nishkalan died. If Sharyaka's death was the first I had experienced, I don't know if I would have been able to do the things that I did.

After Sharyaka had died Gayatri was worried that we should have done more. She said, 'We should have taken her to the hospital earlier'. My point of view though has always been that we did our best at the time and we can't look back. I think its important not to place blame and not to regret the decisions we make. We did as much as we possibly could with what we knew at the time.

I think you cope with certain situations depending on your personality. I am a very independent person. I left home to go to University when I was 17 years old and for a number of years I was on my own. Any problems I faced in my early life I faced on my own. I guess I have a very strong personality because of that. Also, when Gayatri and I came to live in Australia 15 years ago we came alone with only our suitcases and we didn't have any family here to support us when we arrived. We were on our own then and we had to build up a life for ourselves, so I am used to having to adapt to different situations and to coping with different pressures.



We decided not to have a funeral for Sharyaka. A lot of people knew her and knew that she was the type of child who never stopped smiling. We didn't want Sharyaka to have a sad funeral. Instead, we decided to have a Goodbye Party for her. It was like a birthday party. We put up a beautiful photograph of Sharyaka smiling and we played her favourite songs. It was a very good thing to do, but it was still a hard thing to do.

Harshini was very upset at the funeral and it was important for me to not let her see me cry. She wouldn't have been able to handle it. I felt that I had to control my emotions for her sake. It was a very hard day. I felt very sorry for Harshini. Its terrible that she was five years old and she had to go through the experience of losing her sister. Sharyaka and Harshini were very close.



After Sharyaka's death I went back to work within a week. I could have stayed at home for a month if I wanted to, but I wanted to get back to work. My thinking was that I had to keep going and stay in control of my emotions until Gayatri and Harshini were okay. I knew that life wasn't normal and I felt that it was best to try and get back to normal life as much as possible. At home I had to look after Harshini all the time because Gayatri was terribly upset. She spent many days just crying, which I completely understood, and I thought that going back to work would help Gayatri come back to reality. My thinking was that if I wasn't at home then Gayatri would have to take care of Harshini and get back into doing daily things as well, and I thought that would be the best thing for all of us. I thought a time would come for me to cry and to let go, but once I went back to work it was difficult to find the time. As a result, I don't think I've ever had my time.

When I went back to work my Manager didn't talk to me for some time, then one day he came to my office and said, 'Do you feel that you are coping with the workload?'

I said, 'I don't care if I am or not. I'll do what I can.'

He was a bit shocked by that, I think. He had come to Sharyaka's funeral but I don't think he knew how to approach the subject with me. Most of my other colleagues were much better at offering support. Some of them didn't know what to say to me, but that was fine. They came to me and said things like, 'I can't imagine what you must be going through,' or 'I don't know what to say to you.'

When my Manager came in, pretending that nothing had happened, it was very hurtful.

Now, I don't worry too much about the reactions of my colleagues to Sharyaka's death. I have learnt to accept that, at work, there aren't many other people who know what it's like to lose a daughter and that there isn't much point explaining it to them. Most people are very sympathetic, but most people can't really understand unless they've experienced something similar.

One of the hardest things I've found after the death of a child is the pressure to carry on managing your life. You have to act as a worker, as a Dad, as a husband, and as a person in your own right as well. You have to be all those people each day, everyday, and that's not always easy to do.

On days when I felt that I couldn't be everything I wouldn't go to work. I would spend some time at home and then go to Sharyaka's grave. Going to the cemetery and spending some time at Sharyaka's grave has become a very important ritual for me. It's where I find time to myself and time to be alone with my grief. When I've had a bad day at work, or even when I've woken up and felt like I might not be able to face everything, I've often gone to the cemetery and that has helped clear my thoughts. Sometimes all I need to do is go for a walk, but I like going to visit Sharyaka's grave.



The first two weeks after Sharyaka's death was a very critical time for me and I wasn't in the frame of mind where I wanted any outside help or advice. I had my way of getting through everything and I didn't want anyone to get in the way or to upset the control I had on the situation. After that time, when I was back at work and when I was trying to get back into life, I wished I had someone to talk to.

What I have found useful is sitting down with other people and talking about the experiences I've had. You know you are never going to change anything that has happened but you can learn from what others did and didn't do when their child died, and that can be very informative. I've found going to support groups for men who have had a child die very good for this.

At support groups for men who have had a child die you usually find there are other father's there who can at least understand what you are talking about and who can understand some of the things you have been through. Its really important to be able to talk about your own experiences in an environment where other people will listen and understand.



One of the difficult things about having a child die is having to tell everyone. When Sharyaka died Gayatri couldn't tell people. She could hardly speak and she couldn't be expected to face friends or get on the phone and start letting people know. Someone had to do it though, and I felt that it had to be me. I had to call people, particularly during the first few days after Sharyaka died, and explain what had happened. I must have told the story a thousand times in those few days and it was very tiring. I wished that somebody could have made all those phone calls for me. Then, when people came to visit us in the time leading up to the funeral, and even afterwards, they expected you to tell them the whole story, piece by piece. Even up

at the hospital, when I arrived back from Melbourne with Harshini, people were wanting to know what had happened in as much detail as possible. I understand why people want to know, but it doesn't make it any easier.

I think people outside the family tend to think of the man, or husband and father, as the shield protecting the women and children. If they want to know information, they think its better, and perhaps easier, to get it from the man. I think there's an expectation that the man will cope better and that he should be the one to approach. I guess that was partly the case with me, but it becomes very difficult to find a time to let down the shield.

Even now, small things still happen where I am expected to explain the situation and inform people about Sharyaka's death. Recently a letter arrived at our house asking my wife to explain why she had failed to continue immunisations for Sharyaka. It was quite a serious letter almost accusing Gayatri of being a negligent parent. Gayatri opened the letter and burst into tears. I called them and told the man who answered that I needed to speak to someone about the letter and the man said, 'No, the letter is addressed to your wife. You can't answer for her.'

I really got stuck into that guy and he quickly realised what was going on. He was very apologetic. Those sorts of things make me very tired.



The death of a child can cause many problems and difficulties for a marriage. Gayatri and I have had to go through some very difficult times together, but we see the difficult times as challenges and it is about how you come out of a challenge. There are times when we haven't agreed on ways of handling situations, but the bottom line is that we are always there for one another and you work through the hard times together. We also feel that we must share the burden of the grief and not allow ourselves to place blame. There is no point in blaming anyone. We look out for each other. I support Gayatri being involved with organisations like SANDS and BPBP and she supports my need to be a part of the Men's Grief Support Group meetings at Bethany.

At the end of the day, you have to survive and what becomes important is how you are going to survive. You can't ever let the death of a child go, but you can learn to survive with the pain and the hurt. Living with grief is a battle and one that you can't give up on. Early on I discovered a determination to keep living life, and to ensure that my wife and children keep living their lives as best as they can, and that keeps me going.



My way of coping with Sharyaka's death may not have been the best way of coping, but it was the only way I knew how to get through. Some people might think that my actions were a result of trying to deny what had happened. Some people might think that I was trying to keep things as normal as possible so I didn't have to face the truth. I wasn't trying to escape anything though. I was just trying to manage the best way I knew how. I think my determination to get through has been very good for me on most levels, but I know there are some drawbacks to being so determined. I suppose there have been times when it would have been good to let go of my emotions more than I have. There are certain things you need to let go of and I didn't give myself the time to do that.

I think it was difficult for Gayatri to be there when Sharyaka died and for me to not be there with her. Later on she said, 'You were not there'. To a certain extend I do worry about Gayatri being disappointed that I was not there, not because I wasn't there but because Gayatri didn't understand why I wasn't there. In my mind my decision not to be there was



crystal clear. I had to make a choice. I couldn't do both. I don't regret the choice I made. I only hope Sharyaka understands. I'm sure she does. Some people have said that I should have been there with Gayatri, at the time of Sharyaka's death, but they don't know what the situation was like. There were other things that needed to be taken care of. I did what I thought was the right thing to do.



I think it's important for people to understand that men are different. The way they grieve is different. The way they think is different. We are different, but we are still human and we do care. Others might not understand why a man is doing what he is doing or might think that it would be better for him to act in another way, but its important to know that men generally behave in a certain way because they have some purpose in mind. Sitting down and crying might not always be the best way for a man to deal with the death of a child. He might prefer to get things done and that doesn't necessarily mean he's in denial mode.

One thing I found was that people often think that the mother is very attached to the child and that the father isn't as attached. My experience was nothing like that. The only thing I didn't do for Sharyaka was carry her in a womb for nine months, but I was there for everything else. The perception that fathers don't experience grief as severely as the mother is quite wrong. I think people thought I was doing better than Gayatri because I wouldn't have been as attached to Sharyaka. My relationship with her was different, but not any less important.



I think Sharyaka's death has taught me to value people and relationship much more. I was never particularly materialistic, but now I see more than ever the value of people and of life. At work I see people worrying about money and wishing they had more. I think, 'Why worry about \$20 here or there? It isn't even two movie tickets. There are more important things in life than the price of two movie tickets.' Before Sharyaka's death I probably would have been worried about an extra \$20 in my pay packet, but that sort of thing just isn't as important now. It's a real change. We now have our fourth child Sajiva who was born on 5<sup>th</sup> June 2002. We remember Nishkalan and Sharyaka everyday and they will always be part of our life. Love lives on forever.



# the day my world changed forever

MARK BUTCHER

On Friday, January 16, 1998, I arrived home after a long week at work not realising that this day would change our lives forever.

I met my mother-in-law at the front door of our house with the news that Jo, my wife, had started bleeding. We were only 20 weeks into the pregnancy with our third child. I didn't take it in. I seemed like a nightmare or something not real.

I don't remember much about the twenty-minute drive in to the hospital.. I do remember thinking, as I waited for the doctors to work out what was going on, that if we lost this baby it would just be a miscarriage. I thought Jo would deliver a little unformed baby and that it would look like a jellybean. How wrong I was.

I had cut the cord for our first two children, Eryn and Jake, and again the midwife asked me if I would like to cut the cord for this baby, a son we decided to name Izak. When Izak came into the world he was perfect. He was little, but he was perfect.

Jo and I both nursed Izak for a moment, but we had no time for tears or emotions. Jo was still bleeding badly and had to be rushed to theatre for emergency surgery. The doctors asked me to sign a consent form in case Jo required a blood transfusion. I felt torn between the two of them. On one hand I had Jo who was very ill and on the other I had our little lifeless Izak. I didn't want to leave him, but Jo needed me.

I followed Jo down to surgery and kissed her as she was taken into the theatre. As the doors shut behind her I was asked to sign another consent form, this time permitting a hysterectomy in case the doctors couldn't stop the bleeding. I didn't know what to do. How could I be expected to make that sort of decision? Right there and then it was up to me decide if Jo and I would ever have another child. Yet, I signed the form. I had to. Jo's life had to come first. Thankfully the doctors were able to stop the bleeding and Jo didn't require a hysterectomy.



While Jo was undergoing surgery I returned to the labour ward. One of the midwives had taken Izak's hand and footprints while I was gone, and she had dressed him so that he was ready for me to cuddle. I had some time to bond with Izak. I inspected his little fingers and toes. I will always remember his little face. Everything about him was perfect, he just wasn't breathing.

It seemed like I was with him forever. I didn't want to leave him. When it was time for me to go I could smell Izak on me. I could smell that *baby* smell and I decided then that I never wanted to wash my hands again.

The nursing staff were great but they had so many questions. 'Do you want to register the birth?' they asked. 'Did you know that if you register the birth, you will also have to register the death?'

All I wanted to do was take Izak home.

The next hardest thing for me was having to ring our families and friends and tell them what had happened. That's what blokes do. They make all the phone calls and deliver the bad news.



I waited in the labour ward for Jo to return from her surgery. I still didn't really know what was going on. As I sat there waiting for Jo to come back, I was totally stressed out and full of resentment.

Three hours went by and Jo still wasn't back from theatre. I was out of my mind by this time and the tears started to flow.

Another hour later I found Jo. She was in a normal day ward. The doctors thought it best if she didn't go back to the labour ward. I just wanted to hold her and tell her everything would be okay. In the back of my mind I was wondering how the hell I was going to do that.



The few days after Izak died are a blur to me. Friday turned into Saturday and Sunday turned into Monday. Jo was discharged from hospital on the Sunday and we were allowed to take Izak home on the Monday for a private burial on our family property.

I remember shopping for a coffin for Izak. He wasn't very big. He was only 27 centimetres long and only weighed 620 grams. On the drive in to Pathology on the Monday I said to Jo, 'We need to get Izak a little box or something'. We didn't know what to do, so we went to Spotlight and bought a little box, a teddy bear and a small blanket.

When we got to Pathology I said, 'We are here to pick up Izak'. They didn't know what I was talking about. They only knew Izak as 'the Butcher foetus'. When they brought him out he was in a blue ice-cream container. They handed him to me across the counter and I looked straight at the Pathologist and said, 'Do you think you could do us a favour and put him in this box?'. The Pathologist nearly fell over. He didn't know which way to look. He apologised and put Izak in the box for us. We drove home and we didn't look in the box. We didn't want to.

I asked my parents if we could bury Izak on the family property. We were in the middle of a drought and Dad got the old post-hole digger out. He picked the biggest granite stone boulder and sunk a big hole down into it. Just Jo and I went to say our goodbyes and bury him. It was a sad time.

We were told, when Izak was born, that if we registered his birth then we would have to register his death. At the time it didn't seem to matter whether or not Izak was registered. We knew he had been alive. We knew he was a person. We knew that he had been born. Nothing else really mattered. We didn't feel that we had to announce it to the whole world. In hindsight, I wish we had registered Izak's birth and death. I wish we had got our parents more involved, and our other children more involved. My nine-year old often asks me, 'Dad, why didn't you let me nurse him? Why didn't you let me nurse him?'. It just wasn't important at the time, but I can see now how those things were important.



How do you cope with grief? How do you talk about it? How do you keep going? Well, life had to go on. I had to return to work. We still had the mortgage to pay and the car still needed petrol in it, and the kids had to be fed and put to bed. You just have to keep going. I knew it

was going to be hard, but I knew I had to be strong. I had to be the tough one. I didn't want to put my head in the sand and pretend that it was going to go away. I knew it wasn't going to.

I felt that I had to keep going. I thought, 'I can't lose it here. I can't pack up. I've got to keep pushing forward'. I felt like I had to keep going for Jo and the kids. I was the strong one and I felt that I had to remain as positive as I could. It wasn't until later that I could let myself fall down. I packed my grief up. It wasn't in the bottom draw, but it was buried. Perhaps I put it in the second draw. It was always close to the surface, but it was kept out of sight. It wasn't a priority to stop and think about how I was feeling. The priority was to try to fix the situation. I knew I couldn't bring Izak back, but I knew I could fix the problem in the sense that I could make the grief easier for Jo and for the rest of the family. I wanted to try to make everything as easy as possible for everyone else. The way I looked at it, it was my responsibility as a father and as a husband.

I think a lot of how you cope has to do with your outlook on life. My outlook has always been, 'Give it your best shot. You only get one shot at life and you have to give it your best'. There's no point half-doing something. I guess I'm fairly determined.

My brother-in-law was killed in a shooting accident the first year Jo and I were married. He was out rabbiting. It was one of those shocking accidents. He was on the back of a four-wheeled drive. The gun slid out of his hand. He grabbed for the barrel of it and the butt hit the bullbar and shot him through the left eye. He survived for three or four days but then died. I look back at that experience of grief and can see how my way of coping was in place then. I was like the backstop for Jo's family. I was ringing the newspaper asking them to not print Jo's brother's name because we hadn't been able to contact certain family members. I was driving the family back and forth to St Vincent's Hospital in Melbourne. I was the one everyone expected to be strong. I went into that, 'You can rely on me because I am a rock' mode and I guess that was what I switched back into when Izak died.



I was away from work for about three or four weeks after Izak died. When I went back to work everyone asked me, 'How's Jo?'. I don't feel like I got the support I wanted. I think people thought that, because I didn't physically give birth to Izak, I was all right. People seemed to think that Izak's death was something that had only happened to Jo and that it was something secondary to me. On the inside I was chewing away at myself and it would have been nice to have more people show some concern about how I was doing.

For the first month back at work I was on autopilot. I didn't know where I was and keeping up with my usual work commitments just wasn't that important. I was lucky that I didn't have to operate heavy machinery because I probably wouldn't have my arms and legs now. I had no idea what was going on. At the end of that first month back my boss told me that I should be over Izak's death. My boss said, 'It was just a miscarriage. You should be over it by now'.

I remember there was an incident at a staff meeting not long after I was back at work. I often chaired the staff meetings but on this one day I didn't want to do that. I was feeling pretty out of it. I wasn't really listening to what was being said and I wasn't offering any input. One of my colleagues said, in front of the meeting, 'Are you sick or something?'

I said, 'Nah, I'm feeling okay. I'm just doing it a bit tough at the moment.'

My colleague then said, 'Oh why? What's wrong?'

This person knew that Izak had died, but they had no concept of how grief might effect someone.

There was one woman at work who, in the first few days after I got back to work, came up to me and cuddled me in the middle of the store. She said, 'Have you got ten minutes? Let's go and have a chat.'

The ten minutes turned into an hour. That was one of the best things anyone has ever done for me.



In the first few months after Izak died I would often drive home from work, which was a good half-hour drive, and when I'd get out of the car I'd realise that I couldn't remember even getting into the car. I couldn't remember the car park and I couldn't remember a thing about the ride home. Other times I got in the car and drove to the bush, or somewhere quite, and just sat there for hours. I don't know why, but it helped.

I remember one time, about six months after Izak died, when I took a sick day at work. I had the company car and I was meant to go to Melbourne for a two-day seminar at the head office. I got to the outskirts of Geelong and I had to pull over. I sat on the side of the road for a bit and then I rang work and said, 'I'm not going to the meeting. I'm sick'. I was dressed in suit and tie and was all ready for the seminar, but I couldn't do it. I went for a walk around a park, grabbed myself some lunch, sat on a bench for most of the afternoon and then I drove home. I didn't tell Jo about not going to the meeting. The next day, I did the same thing. I didn't go to the meeting.

I felt that I couldn't deal with anybody or anything. I felt like I needed some place to get my head right. I felt guilty about doing it because I was lying to work and to Jo, but I felt that I really needed the time alone. Sometimes I thought it was better not to tell Jo about things like that. I didn't think she needed to know. It wasn't about keeping secrets. It was about something I needed to do for myself.



One of the really difficult things to deal with after Izak died was how some of our friends treated us. There were people we socialised with regularly, people we had dinner with on Saturday nights and whose kids played with our kids, who would cross the road when they saw us coming. I don't think they hated us. It was just that they didn't know what to say, so they avoided us and said nothing. I think silence is the worst form of abuse. To say nothing is cruel. We lost friends because of that.

I understand that some of our friends were naive, like we had once been. In the past, before Izak, I didn't know what to say to someone whose child had died. I didn't know how to act. I can understand other people's reaction to us, but it doesn't make me accept that type of behaviour.

Since then, one of those couples we were friends with has lost a child of their own. I rang them when I heard and said, 'How are you doing?'

I remember one night in particular when we were out with some friends and one of the men had a sister who was expecting twins. We were all talking about her and this guy said, 'The best thing that could happen to her is if she lost one because she couldn't deal with two.'

I turned around and hit the guy. It was very out of character for me to do that. Everyone was like, 'Oh my God. What's wrong with Mark?'

I've spoken to the guy since and said sorry. I told him that I was having a bad day and that his comment just hit a raw nerve with me. I don't know if he understood though. There he was, with four healthy children running around and he was wishing death on an unborn baby. I

don't know how anyone could wish for that. I don't know how he could be so light hearted about wishing grief on the baby's mother and father. I don't have an aggressive nature. I'd much rather talk something through with someone before having to use fists. I guess I was just angry.



Another difficult thing about being the father of a child who dies during the normal term of pregnancy is that you don't really get to begin the parenting process. The woman carries the child and you are waiting to hold it, to change nappies, to take the child for a walk and then you don't get to do those things.

Jo wanted to get pregnant again after Izak. It wasn't that she wanted to replace him, she just wanted to have another baby. I think it was a physical need for her. Her body had been preparing to give her a baby and it didn't work out. I think she was left with a physical craving to be a mother again. It was an instinctive thing. I remember a few days after we came home from the hospital, Jo was crying in the shower. I went in and said, 'What's wrong?'. She said, 'I'm producing breast milk'. I had forgotten all about that. It didn't cross my mind that her body would still carry on as if there was a baby, even though Izak died.

I didn't want to have another child. I thought that even if we tried it would bring up all of the grief we had felt for Izak. I didn't want to go there. I didn't think I would be able to stand it. I guess I was afraid that if Jo did get pregnant, then we'd have to go through the whole ordeal again. Even when I was able to get over the fear of having another child and it dying too, I was still worried about the reason for having another baby. I was full of questions. Are we just trying to replace Izak? Are we trying to avoid the grief we feel for Izak? Are we just trying to fix something that can't be fixed?

I steered away from intimacy with Jo. I think for a good 12 months I didn't want to know about our sex life. I didn't want to go there. I didn't want to know about sex. Yet, I still craved it. I didn't want to have sex with Jo because I couldn't deal with what had happened to us. I didn't want to bring it all up. I didn't want to think about the emotions or about having more children.

I know many other blokes who, when their grief has kicked in, have wandered from their wives because they haven't been able to deal with getting intimate again. They've been too scared. They've been afraid of what they might have to confront. Instead of facing their problems with their partner, they've tried to escape. There was a time when, if the opportunity had of come up, I might have done that too. Not because I wanted to cheat on Jo, but because I was finding it really hard to go home everyday and face what we had lost.



When my sister was expecting her first child I couldn't get close to her. My sister's baby was the first baby to be born after Izak's death. I told her, 'Look, this is really hard for me.' She said, 'That's fine. I understand'. On the day she went to have a Caesarean section she rang me and I went up to the hospital and waited with our Mum and Dad. We expected the Caesarean to take an hour or so. Two and a half-hours later I was in such a state. In my mind I had organised the funeral service, I'd organised what I was going to say to the baby's father, I'd organised how I was going to handle Mum and Dad, and I had organised who I was going to call for counselling for everyone. It was ridiculous. I wasn't excited for my sister or the child being born. I was preparing for the worst. Then, when the baby was finally born and I found out it was a healthy boy, I had to leave. I lost the plot. I was very emotional. I felt like it was something I had missed out on. I felt like a real idiot the next day. It was hard not

being able to enjoy the experience of the birth of a child. Its the loss of naivety. You can't go back. I think I often plan for the worst these days, and hope for the best.



Twelve months after Izak died, perhaps as a remedy to how we were all feeling, we decided to head off around Australia. We'd had a gut full of everything. Different things had become important. When I looked at it, my wife and my kids had become very important. Things had fallen apart and I felt that I needed to do something about it. We decided to head off. We sold our house and resigned from our jobs. We bought a 4WD and a caravan and set off into the sunset.

People said to us, 'You guys have lost it'. I don't think we lost it at all. I think we found what we needed to find. I'd spent do much time at work that I didn't know my kids. I was working 7.00am to 7.00pm weekdays and then going into the office on weekends. I needed to get to know my kids. I realised that houses and cars weren't important. I was a bit materialistic before Izak died.

We had time out from everything on our trip around Australia. We had time out from distractions. We didn't have work, or our families or friends around us, so Jo and I found we had time to talk about the things we hadn't ever had time to talk about. It was a great learning curve. We had the time of our lives.



There seems to be a time, at about the two year mark, when things come up for some men. You've been through the first anniversaries. You've been through the birth date and the death date. You've had your own birthday and Christmas and Father's Day. You've been through a year of grief and everyone around you is starting to cope better than they initially did. Then, you hit the second year and it can be like, 'Okay, now I've got time. Maybe now I can look at my own feelings.' I think that is a time when many men allow themselves to fall a part.

I think, because many men leave it so long to start dealing with their grief, that there isn't the support they need. People look at you and say, 'What's wrong with you?'

They are thinking, 'What's his problem? Hasn't he dealt with it yet? It was two year ago and he still hasn't got over it.'

For me the two-year mark was very significant. I remember craving affection. All I wanted to do was to be held and to talk to somebody. I wanted to talk to people who knew what I was going through. I didn't want to feel like I was the only person going through what I was feeling.

My family was concerned about me. Jo was saying, 'What's wrong with you? Why are you so grumpy?'

I can generally talk to her about anything, but I couldn't answer her questions then. I was really unsure about what I was feeling and, in the back of my mind, I was concerned about bringing up issues that would trigger her grief at the same time. I didn't want Jo to have to suffer all over again. She'd dealt with Izak's death for two years and was just starting to get back on her feet. But, I felt like it was my time to start dealing with it and I didn't know where to turn. It was a real catch-twenty-two situation. I didn't want to rock the boat for everyone else.

Everything else was going really well for me at that time. Our other two kids were doing really well. We had a great house. I had a good job. Everything was good. But I didn't want

any of it. I started thinking I didn't want Jo, or the kids, or the house. I just wanted to huddle in a corner somewhere. I was looking for a hole big enough to eat me up.

I threw myself into work and study so that I knew my time was filled up. Whenever I had spare time on my hands I'd fill it up with work or education commitments so I wouldn't have time to think about how I was feeling.

I remember sitting down with my younger brother and saying, 'I don't want to go through this any more.'

He said, 'What do you mean? You've got a great wife and two terrific kids. You're so bloody lucky.'

I said, 'I don't care. I really don't care.'

Finally, it got to a point where I stopped and went, 'Mark, what is going on here?'



After Izak died Jo grabbed everything she could to read about how to deal with the death of a child. She couldn't get enough material to read. I was the complete opposite. She brought things home for me to read and I told her, 'I don't have time to read anything. I've got paperwork I need to do.' I always found other things to do.

I was happy for Jo to read about other people's stories, but I thought, 'She can wallow in that stuff. I don't want any part of it.' I thought that reading about other people's experiences would force my own experiences into the top draw and I wasn't ready for that.

It wasn't until about two years after Izak had died, when I didn't know what was happening and I didn't understand the way I was feeling, that I was prepared to accept that I might benefit from knowing about what other people have been through. I thought I'd dealt with my grief, but the truth was I hadn't even begun to deal with it and that's when I realised it might help to know about how others had coped with the death of a child.

Initially I didn't want to do anything like attend a group meeting for men who have lost a child. I was happy for Jo to go to support groups, but I didn't think anything like that would benefit me. I was happy to keep my feelings and thoughts to myself. I thought it was best if I left it all festering inside. In the beginning I wasn't ready for a group.

A time did come though, at that two-year mark, when I wanted to talk to other blokes who knew what I was going through. That's when I got involved with the Men's Grief Support groups at Bethany. I just wanted to know that it was okay to feel lousy. I wanted to know that it was normal to feel the way I felt at times.

The group is about nothing more than a normal bunch of fellers who are just trying to cope with life in general getting together to talk. Going to the group is about having the chance to talk to other guys who know a bit about where you are at, a bit about some of the experiences you might have had, and a bit about some of the things you might be feeling at any given time. Sometimes it's about talking about your kids and your wife. Sometimes it's about talking about something like Father's Day. Sometimes it's about your attitude to work. Sometimes it's about listening and being able to say, 'Hey, I know what you mean.'

Sometimes it's about hearing, 'Hey, you're doing okay.'

An important part of the Men's Grief support group I attend is letting men know that it's okay for a bloke to grieve, and that it's okay to talk to other guys about your experiences. You can meet up at the pub and talk about things if you want to, but I do think having a few drinks or a bottle in your hand can sometimes shadow the truth.



The men who attend the support group are not stupid or weak. We are normal blokes. We swear and carry on and talk about lots of things. Sometimes we share our stories. Sometimes we cry and there is no shame in that. I'm not afraid to cry but sometimes I do try and keep it all packed up inside. Sometimes I might feel like having a good hard sob, but there will only be a few tears in my eyes.

Grief is a funny thing. It affects everyone differently, yet it is so common. All of us, at some point in our life, will experience grief. It just hits you in different ways. Some guys get really angry. Some guys hit the bottle. Some guys bury themselves in work. I've thought to myself, 'Is there a right way to handle grief and is there a wrong way?'

I don't know what the answer to that question is, but I think the way I've gotten through is, 'If it feels right then do it. If it doesn't feel good, then tell someone.'



The lessons I've learnt are little things. For example, when I'm going through the checkout at the supermarket and I see that the girl behind the register is having a bad day, I think to myself, 'I wonder what's going through your mind. I wonder if you've had grief in you life.'

I might see an old man sitting on a park bench all by himself and think, 'I wonder if he's a Dad. I wonder what hard times he's had in his life.'

Before Izak died I was naive and I didn't think about life or other people in the ways that I do now. I think I'm a better person because of Izak. Izak's death has made me realise what's important in life. Izak has helped me find a stronger focus on family and on living life to the fullest. I say we are stronger, better people because of Izak.

One of the important things I've learnt from my own experiences, and one of the things I think other blokes need to know, is that there is nothing we can do to fix what has happened. There is nothing we can do to make it go away. At home you can fix almost anything. A leaking tap. A flat tyre. The chook house roof blows off and you nail it back on. If something is broken, you fix it. But you can't do that when someone dies. You can't fix it. For the first few years after Izak died I didn't accept that.



Izak will always be little in my eyes. I've never 'grown him up'. Jo's cousin has a child around the same age as Izak and when I see that child I think, 'Gee, Izak would be that age now,' but I still see Izak as that baby in the basket. He's that little baby that has never grown up. I don't see Izak ever growing up.

I do get a bit down sometimes because I don't have the physical presence of Izak. I don't have him to nurse, or to kick a footy with. However, although I'm not a religious person, I do think that wherever he is he is happy and at peace, and maybe even proud of how his father has coped without him.

Some blokes are not big cemetery goers. Other blokes like to go all the time. I've only been to Izak's grave about three times in the four years since he died. I don't feel that I need to go to remember him. I remember him in different ways.

We have a little plaque we got made to put on the granite boulder where Izak is buried. For one reason or another we have never gotten around to putting the plaque on the boulder. Instead, it sits up near the kitchen window next to this little glass jar that has always been used as a vase. The kids pick flowers and the vase is always full. There is never a dead flower in it. In a way, it's turned into our way of remembering Izak. The other day Jo bought a Cyclamen and she put it on the window. I don't think she really thought much about it. She

just put it on the window because that was a good spot for it, but it turned into a bit of a memorial for Izak.

I said, 'Hey, you bought Izak a plant.'

She said, 'Yeah. I guess I did.'

I don't think that plaque will ever go up on the boulder, and I don't mind that.



# madeleine lived for 25 days

**GREG ROBERTS**

Our daughter Madeleine died on 25<sup>th</sup> August 1995. She would be seven years old now.



When we found out that my partner was pregnant with Madeleine we were given a baby book. We started to fill it out with the standard information. There was a section on what the mother ate during different stages of the pregnancy, a section for what the father's reaction was to the news of being pregnant and a space for lots of photographs taken throughout the course of the pregnancy.

We'd had a series of miscarriages in the lead up to getting pregnant with Madeleine, and my partner wanted to include our previous pregnancies in the book. She had an image from the first ultrasound she had for our first pregnancy and we decided to put that at the beginning of the book. We had the first ultrasound for that first pregnancy and the miscarriage occurred in the same week.

When I think back to that time I see it as a very black period in my life. We were living in Ballarat at the time and a business partnership I had been involved in for a number of years had unexpectedly, and rather unpleasantly, ended. Around the same time my mother, whom I was very close to, died unexpectedly. When my mother died we knew that we were pregnant but it wasn't until after Mum's funeral that we started telling people that we were expecting a child. We were telling people that, if we had a girl, we would name our child after my mother. At the same time we had sold our house in Ballarat and were in the middle of building a house down at Barwon Heads. There were a lot of changes taking place.

The day of the first miscarriage my partner noticed some bleeding and we went to the hospital and had the ultrasound taken. The ultrasound showed us that the baby seemed fine. There was a heartbeat. We were sent home.

Then, my partner started to experience a lot of abdominal pain and cramps, so we went back to the hospital. At first the doctors didn't quite know what was going on. Jeanette started to run a very high temperature. The doctor ordered another ultrasound and it was at that point that we discovered the baby wasn't going to make it.

While all of this was happening I had to go and pack up the house we had owned and built together in Ballarat. I remember going out to the house on the final day before the sale went through, sitting on the veranda looking out over the paddocks with the dog we had at the time, and just bawling my eyes out. Everything seemed so overwhelming. In such a short period of time my Mum had died, my business had collapsed, we were moving house and my wife was in hospital having just had a miscarriage. I was thinking, 'What have I done to deserve all of this?'. It was a very stressful time.

My way of coping was to plough on. I just got stuck into doing things. I picked myself up and just kept moving. I think it was the day after Jeanette had the miscarriage when I had to travel down to Barwon Heads from Ballarat to talk to the people who were building our new house.

I remember having to discuss colour schemes and design issues. It seemed rather pointless, but I threw myself into it anyway. Looking back now I can see how keeping busy was about pushing everything aside.

We didn't really talk to other people about what we had experienced after the first miscarriage. We felt a general tension in society that people weren't supposed to talk about miscarriages. We felt that the hopes and expectations we had attached to the pregnancy were discounted by a very general attitude that seemed to be summed up in the notion that miscarriages don't really matter.

Contrary to the attitude I sensed in people around me, I had attached a lot to that pregnancy. It linked in with my mother and her death. Even though my mother died before she knew we were expecting a child, I was very attached to the idea that she had been alive when the child was conceived. The presence of an unborn child became a comforting thing for me. I was able to see my mother's death as part of the cycle of life and though her life had ended I felt comforted by the idea of a new life beginning. The miscarriage shattered all of that very personal mythology and I felt like I was grieving for my mother all over again, as well as for our first child.

My partner and I began to feel very isolated soon after the miscarriage. Initially our families were supportive, but they were only immediately supportive while Jeanette was in hospital. I suppose it was difficult for other people to feel connected to our loss because it was such an early miscarriage. People were really only concerned about how Jeanette was doing and when they knew she was okay they seemed to be less worried. When we left the hospital people were still looking out for us. They would call and say, 'How's Jeanette? Is she feeling better?', but there was nothing mentioned about the experience of the miscarriage and what it meant to us. It was more like people were calling to inquire about someone who'd had an illness and had been in hospital. The issue of the pregnancy, and the death of a baby, was mostly ignored.

One thing that did come out at that time, which really shocked me, was my older sister telling me that she had some idea of what I was going through because she'd had a miscarriage. I'd never been aware of her experience. I am the youngest in my family by many years and I would have only been seven or eight when it occurred, but it was still strange to think that I had never been told. It confirmed the existence of a misconception in society that it is best not to talk about miscarriages.

I think Jeanette and I got caught up in the expectations of people around us. I think people wanted us to put the experience behind us and to focus on getting pregnant again as quickly as we could. I think we liked the idea of another pregnancy making us feel better, but we also wanted to move away from the intangibility of the grief we felt. I felt like I'd experienced something very significant, but it did feel intangible and I didn't know how to communicate my thoughts and feelings about it. As a result, I don't think I tried to express myself or to talk about my experiences with other people as much as I could have.

One slightly positive thing to come out of the collapse of my business was that, because I wasn't engaged in full time work, I was able to spend a lot of time with Jeanette and we were able to talk about what we had experienced. Even if other people didn't want to know, we were able to discuss what was going on. It was at this point that I began to get a sense of how different the grief experience was for Jeanette and myself.

Initially I felt sad and upset, but I kept thinking to myself, 'If I feel sad and upset, then what must Jeanette be feeling?'

I was emotionally and spiritually involved with the pregnancy, but Jeanette was even more particularly involved and I could see how it was affecting her in ways that I hadn't really

considered. While our relationship was still very close, I began to sense a separateness in what we were going through.



Between the first miscarriage and Madeleine's birth we experienced a second miscarriage. It was about seven months after the first miscarriage. We had moved down to Barwon Heads and were beginning to feel that we were making a fresh start when things started to go wrong again. All through the second pregnancy I had some discomfort. Part of me kept thinking, 'I wonder if this one will be okay?'

It was like a twinge of concern in the back of my mind. Another part of me felt quite optimistic though. After the first miscarriage Jeanette and I got hold of some statistics that showed us that it was quite common for miscarriages to happen in the first 15 weeks with the first pregnancy, and that usually subsequent pregnancies are okay. On top of that we had people saying to us, 'It will be okay. You'll have better luck second time round.'

When the second pregnancy did end, it ended at quite an early stage and it I was like, 'Oh, okay. Here we go again.'

It was a little bit different the second time in that the first pregnancy had ended after the 10-week stage whereas the second one ended at week eight. We were told that it was a lot more common to have a miscarriage before the 10 week stage and even though it was only a difference of a couple of weeks, I think I was less attached to the second pregnancy. Perhaps I was also hesitant, after the first miscarriage, to get too attached early on. Given what had happened the first time, I suspect I might have been protecting myself.



About three or four months after the second miscarriage we were shocked to discover that Jeanette was pregnant again. I was happy on one hand, but quite terrified on the other. I felt a bit emotionally scarred by the first two experiences and I was concerned about going through the experience a third time. A big part of me was saying, 'Oh no, here we go again. I don't want to go there.'

I felt really torn. I wanted the pregnancy to progress, but at the same time I was concerned about what the outcome might be.

The pregnancy with Madeleine progressed well and once we moved beyond the ten-week period I started to shift into a comfort zone. I started to think, 'Well it seems like this pregnancy is going to be okay'. As time progressed, I built on that and began to allow myself to get excited about the birth of our baby even though there was still a part of me thinking, 'I don't know if I want to go down this path.'

I felt like a child afraid of getting back on the Merry-Go-Round after a couple of bad experiences.

I remember the end stages of Jeanette's pregnancy with Madeleine as being incredibly blissful. The pregnancy went to full term and there had been no problems or complications along the way. We'd had ultrasounds done and they hadn't revealed any problems. All the testing that had been done hadn't shown that there was anything wrong. I remember Jeanette and I taking long walks along the beach and getting very excited about finally having a full term baby in our arms. There was a real sense for us that it was actually going to happen.

Even the labour went well. Most of the labour happened at home, not because we had planned it that way, but because we didn't realise that Jeanette was in labour. I remember calling the hospital repeatedly, trying to describe what was going on and they were saying,

‘Oh no, it sounds like she’s going fine. Come in if you want to, but it sounds like everything is progressing well’. When Jeanette told me she felt like she wanted to start pushing, I rang the hospital and they told me to bring her in straight away. It was a 25-minute drive from Barwon Heads to Geelong Hospital, but everything was going fine and it felt like it was happening as it should.

When we got to the hospital the nursing staff took one look at Jeanette and whisked us to the maternity ward. They said they could almost see the baby’s head popping out. We were taken upstairs and it didn’t seem like it as much later when Madeleine was born.

About two hours after Madeleine was born Jeanette went off to have a shower and the nursing staff left me alone in the room with our daughter. I remember feeling an incredible sense of euphoria and an overwhelming outpouring of love and complete happiness. It was one of those moments you know you’ll never forget.

Not long after that family and friends started arriving at the hospital. My family came from Ballarat and Jeanette’s family came from Melbourne. I got to do the, ‘I’m a proud new Dad’ thing, which was terrific.

During the afternoon we noticed that when Madeleine cried she would lose the colour from her face and start to turn blue, but as soon as she stopped crying she would go back to her usual colour. By the evening Jeanette’s mother was starting to get alarmed by Madeleine’s ‘blue turns’ and she wanted us to alert the nursing staff. We had mentioned what was going on to the nurses during the afternoon and they had told us that it was usual for baby’s to lose a bit of colour from their faces because they put so much effort into crying, so we hadn’t thought too much of it. However, when Jeanette’s mother raised her concerns we started to think maybe there was something more to it and we alerted the nursing staff again. One of the nurses came and said, ‘I’ll take Madeleine down stairs to the Special Care Nursery and get her checked over.’

When the nurse came back she said, ‘Well, there does seem to be something abnormal going on. There does seem to be a problem. Its best if we leave Madeleine in the Special Care Nursery for a while.’

Earlier in the day, about three hours after the birth, Jeanette had asked me, ‘Do you think Madeleine might have Downe's Syndrome?’

Madeleine didn’t have particularly strong Downe's Syndrome features, but Jeanette had worked with children who have Downe's Syndrome when she was as a teacher in Special Education and I think there was something about Madeleine’s appearance that Jeanette recognised. It was either that, or some kind of mother’s intuition.

When I think back to the day Madeleine was born I remember a few incidences where medical staff were standing around us and it was like they knew something but weren’t saying anything. I recall when Madeleine was being weighed for the first time, a nurse was standing next to me and there was something about her posture that indicated something was wrong.

One of the doctors came in while Madeleine was down in the Special Care Nursery and said, ‘We’re not sure, don’t jump to conclusions, but we suspect Madeleine might have...’

Jeanette cut him off and said, ‘...Downe's Syndrome?’

The doctor said, ‘Yes’.

During that evening there was a real sense of things not being right, but at the same time we didn’t really know exactly what was going on. I remember going home that night with very mixed feelings. I felt some of the euphoria I had experienced earlier in the day, but there was something in the back of my mind saying, ‘Hang on, there is definitely something wrong’.

From that point on we got a progression of prognoses for Madeleine that got worse and worse on a daily basis. On top of that, we experienced a sequence of difficulties with medical staff, both doctors and nurses, that was partly a result of Jeanette and I not being keen on medical intervention, and partly a result of not being adequately informed of what was going on. As the days went by and as Madeleine's condition deteriorated, both Jeanette and I increasingly felt that we wanted to pick Madeleine up, race out of the hospital and take her home. We felt that whatever was going to happen was going to happen and we didn't want it all to take place in the hospital environment where people were poking and prodding Madeleine constantly.

In many ways Jeanette and I felt sidelined. On the second day Madeleine was put into an isolette/humidicrib and most of the contact we had with her from that point was through that. She was allowed to come out for breast-feeding, but even then she was attached to oxygen and monitors and staff hovered around her. We didn't ever get back that sense of having her to ourselves.

It was like a nightmare that kept getting worse and worse. Within a couple of days Madeleine was transferred to the Royal Children's Hospital in Melbourne for some tests. She was taken in a special neo-natal ambulance and we had to follow in the car. When we got to the hospital we were told that there were three major problems with Madeleine's heart, but the doctor presented the information in such a way that by the time we left we were thinking, 'Oh, what are we worried about? Everything should be fine.'

The doctor had said, 'Go back to Geelong. Establish breast-feeding and come back in six months for some more tests.'

We knew Madeleine wasn't well, but the medical staff kept propping us up and reassuring us that things would be fine. I know it's part of their job to keep you focussed on the positive, but it was hard to know what to think and what to expect.

When we got back to Geelong with Madeleine, things didn't improve. Madeleine's body began to swell and she developed a rash. Her breathing became more difficult and by the end of the week she started to experience heart failure. The medical staff told us that they were transferring Madeleine back to the Royal Children's Hospital. They didn't ask us if we wanted that to happen, they just told us it was happening and suggested we go home and get some things as we would need to stay in Melbourne for a few days.

For a short period of time, back at the Royal Children's Hospital, Madeleine's condition stabilised. She was allowed to sleep in a normal cot and wasn't as dependant on oxygen and monitors. For a very brief period of time things almost felt normal, but then we were told that new tests revealed Madeleine was in a much worse condition than was initially thought. Suddenly things started spiralling downwards again and each day we were told more bad news. Finally we were told that Madeleine was booked in for heart surgery. There was no discussion about it. We were told it had to happen and it was booked in.

Jeanette and I were lost and did not know what to do. We approached a Social Worker in the hospital and said, 'We need some help here. We don't know what to do. Things are getting out of control.'

The Social Worker responded quickly by setting up a meeting with the Chief Surgeon. We listened to what the surgeon had to say, but from what he was telling us, it didn't seem that Madeleine was going to live for very long, even if she did have heart surgery. As Madeleine's parents we questioned the need for surgery if she was likely to die anyway. We wanted to focus on making Madeleine's life comfortable and painless, for however long it lasted. We said, 'If this is going to happen, we would rather have her at home.'

The surgeon was determined that we should give the surgery a chance. He admitted that it was risky and that if Madeleine did survive she would continue to have complications, but he was adamant that the surgery proceed. There seemed to be some suggestion that we didn't want the surgery to go ahead because we had difficulties accepting that Madeleine had Downe's Syndrome, but we weren't concerned about that at all. We were concerned about her heart condition and the fact that it was likely to end her life regardless of the Downe's Syndrome. Discussions with the surgeon did not go well and eventually we were told that if we did not sign a consent form for surgery, then the hospital could take out a Guardianship Order and they would proceed with the surgery anyway. It was an unfortunate situation.

I had some work commitments back at home while all of this was going on and I thought I would attend to them as I had to go home to get fresh clothes anyway. I was intending to drive down to Barwon Heads, go to work and stay the night, then drive back to the hospital the following morning. As I was leaving the hospital after our meeting with the surgeon, I walked past one of the nurse's stations and overheard a doctor saying to one of the nurses, 'So, baby Roberts is first on the surgery list tomorrow.'

That was the first time I heard that the surgery was actually going ahead. I was still grappling with what we had been told in the meeting I'd just come out of and we hadn't decided what we wanted to do. I was absolutely floored and became hostile. I leaned over the nurses' station and said, 'Excuse me, are you talking about my daughter?'

The doctor said, 'Oh, haven't you been told yet? She's going to have surgery tomorrow morning. We'll bring around the consent form.'

Looking back now I can't believe it, but an hour later I left the hospital and drove back towards Barwon Heads with the intention of meeting my work commitments. I remember turning onto the Barwon Heads Road and then having to pull over. I broke down and started sobbing uncontrollably. Somehow I got myself together to drive the rest of the way home and when I got there I called the coordinator at work and bawled my eyes out over the phone to her. She told me not to worry about coming in. She said, 'Do whatever you need to do.'

Half an hour later I jumped back in the car and drove back to Melbourne. As I drove I felt an extreme mix of emotions. I felt guilty and grief-stricken. I thought to myself, 'What on earth am I doing driving around? Why am I in the car? Why aren't I at the hospital with Jeanette and Madeleine?'

I guess it was about me being a male and thinking that it was best for me to stick to work commitments and plans. I guess, at the time, I thought that was the best way of getting through everything that was happening.

When I got back to the hospital Jeanette and I signed the surgery consent form, but we told the doctors that we were only doing it because they threatened us with a Guardianship order. The next thing I remember is taking Madeleine down to surgery. I carried her down to the surgical ward in my arms and it was horrible. On one hand I felt happy because Madeleine was doing well enough for me to carry her, but on the other hand I felt like I was taking someone to the guillotine. I really felt like it was the wrong thing to do and for the whole time Madeleine was in my arms I wanted to turn and run the other way towards the car park, jump in the car and speed away.

After the surgery the nightmare that Jeanette and I had wanted to avoid started to eventuate. Things started to go horribly wrong. Madeleine had a Cardiac Arrest in Intensive Care and over the course of twenty-four hours after surgery she gradually got worse and worse.

Eventually Madeleine's condition deteriorated to the point where the staff agreed there was nothing more they could do to help her and they allowed her to move to a palliative care situation. They agreed to take her off life support. At last, towards the end of Madeleine's



life, Jeanette and I started to feel some sense of peace. Once the decision had been made to take her off life support, most of the tension in the hospital environment evaporated and we were able to spend some time alone with Madeleine. She lived for 8 or 9 hours without assistance and her death was very calm and gradual and gentle. It was a very emotional time for us. We held her and said long goodbyes and, though it was incredibly painful and sad, we were left with a feeling of peace.



Madeleine lived for 25 days.



When Madeleine died the experiences of loss I'd encountered with the two earlier miscarriages was magnified. Although I wasn't working full time around the time of Madeleine's death, I was doing some study, and I felt that I had to maintain my work and study commitments and get back to them as soon as possible. I thought it was important for me to maintain other elements of my life because so much of my personal life was falling apart. However, I didn't like the idea of going off to work or to classes and leaving Jeanette on her own in Barwon Heads. So, often I would drive Jeanette to Geelong and she would catch the train to Melbourne where a family member would be waiting to pick her up. She would spend the night in Melbourne and I would go to work or to a lecture and then drive to Melbourne to collect Jeanette the following day. The problem with that was I would have to spend a night alone in Barwon Heads. I would get home at night and be alone in the house and wonder who I could talk to. Some of those nights were very long and lonely. I experienced some of the worst feelings I've ever had on those nights.



It wasn't until about a year after Madeleine's death that I felt like I was ready to start talking about the experiences I'd had. I went and got some individual counselling which was very good. Earlier on I'd attended a few support groups with Jeanette, but I hadn't felt they were really for me. I was often the only man in the room and the types of issues and experiences people talked about at those meetings didn't really connect with how I was feeling. Once I started seeing a counsellor one-on-one, I started to get a better idea of what I was going through, and Jeanette then started seeing the same counsellor. At times, we had counselling sessions together and that was very helpful. It allowed us to gain insight into how each other was grieving and to see the differences and similarities of our individual grieving processes. We were able to understand better the things that got us down and the things that stopped us functioning. We identified how difficult things were for us when we both felt down at the same time and how that affected our relationship. We were able to discuss ways of supporting one another and ways of avoiding shutting down. It was a challenging time, but it was a time of tremendous growth in our relationship.



One of the hardest things about having a child die is coping with the ongoing reactions of people around you, whether they are family, friends or society in general. You know that other people who haven't been through a similar experience struggle to understand what you have been through and accept their lack of understanding, but it doesn't make it any easier when awkward situations come up. Someone can make an off-the-cuff comment, with even the best intentions in mind, and it can really wound you. It happens at work, at parties and

social gathering and at family get togethers all the time. Someone might ask you, ‘How many children do you have?’ and that takes a bit of answering. Worse, someone might meet our son Dylan and say, ‘You’ve only got the one? When are you going to have more?’

It then becomes a matter of having to decide how much you want to tell. Sometimes I’ve told people about Madeleine and the miscarriages and their response has been, ‘Well, at least you got one out of all that.’

You do get better at dealing with things like that, but it takes time.

There was an incident around the first Christmas after Madeleine died. It was a pre-Christmas get together with my family. I remember Jeanette and I walking into my sister’s house and the rest of the family was there. As we walked in a silence fell upon the room. People started saying, ‘Hello,’ but you could see that they were feeling uncomfortable. Jeanette and I quickly moved through the room and sat down on some chairs in the corner. Gradually everyone started returning to what they had been talking about before we arrived. No one approached us and tried to start up a conversation. It was a bit like we had a disease they didn’t want to catch. Then one of my nephews turned up with some friends who had a four or five month old baby with them, and people started gathering around the baby’s parents asking, ‘How old is she?’, and saying things like, ‘Isn’t she beautiful.’

We just sat in the background feeling numb and empty and then we decided we couldn’t cope with it. We got up and said, ‘We have to get going,’ and then we left. It was a moment of absolute isolation.



I see quite clearly now how much of a taboo death is in society. We live in a death denying culture and people are not permitted to talk about death at length. It almost comes as a surprise to most of us, when someone close to us dies, to realise that death is actually a natural part of life. Up until that point, it can be something you never think or talk about. When someone close to you does die, and you begin the grieving process, you can feel quite marginalised. I’ve often tried to talk about my experiences in certain social settings and the reaction I’ve received from some people has almost been, ‘There are places to go and talk about that stuff. Don’t talk about it here.’



It’s hard to imagine what Madeleine would be like now. For Jeanette, Madeleine will eternally be a baby, but for me it is different. Recently I had a very vivid dream in which my son, Dylan, who is five, was playing with Madeleine. She was faceless, but she was about the height of a seven-year-old girl and I had this very strong feeling that it was her. It was a very pleasant dream. While I don’t have a clear picture of her in my mind, for the past couple of years I’ve had this intuitive sense of who Madeleine would be.



We did go on to have a subsequent child. On 26<sup>th</sup> February 1997 our son Dylan was born. He has always known about his older sister and on Madeleine’s birthday each year we have a cake with her name on it and we all blow out the candles and sing ‘Happy Birthday’. Madeleine will never be forgotten.



# why so young?

**CRAIG MULDER**

Andrew was born on the 17<sup>th</sup> of December 1997 at 6.25pm after quite a quick labor of only 2 hours weighing in at 9lb 3oz. He was a very healthy boy when born and took to breast feeding very well. Over the next few months he was growing well and developed a very happy nature, always greeting us with a big smile whenever he woke from his sleep time. Andrews sister Karley who was about 3 doted on him like she was another little mum, ever since Andrew was born she just loved him and there wasn't any jealousy from the attention he received.

The 24<sup>th</sup> of November 1998 began just like any other day, I was on afternoon shift, so I had the pleasure of looking after Andrew for the day while the girls went shopping to buy Andrews birthday presents and Christmas presents for our relatives. We had a great time playing together with all of his toys. I then took him in the pram for a walk up to the shops, which he enjoyed because so many people used to stop and say how adorable he was.

At about 3.00pm the girls came home from shopping and not long after that I went to work and Linda put him to sleep for his afternoon nap. It had been a very normal day, but Linda told me on the phone that night when I rang her, (I just check up on them and say goodnight to Karley before she goes to bed) that Andrew didn't seem as hungry as he normally is, but he was still happy. When Linda put Andrew to bed that night he did his usual trick of pulling himself up to standing in the cot and had a bit of a play. Linda went back in to put him back under the sheets but picked him up first and he gave her a really big cuddle and did not want to let go. He finally did and he went to sleep almost straight away. Linda checked on the children just before she went to bed herself and they were both sound asleep.

I arrived home at 12.45am I went straight to bed as I was very tired after a busy night, but 15 minutes after I hopped in Linda and myself heard a very strange squealing sort of noise we had never heard before coming from Andrew. As I had not been in bed long I told Linda that I would go and see what the matter was. As soon as I picked Andrew up he had a massive seizure in my arms which continued for what seemed like an eternity but was probably for about a minute or two. He was shaking so violently that I was struggling to hold on to him. I called out to Linda and we took him to the family room once the seizure had stopped.

Linda took hold of Andrew and I phoned the ambulance to come, and while I was on the phone Andrew stopped breathing temporarily but Linda was able to revive him. The ambulance was going to take 25 minutes because the nearest station to us was only 5 minutes away, but all their ambulances were being used. (Great help they were for us)

When they finally arrived Andrew had regained consciousness but was pale and very weak. Linda went in the ambulance with Andrew to the emergency department where he was looked at by a junior doctor, who on first inspection of our son diagnosed him as having a bout of gastro, but did no more.

20 minutes passed by with Linda and Andrew just sitting in the waiting area until he started having another seizure and a different doctor walked by and immediately took Andrew and put all these monitors on to him and they now realised that they had a major problem on their hands. As soon as he was placed on the bed he was sedated and a pediatrician was called in. When he arrived he thought that there was a brain-related problem, suggesting that it may be meningitis or something like that but was not sure. Andrew had to be transferred in an ambulance to the Royal Children's Hospital, which was 75 kilometers away. We were told

that we could not go in the ambulance with him, but to go home, have a quick shower and breakfast and drive up as soon as we could.

When we arrived at the hospital we were taken up to intensive care where two doctors met us. The first thing that the head doctor in intensive care said to us after he introduced himself were we believe your son is going to die. This absolutely stunned Linda and myself that our little boy could die when there was nothing wrong with him before that day. Once we had slightly gained some sort of composure they explained that they did an M.R.I. on Andrews brain and discovered that he had a massive bleed from what they said was a right communicating artery aneurysm. The doctor said that it was about 15mm (9/16") in diameter when it burst. I must admit I had to ask them what an aneurysm was, which they explained to us and also told us that it normally does not occur in children, but in older people.

We were then introduced to a neurosurgeon who said that there had been irreparable damage done with such a massive bleed that if Andrew did happen to survive he would be totally incapacitated. At this stage we did not know which way to turn because everything was happening so quickly and everyone that spoke to us had nothing but bad news. The neurosurgeon said that there was only one thing that they could try which would be to clip the aneurysm by cutting Andrew near his groin and feeding an attachment up through an artery and try and clip it from the inside.

One of the problems they had was they could not do the operation at that hospital, but he would have to be transported to another hospital. We agreed to this, as we wanted our little boy alive even if he was retarded, it didn't matter.

Andrew was then prepared to go to the other hospital and as he was being taken we could not stop crying and holding his hand and trying to reassure him we loved him and he would be all right. The doctors suggested that we get something to eat and they would send for us after the operation was over which could take several hours. No sooner had we just sat down to have a bit of food, than we were asked to come over to the other hospital. Because such a short time had gone by we knew the news was not good. We were then told that Andrew had died in the ambulance being transported to have the operation. It was less than 12 hours after Andrew had his first seizure that what was a very happy life had suddenly ended.

The next time that we spoke to the doctor was when they asked us if we had considered organ donation. This question really threw us because we thought Andrews's organs would have been too small to use. We agreed to this as we hoped Andrew might be able to help save the life of another child perhaps. Over the course of the next 24 hours all the tests were done on Andrew which was terribly stressful seeing our boy lifeless except with the aid of the machines keeping his organs going.

It was during this time that our 3 year old daughter arrived at the hospital and now we had to try to tell her that the brother she loved so much had died and would not be with us any more. Trying to explain this in the state that we were in was extremely hard on everyone.

The doctors came and told us that they could only use Andrews's liver, because all the other organs were too immature or had taken too much shock. The operation took place and a beautiful little 14-month old girl received his liver. Unfortunately for her and her parents there were complications and she died 2 days later.



Andrews's life was such a happy one that was filled with so much love that even now it does not seem possible that this could have happened.

When Andrew died the doctors thought he was born with the aneurysm and suggested that Karley, Linda and myself all have an M.R.I. to make sure we do not have one as well. As it turned out we are all clear of any problems at this stage.

On January the 11<sup>th</sup> 2000 we had another child, a beautiful little girl we called Lauren, who we were worried about having an aneurysm as well and once she had reached 3 months of age she had an M.R.I. also. The tests came back all clear and we are only now just starting to get our lives back in order.

I was told by the neurosurgeon who has had 25 years experience at the hospital that he has never seen another child as young as Andrew with an aneurysm, which makes me wonder why did it have to happen to Andrew for. If anyone who reads this story knows of any cases involving young children, could you please let me know as that it is just so rare?

Andrew was a wonderful little child with his whole life ahead of him and we will never ever forget the love and happiness he brought to our lives and to all that knew him.

***ANDREW JOHN MULDER***

***BORN: 17<sup>TH</sup> DECEMBER 1997.***

***DIED: 25<sup>TH</sup> NOVEMBER 1998.***

***AGED 11 MONTHS AND 8 DAYS***

# small but mighty

ARRAN ADAIR

Finn: 'small blonde soldier'

William: 'strong willed warrior'

Adair: 'noble spear from the ford by the oak tree'



Finn sadly lost his battle on October 11<sup>th</sup> 2006. He fought for seven months and seven days, all the time with a smile on his face...



Our pregnancy with Finn was non eventful, all the scans and tests came back normal. Martine; my wife, Charlotte; our two and a half year old daughter and myself were excited about meeting the newest member of our family, especially since Martine and I lost a baby in February 2005 at 15 weeks gestation.

Having lost a baby at an early stage of pregnancy, we were a lot more apprehensive about Finn than we were with Charlotte. Even after he was born it was very hard to relax, as there was something in the back of our minds telling us that things can go wrong. Finn's birth was relatively quick at four hours, and just after he was born we noticed that he had turned blue. We were told that this was normal when a baby is born so quickly. After a few hours he was a much more natural colour. Thinking about this much later, we have always wondered if this was an indication of Finn's severe heart problems. No one has ever been able to tell us with any certainty.

At two days old under some florescent lights, Martine noticed the whites of Finn's eyes were yellow. Being a nurse, she asked if they could do a blood test to see if he was OK. The results came back and we were told that the jaundice levels weren't high enough for him to have phototherapy, so we were to go home and it should sort itself out.

Once at home, I started to feel that I could relax. Finn seemed healthy, he was doing all the usual baby things, his big sister Charlotte adored him and we were all happy. We had the family that we wanted and deserved to have.

Over the weeks Finn's jaundice didn't get any better, however it didn't get any worse. He was slow to gain weight, but he seemed bright enough. We were told not to worry, it was just breast feeding jaundice and by 12 weeks it should fade. At 9 weeks while Martine was at her post natal check, her obstetrician made the comment that he had never seen a 9 week old baby so jaundiced and felt we should see a paediatrician.

It was during the appointment with the paediatrician that we were told that Finn had a heart murmur, then the double blow; he felt our son had a rare genetic condition called Alagille's Syndrome. Alagille's Syndrome affects approximately 1 in 100,000 births and although it is a genetic disorder no one in our families are affected so Finn is classed as a 'spontaneous mutation' (terrible term!). It affects the liver, the heart and in 10% of people with Alagille's, the kidneys. It is a broad syndrome, some people are slightly affected, but as we were to find out, Finn was one of the cases where everything that could go wrong, seemed to.

Up until now, I had remained positive about Finn's slow weight gain and jaundice. With this news, things started to change. I started to feel angry about terrible things happening to my family. Just like our previous pregnancy, these are things that happen to other people, not us. It was also hard to accept that Finn may have a rare genetic disorder, especially when our previous baby also had an extremely rare (yet unrelated) genetic disorder. With no family history of these disorders it made it even harder to believe.

We still had some hope. Although the paediatrician thought that the signs were pointing to Alagille's Syndrome, there was a small chance that Finn may have been suffering from a liver infection as the blood tests had shown some abnormal results. It is a horrible feeling when you are hoping and praying that your son has a liver infection.

We were referred to The Royal Children's Hospital, where we would be able to see all the relative specialists and have all the tests conducted at the one place. So when Finn was 10 weeks old we drove up from Geelong, fully convinced that they would tell us it was breast feeding jaundice and please go home. We found out quite quickly that wouldn't be the case. Test after test followed and we were overwhelmed by all the information that we were given. X-rays, ultrasounds of his liver and kidneys, blood tests and meetings with geneticists. All signs seemed to point to Finn having Alagille's Syndrome.

Naturally Martine and I were more concerned about Finn's liver (since this was causing his jaundice) than his heart as we thought it would turn out to be a 'hole in his heart', which is a bit more common than the heart problems that Finn did actually have. We were taken up to the 7<sup>th</sup> floor for an echocardiogram that we were told would take about an hour. We started to get a bit worried when the doctors seemed to be taking a long time to be doing the scan. (In all, close to 3 hours). It was hard trying to keep Finn settled for this amount of time.

Being a nurse, Martine was able to understand some of what they were talking about and we eventually both became very worried when they tested his oxygen saturations, only to discover they were in the 60's. One of the doctors even tested the oxygen saturation monitor on herself to make sure it was working OK. It was. Eventually they brought in a sonographer, and when the cardiologist walked in and looked at Finn's scan, he asked if we wanted to come with him to his office and talk about what they were seeing.

Nervously we sat in the office of the Professor of the cardiology department and he told us the terrible news. We both cried as he told us, with Finn in our arms looking, happy, well and content. He wasn't a sick baby to us.

Finn had Pulmonary Atresia with a restrictive VSD and MAPCAS. The reason Finn's scan was taking so long was because they couldn't find Finn's pulmonary arteries (the arteries that carry the blood from the heart to the lungs). All they could see were the MAPCAS (small multiple arteries that were doing the job of his pulmonary arteries) and they didn't know if Finn had main pulmonary arteries at all. The only way they would know was by doing a CT scan, and if that still didn't show the arteries then they needed to do a cardiac catheter. Our only hope was that they could find his pulmonary arteries. His body was working fine at this stage with the way his heart had formed, however as he would grow his heart would not be strong enough and he would die.

Although the day Finn died has been one of the worst days of my life, this day wasn't far behind. In the space of a day we had gone from possible breast feeding jaundice, to a major heart condition that would require multiple open-heart surgeries throughout Finn's childhood, just for him to have the chance to survive. No one yet realised the extent of Finn's liver condition.

This one-day at The Royal Children's Hospital was hard. We had many more hard weeks and months here to come.

We were sent home the next day, the full seriousness of the situation still to sink in. We felt it had to be a mistake, sure Finn was a bit yellow but he wasn't sick. Finn was a happy and content baby who had the best smile that could light up the room.

We returned to The Royal Children's Hospital the following week, for more liver tests and for the all-important CT scan. It was a disappointment to learn that we would not know the results until the following week. We prepared ourselves and our families for both possibilities.

It was hard leaving Charlotte at home with our parents for this time. She was too young to realise what was going on, but old enough to realise that she was not with her parents and her new little brother. For all our days at the hospital so far, Finn was not 'sick'. Only sick babies need to go to hospital.

We returned home to Geelong on the Friday, but on the Saturday Finn became unwell with a very high temperature and decreased feeding. We took him to the doctor who felt Finn had got a Urinary Tract Infection (UTI) from having a catheter test to check his kidney function (which found he had grade 5 reflux of his left kidney). Our paediatrician wanted Finn to have 'at least 48 hours' of intravenous antibiotics. We went in to Geelong Hospital, thinking we would be home in a couple of days. Finn responded well to the triple intravenous antibiotics at first, but then started to become unwell again. He gained 700 grams of fluid in 3 days and his breathing rate had become more rapid, shallower and he was working quite hard. Finn's oxygen saturations had also risen into the mid 90's and since Finn would normally sit in the mid 80's, all these things combined meant he had to be transferred to 7 West at The Royal Children's Hospital.

On arrival, Finn was diagnosed with Meningitis resulting from his UTI turning septic. It was a very scary time for us as this was the first time that Finn had appeared 'sick'. He ended up staying on 7 West for 2 ½ weeks to run the full course of the antibiotics.

This period of time was the start of living out of suitcases. We were staying in combinations of chairs by Finn's bed, my brother's nearby flat and a motel across the road. We were waiting to hear from Ronald McDonald House, as this accommodation would make it a lot easier to have Charlotte with us. I felt that it was important for Charlotte to be with us as for as much as possible, however there were only so many ways of entertaining a two and a half year old every day in a hospital and motel. We did become very familiar with the Starlight room and the playground. I think Martine found it harder to split her time between Finn and Charlotte. I think all her emotional energy was tied up with Finn. She was still breastfeeding him, which was a tremendous achievement.

During this period Finn had a cardiac catheter done and to our relief Finn's pulmonary arteries were found. They were tiny, but they were there! Plans were immediately made for Finn's surgery, a right ventricle – pulmonary artery (RV-PA) conduit. We were able to go home to Leopold for 5 wonderful days before we headed back up the road once again, this time for open-heart surgery.

Saying goodbye to our 15-week-old baby on the day of the surgery was one of the most heart wrenching things Martine and I ever had to do. We had to be hopeful and stay positive, however I honestly didn't know if I would see him alive again. A lot of the time you just put on a brave face because it hurts too much for too long otherwise. We still had a long journey ahead with Finn.





As a parent you never imagine this is something that would happen to you or your family. This is something that happens to ‘other people’ not to us. It was overwhelming at times to sit back and think about the reality facing our family, so it was easier to focus on what needed to be done for Finn and the best way to achieve that. One day at a time.



Finn came through his surgery really well, and was out of the intensive care unit (ICU) in 2 days, even though we were told by the ICU doctors to expect a week. Seeing him in ICU was upsetting as he was so still and all the machines were around him doing the job of keeping him alive. We were pleased at the same time that our little man was doing a fantastic job of holding on, and fighting so hard, which had become his trademark. He was small but mighty.

He returned to the ward, but suffered a set back 2 days later and had to return to ICU overnight due to a change in his conscious state. We were told they weren't really sure what had happened, but they thought maybe Finn had suffered a seizure, but there was no real way of knowing.

This was a scary time for me. I had Charlotte with me downstairs in the hospital family room, when Martine rang saying that Finn wasn't well and I needed to go up to the ward straight away. While I was on the phone I heard a MET call being made to Finn's room over the hospital PA. I knew it was Finn. Martine yelled at me to hurry. I just grabbed Charlotte kicking and screaming and ran to the lifts. I was so upset that I wasn't even aware that I got off at the wrong floor. Without waiting for another lift, I ran up the stairs to the seventh floor carrying Charlotte all the way. It wasn't an unfamiliar sight to see people behaving like this at the hospital.

The following week Finn returned to surgery to have a pericardial effusion drained, but seemed to bounce back well and the focus then changed to trying to put weight on Finn. He was 4 months old and weighed just over 4kgs. At this stage Finn was also on about 12 different oral medications. Some were to be given daily, while others were with every feed.

Finn also had a nasal gastric tube inserted around this time, which was just meant to be a temporary measure to help him increase his weight. He was having a combination of breast milk and a special formula designed to help him put on weight. Due to his liver condition, his body was unable to break down the normal fats in breast milk or ordinary formula. We would feed Finn orally with a bottle and then ‘top up’ the rest using the nasal gastric tube. This was to ensure that Finn was given the correct amount of milk. As it turned out Finn had the nasal gastric tube right to the end.

Rather than being a burden to Finn, the nasal gastric tube became his favourite toy. Due to his heart condition, Finn didn't have the usual energy to play with heavier toys and rattles, so the nasal gastric tube became the lightweight alternative. Finn developed his fine motor skills by finding where the tube was taped to his cheek and then worked his hands down the tube to the end. The end of the tube would then go straight into his mouth. A very strange circuit!

This was Finn's life. To me, I couldn't imagine what it would be like to spend all your time in hospital being subjected to daily tests and procedures. For Finn, this is what he was used to. He would still smile with his huge open mouth smile and interact and play with us like a normal baby. He was still annoyed by his big sister when she would continually shove toys in his face! If anything, he got more attention and cuddles than anyone else. We always knew that the odds were against Finn and so for five months we made every single month, day, hour and minute count.



It was just after Finn's surgery that we were able to get accommodation at Ronald McDonald House. This was a great relief as it meant that Charlotte could spend more time with us. Although Charlotte knew that Finn was sick, I think she believed that all babies spend a lot of time in hospitals. Charlotte would still spend some time in Leopold with her grandparents so she could keep in touch with the 'normal' parts of her life. It was hard for me to hear Charlotte say to me once, "We don't have a house any more, do we daddy?"

We were eventually able to return to Geelong Hospital a long 3 ½ weeks after Finn's surgery, and finally got to take him home with weekly visits to our paediatrician. Finn was going well post surgery, but his liver was showing subtle signs of changing. His blood tests were staying borderline on liver failure. It was while Finn was in Geelong Hospital yet again for an unrelated case of bronchiolitis, that the possibility of a liver transplant was raised. The problem was that due to Finn's Pulmonary Atresia, he might not meet the transplant criteria. Also Finn needed to be 8kgs to be listed and he was just over 5kgs at this stage. After the initial shock wore off, we did what we had done all those times before; we picked ourselves up and focused on the positive. We still had Finn.



Finn was weighed daily to track his growth. We had complicated mixtures of formula and medications, weighing wet nappies and recording how much he was drinking. A good day or week was when he put on weight, even if it was only the smallest bit. These were the positives that we had to cling to. Small steps for a small little man.



Our time with Finn became a merry go round of Doctors appointments and hospital stays, and trying to have a semi regular family life since we still had a 3 year old that needed her parents. Finn was home from hospital for Charlotte's third birthday. We were lucky that Charlotte adored her little 'Finny' and that Finn adored her. We really do believe that Charlotte knew Finn was special and he needed all our love and attention.



In the weeks leading up to Finn's final hospital admission, his ascites (fluid in his tummy due to his worsening liver function) was making him more uncomfortable and regular albumin infusions to help reduce the amount of fluid weren't as effective as they once were. There was also concern that Finn's heart surgery hadn't worked as well as the Doctors had expected and another CT scan was done. Deep down Martine and I knew things weren't looking positive for our little boy, but we waited desperately to hear the outcome from the transplant team meeting on whether Finn would be eligible.

A week after Finn was admitted to Geelong Hospital for more albumin infusions, he was transferred to The Royal Children's Hospital, as the Doctors were worried that Finn's cardiac status was changing. We arrived back on 7 West, and were told the news we were dreading. There was nothing more they could do for Finn. Quite simply, they couldn't offer Finn a liver transplant because his heart wasn't strong enough to support such major surgery and they couldn't offer any more heart surgeries because his liver wasn't strong enough. Throughout Finn's life we were always told that without medical intervention, Finn's would survive somewhere between months and years. We were now told that it would be a matter of weeks.

Finn was transferred back to Geelong Hospital and it was with much sadness we said goodbye to the wonderful staff at The Royal Children's Hospital who had fought just as hard as us for Finn to give him every opportunity to live the life he was meant to have.

Back at Geelong Hospital we knew it was a waiting game. Every day and hour was a bonus. Finn's oxygen saturations slowly decreased over the weeks and the use of the oxygen mask became more regular. Martine and I were both staying with Finn when we could, with one of us occasionally going home for a full night's sleep. Finn was still happy and cheerful for most of this time. Other family members would be in and out all day, providing support and spending time with Finn and us.

Although Finn was seven months old, his low weight meant that he needed regular feeds either orally or through his nasal gastric tube. He was also still on a wide range of oral medications. At night time it was still like having a newborn with three hourly feeds. Although we would have liked more sleep, looking back I do not regret this extra time we had together during the night.

A few days before Finn died he was having a regular daily blood test to check his liver function. He wasn't very well and became very agitated during the blood test. When he was back in his room, I noticed that he was gasping for breath like a fish out of water. The doctor and nurses immediately increased the level of oxygen that he was on and they managed to stabilise his breathing. After this episode we said no to any more tests. What would be would be.

A few days later our brave little man lost his fight. I had gone home for a sleep during the night, as Finn seemed quite stable. I was awoken at 5:30am with a phone call from Martine saying that Finn's oxygen saturations had dramatically decreased. I rushed straight in to the hospital where it became obvious that it was only going to be a matter of hours. We called our family and they all came in the morning to say goodbye. Finn just slept in our arms. He was on strong medications to control the pain from the ascites in his tummy. He would occasionally open his eyes throughout the day to look at us. At 10:35pm I felt Finn squeeze my hand incredibly tight. I told Martine and she grabbed his other hand. Finn opened his eyes wide, squeezed both of our hands and took a couple of final deep breaths. Finn passed away from liver failure in the arms of his mum and dad.



In a way we were lucky. Our son did not die a sudden death, but in reality it was over the five months that we knew he was so sick. Our grieving started long before Finn died. Part of it started back in that office at the cardiac ward of The Royal Children's hospital. We knew that Finn's time with us was precious and that we would make the most of every second.

As hard as it seemed, we had stayed positive even when there was only the tiniest bit of hope to cling too. When it all seemed too hard, I only had to see Finn's strong smile to make me fight with every bit of energy that I had. Finn deserved the best life that he could have and I needed to fight for him.



I hate that Finn died. I miss him every day and I want him to come back to us. I am a very logical and sensible person, however if Finn came back I wouldn't even question how it was possible.



I don't have many regrets about the time we shared with Finn. Since he passed away, I have asked myself 'what if and why?' too many times to find any real answers. We did the best that we could for Finn and our family and I believe that he did have the best life that he could for seven months and seven days.

As strong as Martine and I tried to be, we would not have been able to cope the way we did, without the help and support of our family and friends. Our parents especially who looked after Charlotte and would drive to the hospitals when needed at the drop of a hat. Since Finn passed away Martine and I have really come to appreciate the simple things in life. Family is all-important. Everything else in life is just a bonus.

Not a day has passed when I haven't thought about Finn. For whatever reason, he has been taken from us. But no one can take away the memories, the experiences, or that he was and will always be my son. This is what I have and will cherish. This cannot be taken.



Martine and I have since had another baby. Oliver was born in January 2008. This was a very hard decision to make and talking to other parents whose children have died helped this decision. We did not want to replace Finn, however we eventually realised we would have too many regrets if we didn't try for another baby. Having another baby has not made us miss Finn any more or less.

Dads can sometimes be the last people that are asked how they are going after the death of a child. I am guilty of this too with myself. Day to day it seems more important for me to make sure that my wife and kids are OK first. Usually if they are going well then I am too. I do have a lot of bad times though when it all seems too unfair and hard to cope. Just because I may not initiate as many conversations about Finn as Martine may, it doesn't make me care or miss him any less.

It has helped talking to other dads and people whose children have passed away. I see it as if Finn was still alive, I would be doing things for him and talking about him, so it shouldn't be any different that he has died. I listen to their stories and think how horrible that this has happened to you. It sounds too terrible to be true. No one deserves this to happen to them. For a moment I forget that this has also happened to me.

Through sharing these stories, we can try to work out how we can cope. I have to cope for my family and myself. Sometimes I think that I cope because I don't have a choice, whereas other times it is because I don't want to forget. I want to make the most out of life.

There doesn't seem to be a right or wrong way to grieve. You just need to be doing something. Life is too precious not to.

