A PAEDIATRICIAN AND P

by

David Morris

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David Morris retired from his consultant paediatric post at the Woolwich group of hospitals in 1980, but has not stopped working! He is a member of the Perinatal Bereavement Research Group at the Tavistock Clinic and Founder-president of the Uphill Ski Club for Children with Cerebral Palsy. As well as private practice he continues to run a group for playworkers in hospitals, and his dimunitive, dapper figure, flower-in-buttonhole, is often to be seen cycling round London. We asked him to give us an account of his Bereavement Clinic, which was an early example of organised but sensitive psychological care of bereaved families by a paediatrician.

EDITOR

My interest and involvement in peri-natal bereavement did not start suddenly. It emerged out of a growing interest as a Paediatrician in the emotional and psychological effects of a child's illness, both on the child and the family.

I had for some time been seeing families at my special Tuesday clinic, where I could spend time in privacy with a family in contrast to the hurried and "public" atmosphere in ordinary out-patients. These were families who had special needs for which time was needed to try to work out the complex effects of, say, a child with diabetes, epilepsy, mental or multiple handicap, or a family with a life threatening illness.

Then one day I was approached by a Dr. Geoffrey Machin from Guy's Hospital who was carrying out a study of peri-natal deaths in the South East Metropolitan Region of London,[1] attempting to identify those who had died with chromosome abnormalities. It occurred to me that a baby who was born dead or who died in the first few days after birth, must have far reaching effects on the whole family. So why not look into this aspect of human experience? Rather than try to contact the families of those dead babies being studied by Machin, it seemed more appropriate to look at those in the Maternity Hospital where I was working. Before embarking on this new venture I searched the literature on the subject to guide me in the establishment of what became in 1973 the "Bereavement Clinic" at the British Hospital for Mothers & Babies. To my surprise I could find no reference in the world's literature except for a paper[2] written by Dr. Stanford Bourne of the Tavistock Clinic who in 1968 had looked at what family doctors could recall about families who had experienced a Stillbirth. I contacted him and he pointed me in the direction of a recent paper written by an Australian whose name or place of work he could not remember. By good luck I came across this paper,[3] written in 1971 by an Obstretrician—Pat Giles—in Western Australia. He had looked at 40 women who had suffered a peri-natal death. It was sensitive and revealed the intensity of what these women experienced. I contacted Dr. Giles who by chance was on a sabbatical in England. We met and have been close colleagues ever since. I prepared for my clinic by attending one of the Cruse courses on Bereavement counselling.

Learning

From the bereaved parents who accepted the invitation to visit me, I quickly and painfully learnt how delicate a situation it was. So much so that for much of the hour I had allocated for the interview, I could not do any writing as it felt inappropriate. I also realised how difficult it was for them to talk about the experience, since the pain was so vivid. There were long periods of silence which I also learnt were necessary for them, but it took me time to learn to wait and when to intervene. Anger and hostility, criticism and fault finding, disappointment and dissatisfaction were commonplace. The fact that so many couples came, and rarely a single parent, demonstrated the need they had for each other's support.

I tried a variety of different ways of recording what transpired: tape recordings which, while very useful, required far more time than I had available in a busy paediatric department; questionnaires which I tried to complete at the end of the interview but then found so many items missing; note-taking proved too sporadic to be useful. Finally I chose to summarize the main points of the interview in the form of a letter to the parents and, with their permission, a copy to their family doctor.

I found I could not cope with more than two such couples in the one afternoon a week which I had allocated for this clinic, because of the emotional impact it had on me. The experience was enriching but difficult, and taught me a great deal of what parents feel and experience; what the failure meant and what they felt about the future. I made many mistakes, but hopefully learnt from them: the attempt to comfort and reassure: the tendency to be optimistic and hopeful: all instinctual reactions to alleviate pain imprinted from medical training. It was particularly difficult to accept, and took me a long time to learn, that the pain and grief has to be lived through and suffered, and that I could do nothing medical to reduce the suffering.

Awareness

At that time new approaches and new practices were being talked about; seeing and holding and naming the baby; burial and funeral arrangements and the necessity for ongoing counselling.

One of the initial mistakes was my decision to offer parents an appointment six weeks after the baby died, in order to have the findings of the post mortem. My belief was that parents would want to know above all else why their baby had died. Unfortunately this was rarely the case except when there was some congenital malformation, and when that occurred genetic counselling became a useful referral. Evidence of placental insufficiency, asphyxia or the cord round the neck or whatever, did not really help parents to realise how little is known as to why these events should occur. I learnt that bereaved parents need professional support and help from the moment it is known that the baby is dead, be it in utero or after the birth of a premature or small-for-dates baby.

Cover picture: Die Andacht des Grossvaters, (Grandfather's Prayers) by Albert Anker, 1893, by courtesy of the Kunstmuseum, Bern, Switzerland.

ERI-NATAL BEREAVEMENT



I shared the feedback with my hospital colleagues and we became aware of the needs of these parents for support from any member of the hospital staff who came in contact with them. A ward maid taking a cup of tea to the mother after her return from the labour ward and asking how the new baby was, quickly taught us the necessity for awareness and communication.

The experience seen in retrospect is quite different from what it was at the time. I was uncertain what helped parents most; what to do about those who did not accept the invitation to come and talk things over. I still wonder how they managed and if and how they resolved their problems; an area of worthwhile further study. Since the natural tendency is to avoid talking about the loss and to try to forget about it, I suspect that a number are left with unresolved grief feelings and with unfinished business that goes on affecting them and the rest of the family.

I soon became concerned from my experience of the families I was studying about what was happening in the rest of the country and decided to see if I might be able to bring about a change in attitude and practice. There were a number of professionals and bereaved parents who were interested enough to join a small working group to tackle the problem. It took some eighteen months to produce a draft document which we published in the medical and nursing journals, inviting comments before publication. We were surprised at the critical comments the document evoked, rightly saying that what bereaved parents needed was direct supportive help and that such a booklet could not answer their needs. In pursuance of those who wrote we could not find any service being provided as such for bereaved parents after a peri-natal death. Likewise I had a letter published in *The Guardian* asking parents who had suffered a peri-natal death and had been helped, what the nature of that help had been. Of the hundreds of replies I received, they were all without exception accounts of what had happened with innumerable questions which had gone unanswered.

Action

Through the kind and generous support of Sir George Godber—then the Medical Director of the Health Education Council and previously Chief Medical Officer to the Department of Health and Social Security, the HEC undertook to print, publish and distribute what became the booklet "The Loss of Your Baby"[4] for bereaved parents from peri-natal death. It was issued in 1979 and has continued ever since. Some 50,000 copies a year are distributed for virtually 10,000 peri-natal deaths in Britain. Two pilot studies of what happens to the other 40,000 copies revealed the wide group of people who avail themselves of it: midwives, nurses, family doctors, social workers, health visitors and the clergy.

The Stillbirth and Neonatal Death Society was founded in 1978 and recognised as a charity in 1981. It has grown rapidly and extensively throughout the country and there are now some 150 branches. It acts as a resource centre and publishes a variety of leaflets on different aspects of peri-natal bereavement.

Recently a new such organisation has come about called SATFA the Support After Termination For Abnormal Pregnancy. With the advance of ultra sound technology, an increasing number of babies are being detected with gross abnormalities, many of them incompatible with life and for which termination of pregnancy is offered. It all began at Kings College Hospital, London, where Professor Stewart Campbell provides a highly specialised ultra sound referral service. As with SANDS, SATFA is beginning to function as a self-help organisation run by parents for parents with professional help.

Midwives

The role of midwives in peri-natal bereavement is all important, responsible as they are for the majority of all deliveries. To try to clarify the role of midwives in this very difficult and challenging task, a small working party was set up between the Royal College of Midwives and the Health Education

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Council. This resulted in an intensive workshop, the result of which was the publication "Midwives and Stillbirth"[5]. It demonstrates the problems and difficulties that midwives encounter in their everyday work and provides guidelines on how to meet the needs of bereaved parents and their own needs. This recognition of the emotional difficulties professionals experience in dealing with peri-natal bereavement was demonstrated by the "Loss of Your Baby" booklet with its container cover of advice for doctors, midwives and nurses outlining the main problems involved. This booklet has been widely distributed to midwives and is being increasingly used by them.

Perhaps the greatest achievement was the response of the President of the Royal College of Obstetricians and Gynaecologists to the suggestion that the College do something about Obstetricians in peri-natal bereavement. Sir Rustam Feroze set up a working party under the chairmanship of the Hon. Secretary—Mr. Robert Atlay, to produce guidelines for Obstetricians in the subject. The committee consisted of a midwife, a health visitor, a general practitioner, a paediatrician and a representative of SANDS including another Obstetrician. The booklet[6] was produced in 1985 and has been issued to every practising Obstetrician in the country. We all agreed that the Consultant Obstetrician was a key person in the support for parents who lose a baby in the peri-natal period.

The experience was enriching but difficult, and taught me a great deal of what parents feel and experience; what the failure meant and what they felt about the future.

From all reports, consumers and professionals alike, there has been a dramatic change when a peri-natal death occurs. It has aroused considerable interest, so much so, that Esther Rantzen produced two TV documentaries called "The Lost Babies"[7] which brought home the message vividly as to what a peri-natal loss means to families and professionals.

Whilst the practice has changed and families are being helped as they were never helped before, there is still room for improvement and research. The Peri-natal Bereavement Research Group at the Tavistock Clinic led by Drs. Bourne and Lewis in their involvement with families who have been affected by a peri-natal bereavement, has demonstrated how far reaching the effect can be, not only on the immediate family but on second and third generations. Grief is a bad enough experience and a challenge to the integrity of the family, but the realisation that intervention can play an important role in preventing further harm to a family and its individual members, confirms the necessity for all this work. The benefits can be of many sources. Anyone in contact with the family can help and play a part in restorative therapy.

References:

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4 Health Education Authority free pamphlet *The Loss of your Baby.*

5 Royal Coll. Midwives 1984.

6 Report of the RCOG Working Party on the Management of Perinatal Death. Oct. 1985. Free on request from Royal College of Obstetricians & Gynaecologist.

7 BBC TV "That's Family Life", Oct. 1984.

MORTUARY MINISTRATIONS

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The expanding work of Cruse and similar organisations shows that people in need of bereavement counselling can confidently turn for help as and when they are ready, and as and when it is available. Readiness depends on their (a) having overcome the stage of denial (b) having sufficient insight to be concerned about the level of their suffering and its effects on their daily lives, and (c) the value they place upon talking to a trained outsider about their emotional problems. The availability of help depends on the structure and facilities of voluntary and statutory grief Counselling Services, and the distribution, accessibility, selection, training and support of appropriate staff.

Numerous authorities have focused on different aspects of the readiness of those in need (e.g. Worden, 1983; Osterweis, Solomon & Green, 1984) and on the phenomenon of death itself (e.g. Simpson, 1979; Enright, 1983; Kalish, 1985). Others have focused on the provision of services and the work of counsellors (e.g. Spiegel, 1973; Peplan & Goldston, 1984). The point of the present article is to offer

* a conceptual framework to cover the variety of people who might be in need,
* to suggest some modifications in services to meet their need, and
* also to suggest another location in which bereavement counsellors might make the first contact with those who need help.

All three matters referred to arose out of clinical and research experience following the DC10 crash on Mt. Erebus in Antarctica on 28th November, 1979 (Taylor & Frazer, 1981). On that sad occasion all 257 passengers and crew died, and their scattered remains were gathered and brought back to the mortuary at the Auckland Medical School for identification and return to relatives for burial. As a result the mortuary became the focal point for everyone concerned with the disaster—including the augmented mortuary staff, embalmers, reporters, politicians and grieving relatives. Clinical and managerial services were provided to help the staff to cope with the enormity of their three months of immediate work, and a 20 month follow-up (Taylor & Frazer, 1982). Observations were also made about the inadequacies of space, structure, and function of the mortuary itself that compounded the stress experienced by those who worked there (Taylor, 1984).

A consideration of the aircrash in relation to other kinds of disasters led to the development of a taxonomy of disasters, and a consideration of the body recovery and identification workers to the development of a taxonomy of victims