# Panel Discussion

Those participating on the panel were:

# Chair, Patricia Swanson (PS)

#### Researcher in Western Australia

Researcher on how families cope with multiple birth loss 1.

## Jim Brockbank (JB)

#### Family Doctor

I am a twin who lost a twin. My brother Rick died at 43 after five years of a complex rheumatological illness. We had to make the decision to switch off his life support machine. He was a world authority on wave structure. Ten months later I got on my bike and cycled a thousand miles of the British coastline in his memory and raised £20,000. Half went towards arthritis care and the other half went to a university prize for engineering in his memory which I present each year. I have become chairman of a national disability charity. I also wear his watch each day.

## Judith Houghton (JH)

#### Representing the Bereavement Support Group of Tamba

I had a 6-year-old daughter then twins — a boy and a girl. My son only survived for eight hours. They were born nine weeks early. My thriving 5-year-old daughter now makes up in energy for both.

## Patricia Mountbatten (PM)

#### The mother of a lone twin

Our last children, number 6 and 7, were identical twin boys born when I was 40. Nicholas the older by 20 minutes was murdered with his grandfather, my father, and my mother-in-law by the IRA in Ireland, and naturally I have an enormous interest in anything to do with twins. Tim belongs to the lone twins group and I know how enormously helpful and supportive they have been. I think the value of coming to something like this is the mutual learning and understanding. It is only really if you have suffered a bereavement of that nature that you can really understand the depth of feeling that people go through.

#### Barbara Read (BR)

Counsellor and Telephone Adviser for the MBF

#### Alistair Ross (AR)

#### Anglican Minister and Counsellor

I am a non-identical twin and I also grew up with a lone twin. My sister's twin died at birth and my wife is the elder sibling of identical twins so most of the twin experiences and consolations have occurred within my own family.

#### Joan Woodward (JW)

#### Psychotherapist

I lost my twin when we were 3 with fairly dire results for me. It made me decide to carry out the first ever study of the effect on twins of the loss of their twin. This later resulted in the Lone Twin Network, now with 650 members and still expanding.

## A = member of audience

## **Shyness**

**A1:** Is shyness a particular trait of lone twins?

W: That would be far too big a generalisation but lone twins probably do have some difficulty in being deeply confident about their own identity. Shyness can be caused by so many different things. And I've never noticed lone twins being shy when they get together!

The loss of a twin, especially an identical twin, in adulthood suddenly forces one to deal with new

situations alone without being able to confirm with another person and that can be quite intimidating.

**JB:** Although I lost my twin at 43 I certainly didn't suddenly become shy but there were issues about adjustment, self-esteem and sense of identity over a period of years.

In fact two years later I fell down in a heap for about 10 weeks, partly from physical and emotional exhaustion from a number of factors including having seen somebody through illness over several years. I actually kept two diaries which were very

helpful in my transition. I had a fear of forgetting my emotions in a busy life. (I looked at one of them recently. The other I haven't faced yet.)

PS: I have interviewed the surviving twin of two sets both of whose co-twins had committed suicide. Both said that they were very shy and retiring. Both had been the non dominant twin and after accommodating to the loss they became more outgoing than before. In one case the mother said the surviving twin no longer seemed to be a shadow or reflection of her sister but had become her own person.

## **Delayed Grief**

PM: I had a curious experience only a few weeks ago when it suddenly dawned on me that 50 years ago next year my third child was stillborn. In those days this would have been a common experience and I wasn't even shown the baby. He was cremated I believe. My husband did register his stillbirth but over the years he has acquired a name (Anthony) and I found it very comforting to attend a service organised by our district hospital's chaplain for babies who were stillborn or died shortly after birth.

Then I suddenly realised I had nothing of this baby at all — no photograph, no record, nothing. So I wrote to the Registry Office and finally lo and behold a stillbirth certificate arrived, without a name of course but at least with our names, the date and the place. This is the first evidence I have had of the existence of my third child and it was curiously comforting and a very valuable addition to the family. Thank goodness stillbirths are now treated as they should be, as the birth of a child who sadly happens not to survive. It is interesting that half a century later the memory remains very strong. And it's wonderful to have been able to do something about it.

PS: I have found exactly the same thing. The older mothers who gave birth 18 or 20 years ago are the ones who weep profusely during the interviews and it seems to be for the same reason: they had nothing. Nor were they allowed to see the baby. And the fathers weren't in delivery rooms in those days either. Nobody took pictures of the babies and they had no mementos. Some said their babies were buried in a common grave and had found this even sadder.

At least in Western Australia that's changed a lot now. The parents are given a beautiful little book like a photo album with fingerprints and handprints and pictures of the baby alone and with the living siblings and twins. They treasure this and it also eliminates the old secrecy that is so hurtful to the adult twins who find out much later. One young woman had only recently found out that she had had a stillborn twin. She said she always felt an emptiness, a loneliness and yet didn't understand why. She then came back to England to see her sister's grave which made an enormous difference to her.

**BR:** The MBF is actively encouraging units to help parents in seeing both the live and dead baby and to take photographs together and separately. These photographs are hugely important to the parents and, later, to the surviving twin as often is the blanket the babies were wrapped in. An alternative is a drawing of them together.

JW: Twins who lose their twin at birth often feel they have not only nothing but have no memories. One lone twin only knew the cemetery where her twin had been buried. There was no marker on it but we walked up, down and across it until she said 'Well, at least I have walked over her grave.' Finally she planted a shrub together with half of a necklace. She wears the other half.

### **Bereavement Rituals**

AR: At the national bereavement service for Tamba we tried to find symbolic ways of expressing both celebration and sadness at the same time. As one of the symbols we used lots of pebbles. Some were varnished, some painted and had glitter on them. Everyone could select two stones (or more if they had more children). These they could hold during the service. The stone initially is cold but as you hold it it becomes warm. At the end of the service, everybody put one of the stones in a basket and retained one for themselves. At that point I prayed and offered support while acknowledging the loss. It was very moving and tearful and I was crying myself.

We had meanwhile filled lots of helium balloons and everyone collected two. Then we let one balloon fly up into the air but kept the other balloon for the surviving twin. In effect we had all learnt how to let go and yet to keep something solid that could sparkle and also bring back powerful memories. Most people there felt it to be very moving. There was an older couple who I assumed were grandparents. But it turned out that their twins had died 40 years before but they had never been able to express their sadness in any way.

## **No Right Way**

A2: I work with a group that supports families of triplets, quads and quins or more. Therefore we often have parents who have lost one or more of their children and have difficulty with questions. On a grocery line, for example, someone exclaims 'Oh twins, they're beautiful!' And the parents felt they are somehow betraying the lost child saying 'No, actually they're triplets'. Yet do they want to invest such emotions in a person they will never see again?

**A3:** I am a mother of a lone 3-year-old twin whose twin died two years ago. I think how you acknowledge

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your lost twin depends on the day. There are times when I am very angry and distressed, especially birthdays and Christmas. It can be a very difficult time for the whole family. Sometimes that anger has to be released somehow and I feel quite sorry for some of the people who might receive that anger but I don't yet know of any other way to get rid of it.

- JH: We have always spoken about George so she has grown up knowing that he existed and the question of timing hasn't therefore arisen for us. The children are very matter of fact: they will just tell all and sundry. They say 'When he was born his lungs didn't work'. One of the other speakers asked how you answer about how many children one has. In the early days I used to definitely answer three. (In my head I always have a son as well.) But if it's people you don't know you don't want to burden them with that. As a bereaved parent you often end up having to support everybody else. In your own time of direst need you have to be strong for them as well which is sometimes quite hard.
- **BR:** In a counselling situation I very much support the parent in what feels right for them and that may change over time. Sometimes they want to share things even with complete strangers and other times choose not to do so. My message is that whatever feels right for you is fine and that's right. The other question is how you share the information. If you are feeling angry you may give it in a way that shocks and hurts that other person.
- **A4:** What about burdening the surviving twin with the parent's grief? The surviving adult twin must sometimes be fed up being always reminded that they were a twin. Perhaps they would now like to have their own life.

PM: In our family we very much feel that Nicholas, and now little Anthony, the stillborn one, who we've only recently got to know, are very much part of the family. We talk about them perfectly normally. When people ask how many children we have, it depends on circumstances, when, where, and how much they really want to know.

## **Pathological Grief**

- A5: Might I say generally that there are pathological grief reactions to the loss of a single person, twins, triplets, however many, and one of the dangers is that these can be focussed on the surviving twin. This is not just about twin loss. A singleborn child has died and parents have never changed the bedroom. They have made it like a museum and this burden can be focussed on the survivor.
- JH: The challenge we have at the moment is trying to sort out emotions with my surviving twin daughter. She is five and often says she is sad about George and then happy. We hope she won't always associate sad feelings with her twin but equally we must not put him on a pedestal so that he gets thrown back at her later in life. He would have got up to all sorts of misdemeanours as well!
- JB: I should just like to thank Patricia (PS) for permission to continue, as it were, to be a twin. I find it quite difficult at times to say I am, or was, a twin and so on. I was lucky to have had 38 years of very close relationship thriving and competitive. I think he was my only true contemporary.

#### **Endnote**

1. Patricia Swanson et al. (p. 156)