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Matters of death and life

A study of bereavement support in NHS hospitals in England

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Anthony Wright is a university lecturer and former Chairman of the South Birmingham Community Health Council.

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1 Introduction: what's the problem?

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Many reports and inquiries, not least in matters of health and welfare, have had their origins in particular and personal experiences.

This report is no exception. It began life with a death – that of my son. Jo was two years old, soon to be three. He had been born with a heart abnormality, and although this did not affect him as a baby or toddler, he needed to have corrective heart surgery to give him a future. In nine cases out of ten this particular surgery is successful. Jo was the tenth case. His repaired heart simply would not work. Within 24 hours of the operation the liveliest and most engaging two-year-old in the world was dead.

This is not the place to describe how difficult it was, and is, to come to terms with this. It is the place, though, to say something about the aspect of this experience which eventually gave rise to the project described here.

In important respects the hospital and its staff were helpful and supportive. When it became clear that Jo was not going to make it, we were able to sit and stroke and talk to him all the time. The moment of death was handled with compassion and dignity. Then, freed from his drips and tubes, Jo was placed in a quiet side room where we could talk and cry and touch our goodbyes. We were able to go home and return to see him again later, taking with us his devoted and bereft little brother who wanted to go to the hospital and hold him forever. The ITU nurses were kind and enabling. One helped us to cut some locks of his soft, fair hair. Another just kept saying how beautiful he was. They even sent a message later to thank *us* for making things easier for *them*.

In other respects, though, we felt at the time, and certainly came to feel subsequently, that the hospital could have taken steps to make things easier for us. Jo had died in the middle of the afternoon at a major children's hospital but no social worker or counsellor had been put in touch with us (but the parents of a Down's syndrome baby, also undergoing heart surgery, had offered, kindly but inappropriately, to go and look for the chaplain). I had to phone our GP from the hospital call box to ask if she could perhaps call in at our home later to see my wife. When we returned to the hospital on the morning after Jo's death to collect the death certificate, we were able only to see a medical records officer who, while helpful on the official procedures involved, could not answer the kind of questions about Jo we wanted to ask or offer the kind of emotional support we obviously needed. A health visitor called at our house several weeks later, but only because she had happened to see Jo's name and address on the statistics crossing her desk.

Most unsatisfactory of all, in our case, was the way in which our need to talk through Jo's death with the doctors involved was not catered for at all by the hospital. Unlike the nurses, the doctors made no effort to talk to us in human terms when Jo died, or even to communicate with us as grieving parents who knew all about their son's life but also needed to know as much as them about his death if we were ever to learn to live with it.

In the days and weeks after his death we had expected that the hospital, where he had been seen regularly since birth and in whose care he had died, would contact us to talk through what had happened and to clear up the many anxieties and unanswered questions we naturally had. When, over a month later, we had heard nothing I wrote to the hospital expressing disappointment that we had not been contacted and explaining some of the reasons why we felt so abandoned, isolated and dissatisfied. Eventually, this produced a long and enormously helpful meeting with the consultant, an acknowledgement both by the consultant and the hospital administrator that our experience had 'highlighted certain problems' in relation to the management of bereavement and, when pressed further, an account by the hospital of the practical steps that would be taken to improve matters in the future.

Meanwhile, and subsequently, I began to wonder if the experience described here was perhaps simply one example of a general problem about the way in which death was handled by hospitals. If so, this would clearly be a significant cause for concern, if only because of the large numbers of people (around 60 per cent of all deaths) who die in hospital every year. Hospitals are concerned with treating sickness and saving life, but they are also inescapably concerned with the management of death.

As I began to look at the literature which offered guidance to hospitals on this matter (for example, Williams 1982), I was struck by how 'official' it was. Its purpose was clearly to enable hospital staff to fulfil their legal obligations and perform the appropriate administrative procedures in relation to death, not to integrate bereavement into a general programme of care.

My own feeling that there was something inadequate and unsatisfactory about this, in human terms, was further strengthened at this time when I noticed that the Health Service Commissioner (Ombudsman) had just reported on several cases where the complaint turned on poor communication and insensitivity in relation to the death of children and adults in hospital (Health Service Commissioner, 1985). It was the criticism from this source, and the publicity surrounding it, which then prompted the DHSS to issue supplementary guidelines at the end of 1985 on *Patients Dying in Hospital* (DHSS 1985), extending the earlier guidance contained in a 1972 circular of the same name (DHSS 1972).

The new circular made explicit reference to the fact that 'a number of complaints have been investigated and upheld by the Health Service Commissioner relating to inadequate management of events at the time of death'. It asked all health authorities to 'ensure that all staff who come into contact with relatives of the dying and deceased are familiar with the necessary procedures so that they are able to manage them sensitively'. To this end it also asked health authorities to 'draw up comprehensive written instructions on action to be taken when a patient dies in hospital', and listed 24 topics on which advice was to be included in such instructions.

A number of these items were now concerned with the sensitive management of death and with a proper regard for the needs of the bereaved. Matters covered included the provision of information; opportunities for discussion with the bereaved; arrangements for compassionate management following the death of a baby or child; and the availability of staff training and bereavement counselling. A final item asked for consideration about whether a 'bereavement officer' should be designated, though adding, in case there should be any misunderstanding on the point, that this was to be from 'existing staff'.

It was clear, then, that there was a problem, and that it had at least received some official recognition. However, what the available literature also revealed was the widespread lack of awareness and attention to the problem, and some of the reasons for this. If there has been a growing awareness, stimulated by the hospice movement, of the needs of the dying, the fact remained that 'despite much excellent work on the care of the dying, remarkably little attention has been paid to coping with death itself' (McGuiness 1986). As one study of the bereaved relatives of cancer patients concluded, 'for 44 per cent of respondents to have received no bereavement visit from anyone should be seen as evidence pointing to a gap in service provision' (Bolton Community Health Council 1986). At best, as in the excellent King's Fund guide on *Good Practice in Hospital Care for Dying Patients* (Henley 1986), the needs of the bereaved are integrated into the care of the dying, but even this still sees the problem as part of another, more clearly identified, one.

Yet it is not just 'the dying' who die, in hospital or elsewhere. In case this seems too obvious to state, it is remarkable how often our enquiries to health authorities (described later) produced responses which only directed us to their provision for the terminally ill.

If one avenue to awareness about the need to provide support to the bereaved has come through the hospice movement and the increased attention to the care of the terminally ill, another avenue has come through the particular attention that has been paid to the death of babies. 'In recent years', as the Stillbirth and Neonatal Death Society (SANDS) says, 'an increased awareness of the issues surrounding stillbirth and neonatal death has resulted in a marked improvement in the quality of care and support given to bereaved parents and their families' (SANDS 1986). Reports from both the Maternity Services Advisory Committee (DHSS 1985) and the Royal College of Obstetricians and Gynaecologists (1985) have given guidance on good practice in this area, while other guidelines for hospitals have been produced (by the Foundation for the Study of Infant Deaths) in relation to cot deaths.

What comes through from the literature, then, is a picture of growing awareness about the problem of bereavement, and the responsibility of health services, in relation to particular kinds of death (broadly, of babies and the terminally ill), but much less awareness that there is a *general* problem to be identified and addressed. For example, other studies suggested how inadequate and unsatisfactory was the management of sudden death in terms of the needs of the bereaved by nursing staff in accident and emergency departments (McGuiness 1986). There was no unified approach; the bereaved were discouraged from seeing the body; nurses only spent an average of 10–12 minutes with bereaved relatives (and doctors less than three minutes); and nurse learners were socialised to stifle spontaneous human emotions 'as inappropriate and incompatible with being a "good nurse"'.

This directs attention to the training given to nursing and medical staff on death and dying. The evidence available points to its inadequacy in the case of medical education (Horn and Brown 1985; Field 1984) and to the dissonance between the classroom and the ward in the case of nursing education (Field and Kitson 1986). It is easy to see why doctors could regard death as a failure and seek to turn their backs on it, but this also means turning their backs on the bereaved. It is also easy to see why nurse training in death could fail to bear fruit if it is not integrated into good practice on the wards.

It was against this background, then, of personal experience fused with a reading of the available literature, that I became convinced that here was a major deficiency in the care offered by health services. There seemed to be an urgent need for an approach to bereavement that was comprehensive in scope and gave particular emphasis to the emotional support of the bereaved. The need to develop good practice in this matter seemed to me to be of pressing importance.

This, then, was the inspiration for this report. I am grateful to Graham Cannon, the former director of the King's Fund Centre, for listening to me and, having listened, for making available a small grant for the project. I am also grateful to the South Birmingham Community Health Council for hosting the project, but above all to Janet Upward and Jennifer Cousins (both of whom knew Jo) for their willingness to participate in it. We were very fortunate in securing the services of Anne Davis to undertake the survey research for us, and to make a commitment to the project far beyond the call of duty. Much more work needs to be done if good practice is really to be developed in this area, building upon the particular initiatives that have already been taken, certainly if the promise of enhanced quality of health care is to be made a reality. We have, I think, at least made a start here in identifying the problem and showing the need for concerted and imaginative action to tackle it.

2 What we did

Our aim in this project was to discover whether the needs of people whose relatives die in hospital are being met within that setting. Much attention has rightly been focused upon improving care for the dying; but we wanted to look at care for the bereaved, specifically around the time of the death in the institution itself. We thought it was important not only that administrative and practical procedures should run smoothly and sensitively, but also that appropriate forms of emotional support should be forthcoming. Our study therefore attempted to look at both these aspects.

In setting out on our research we were aware that the 'story' probably had two sides. As a group of people active in a community health council and primarily interested in representing the consumers' voice within the NHS, we were keen to seek out as directly as possible the actual experiences which bereaved people had had. We felt that this would raise our own awareness about the kinds of things which people find helpful or unhelpful at this difficult time, and that these insights would then guide us in a more informed way through the subsequent stages of the project.

However, we were also aware that health authorities themselves might have varying degrees of commitment to relatives as reflected in their procedures and practices, and we wanted to find out the 'official' story too. We did not aim to marry the two aspects of our project in any rigid way (and were certainly not attempting to prove which particular health authorities seemed, according to the personal accounts and their own responses, to be 'failing') but merely to show on the one hand the kinds of experiences people had been through and, on the other, the various attempts made across the country within the NHS to address the issue. We hoped in this way to present a rounded view of the problem.

In attempting, firstly, to elicit information from the public, we were aware that our resources would not stretch to a sophisticated study using proper sampling techniques. Instead, we did the next best thing which was, through the press, to invite anyone who wished to share with us their experience of hospital bereavement to write or telephone. Accordingly, a press release was issued in October 1986 which was taken up widely both by the national press and the local press in various parts of the country from Plymouth to Ipswich, from Glasgow to the Isle of Wight. In addition, an item was broadcast on the BBC Radio 4 programme 'You and Yours'.

The public response to this media request for information will go down in the history of South Birmingham CHC. In the first three days, over a 100 phone calls were received in the office and, subsequently, 37 letters. Eighty-two of the phone calls were from bereaved people themselves (the remainder came from health-related professionals and other interested parties), and their accounts of their experiences were vivid and painful. In order to manage this flood of responses appropriately, a rota of volunteers, some with counselling skills, was drawn up so that the calls could be returned in an unpressured and sensitive way. All the volunteers who became involved noted how important this opportunity to talk seemed to be for the bereaved person, and many of the phone calls were long and moving. We were also surprised that in some instances the bereavement had occurred many years previously, and yet there was a sharp recall of the bitterness associated with its handling.

In all this, one overwhelming fact hit us: our tentative premise that there might be a problem was being reinforced many times over, and this was probably only the tip of the iceberg. While acknowledging that people who had had particularly painful experiences were probably the most likely to respond (and were therefore not to be regarded as a representative sample of the bereaved population), we nevertheless came to believe that the scale of the problem was considerable. Our press release had clearly struck a very common chord indeed.

At this stage also we were responding to the stream of letters which poured in to the CHC office, and we are proud to record that each one of the relatives who wrote to us received a personal reply which tried to address the specific points they were making. Many of our replies were deliberately handwritten as we wanted somehow to convey our thanks to people in as personal a way as possible for sharing such difficult and personal memories. Too often, we felt, institutions had treated them impersonally at a time when they were at their most vulnerable. In at least two instances where Birmingham people had responded, the CHC Secretary helped them to pursue their outstanding concerns with the relevant hospital, and we expect that, as a result of some of our advice, other CHCs will have been approached in a similar vein.

Moreover, it was not only bereaved relatives who responded to us. A considerable degree of interest was generated among people already working in the broad area of bereavement, and some of these people who lived locally called at the CHC office to share their own ideas with us. One member of the public who lives nearby had even drawn up her own 'ten day guide' of practical advice following a bereavement; while nurses, administrators, hospice staff and bereavement counsellors came to us with their own experiences. Further ideas were at the same time being gleaned by members of our group from the available range of literature (see References and further reading) and from an excellent conference on 'Handling Deaths in Hospital' at St Christopher's Hospice in Sydenham. Thus initiated, the group then drew up its questionnaire to health authorities.

The purpose of this questionnaire was to discover what policies and practices existed at district level concerning the needs of bereaved relatives, particularly in view of the Government circular *Patients Dying in Hospital* in 1985 which instructed health authorities to draw up written guidelines on the subject. In short, we were seeking the 'official view'.

In constructing the questionnaire we owe much to the excellent King's Fund guide *Good Practice in Hospital Care for Dying Patients* (Henley 1986) which, while not primarily addressing the issue of bereaved relatives, nevertheless acknowledges their needs. Our own aim at this stage was not to compile an exhaustive list of questions which would cover all eventualities, but rather to focus upon those aspects of bereavement support which our 'consumer survey' had highlighted as being the most vital. This questionnaire was then sent to all health authorities in England with a covering letter, and CHCs were also notified.

This then is the outline of what we set out to do. Our aim was to undertake a preliminary study of a largely uncharted area, consistent with the limited resources at our disposal. There is much further work to be done. This would involve looking in detail at practices in individual hospitals (rather than the broad district-wide survey here) and more extensively at the experiences and expectations of bereaved relatives. It would mean identifying how different 'types' of death may call for different responses (for example, an untimely, violent or sudden death will be different from an expected one; and a parent will grieve differently from a child or a spouse). There is a need to look closely at those hospitals (some of which have already come to our attention) where notably good practices seem to operate, and at the role of 'bereavement officers' (however designated) where these exist. Then there is the vital matter of staff training and support and the question of who are really the staff best placed to help relatives at this overwhelmingly difficult time. There is no shortage of further work to be done, either by ourselves or others. Here we claim only to have made a necessary start.

3 What relatives told us

In response to our request for information about people's experiences of bereavement in hospital, we received 82 telephone calls from bereaved relatives and 37 letters – a total of 119 responses. Each of these was dealt with personally and at some length, some by people with counselling skills whose help we enlisted especially for this task. It was evident that many people felt a strong desire to share their story with someone – albeit a stranger – and this in itself indicates a need in the community which for most of the time is presumably unmet.

Our aim had been to discover what hospital practices people had felt to be helpful and unhelpful at the time of their bereavement. Of our respondents, 25 had had very positive experiences.

> When the end came, my mother was taken into an adjoining room by the entire team of doctors and told exactly why my father had died. When I arrived, two of the nurses came to comfort me and said that should I want someone to talk to during the following difficult weeks, I must not hesitate to contact them.

Many people reported kindness and sympathy such as this and, of all the comments, it was probably the most important aspect of all. People found it particularly supportive if they could see that the staff themselves were also saddened by the death. One letter summed up many of the features which other people across the country had found helpful:

> We were with my mother for about 12 hours each day and I was offered a bed for the night as I lived away ... The young house doctor explained fully what they were doing, taking us

> privately into the office each time. When it was clear that the end was only a matter of time, mother was treated with tender loving care, which helped us enormously and we were able to 'let go' gradually and unhurriedly. After she had gently passed away we were told to take our time ... and then tea was provided in sister's office. Then for me the best thing of all, a very young nurse popped her head around the door and asked if I would like mother's wedding ring ... The next day we saw the bereavement officer who took us gently and carefully through the 'procedures' in an atmosphere which was warm and sympathetic ...

Unsympathetic attitude

Unfortunately, however, the vast majority of our respondents had had very negative experiences of hospital bereavement, and some were still disturbed by this many years after the event. The CHC staff dealing with these phone calls and letters (accounting for 94 of the 119 responses we received) were very moved by the strength of feeling generated by these unhappy memories. Comments about the insensitive and unsympathetic attitude of staff included the following:

> When our 16-year old son died of leukaemia the consultant said, 'We all have to go sometime'.
>
> The sister on the ward was very unhelpful and aggressive. My daughter and I still talk about this hurtful and uncaring attitude in our hour of grief.
>
> The porter was the only person in the hospital who showed any concern.

Bad news was delivered in ways which seemed uncaring, even brutal. One woman told us that she had accompanied her still-conscious husband to hospital and had then waited while he was examined. A doctor came out of the patient's cubicle and handed her husband's watch to her. Thinking that it had been removed for an injection, she questioned this, only to be told quite casually that he was dead. Another person told us:

> The ward sister was preparing trolleys in the corridor when, almost in passing, she informed me that my wife was dying.

It was suggested to one mother that the only thing to do now after her son's death was to go and get drunk. Time after time relatives reported that staff appeared to be impersonal, off-hand, even callous; that death seemed 'just another job' for the doctors and nurses.

> It was obviously just part of their job, granted not a very nice part of it, but no one seemed to appreciate that the 'body' they were discussing was actually the person I loved.

The apparent lack of humanity in all this hurt people very much indeed.

Poor communication

Another common complaint from bereaved relatives was the poor communication between medical/nursing staff and themselves. Often relatives did not realise how seriously ill their loved one was, and were not emotionally prepared for the death. One woman was told her husband's condition was stable; her next information, two hours later, was that he was dead. No interim bulletin about his deteriorating condition had been given to soften the blow.

It was also extremely important that people knew the reasons why the person had died, and a disturbing number felt they never really got to the bottom of it all. Sometimes the medical explanations were inadequate and poorly communicated. Some people persisted for many months in correspondence with the hospital (and in one case with the DHSS) in attempts to understand. An elderly couple wrote to us six months after their son's death, still not knowing why he had died. They listed 13 questions which had been troubling them during the whole of that period. Occasionally people had been told different versions about a death, and this they found very distressing indeed. Once or twice a death certificate recorded a cause of death which came as a complete surprise to the relatives and required further questionings and emotional adjustment.

Missing a death

One of the most haunting issues, which badly affected a lot of people, was if for some reason they had failed to be with their loved one when they died. Their guilt was enormous.

> Only two of us were allowed in the room. We were not a very large family – just dad, myself, one brother and one sister. We should have been around mum's bed, all together, to the end.

Often people blamed the hospital for summoning them too late; but quite a lot of people had been refused permission to remain in the hospital although they had very much wanted to do so. This meant that they had not only missed the moments of death, but also had squandered the last remaining hours. They bitterly regretted this.

> I feel that doctors should give relatives the opportunity of staying when they know the end is near. It would save a lot of heartache and feelings of guilt.

One woman accompanied her husband when he was admitted and waited 2½ hours in the corridor outside the cubicle. She was not allowed to see him and, to her great distress, he died without her. Some people were made to feel 'in the way' and were not made welcome on the ward or shown any signs of hospitality. Matters were made even worse if relatives discovered subsequently that no one at all had been with the person when they died.

Neglect of patients

Another recurring theme, which relatives found very difficult during their adjustment to their loss, was if their loved one had been 'neglected' during their final hospitalisation. A surprising number of people reported that the standard of physical care had been so poor that the patient had lost dignity. This distressed everyone greatly. One elderly woman reported that her husband appeared totally unkempt – his hair unbrushed, his dentures clogged with food, and his nails uncut and dirty. He had difficulty walking about with his catheter attached and she felt the staff treated him as a joke. Another family were upset because their relative was wearing someone else's clothes. Many relatives seemed to assume part of the responsibility for this deterioration in care, and were troubled by feelings of guilt. People felt that they should have left no stone unturned in caring for their loved one, even though much of that responsibility actually lay with the hospital.

No comforting after the death

Immediately after the death, relatives were at their most vulnerable, and it was at this time that tiny gestures of kindness were most noted for their absence.

> After saying my final farewell, I turned to the nurse at the door and said: 'How do you say goodbye to your own mother?' The expression on her face was without emotion.

Some expressed a need to talk, but no one came forward. Sometimes a chaplain was on hand, but this was not a useful resource to the non-religious. Several yearned for privacy in which to grieve with the family but ended up only in a corridor. Many were kept waiting for long periods before a doctor was available to tell them about the death.

> We waited a long time for the doctor. When he did come there were no words of sympathy – only that 'It was better for him to have gone'.

Once a wife was told 'unofficially' at 6pm that her husband had died, but the hospital were not able to confirm this definitely for a further hour and a half, leaving her for that period in a limbo of false hope. One woman, when she said that she would be having her husband cremated, was asked there and then for the £30 as the fee for the extra medical signature necessary. This was within half an hour of her husband dying.

Several people reported that staff generally seemed more involved in the paperwork immediately following the death than with attempting to comfort them. One parent was told to 'snap out of it'. Another person, summoned to hospital following a death, needed to contact a relative and, although being shaken by the news, was told to go and use the pay phone.

Practical arrangements

A large number of complaints centred around the practical details following a death. People found the use of the tin coffin deeply upsetting. One woman saw this on the ward before her husband died. The manner and the place in which the dead person was presented for relatives to see was often inappropriate, and left them forever with disturbing memories. One woman who was taken to see her dead husband was told to 'hurry up'. Another found that her grandmother's eyes had not been closed after death and that her false teeth had not been put in; another that her mother's mouth was 'gaping'. One man asked to see his dead wife, but was told 'Oh, you don't want to do that'.

Use of organs

There were three incidents where permission to use parts of the dead person's body was sought in a clumsy, insensitive way. In one case the doctor did not accept the wife's first refusal of this, but just stared at her and said 'but it would help others'. Only after her second refusal did he reluctantly sign the death certificate. In another case the parents whose son was on a life-support machine following a road accident were told that he was clinically dead and were then in the same breath brusquely asked what they wanted done with his heart and kidneys.

Post-mortems

There were quite a number of complaints about post-mortems. Four people had not been asked for their permission to carry out a post-mortem and were later shocked at the discovery. People who were never told the results found this upsetting. In one or two cases the post-mortem had left the dead person's body in a condition which relatives found offensive.

> When I saw mother it hurt to see what they had done. Just below her chin they had made an incision right down to her private parts which they never even put back right.

In other cases, confusion and delays over these examinations added to the general pressure on relatives.

> Three days passed before the examination was carried out. All this time we did not know why he had died. We were told that as it was Easter, the pathologist had a back-log.

One woman made all the funeral arrangements only to be told that they had to be cancelled because a post-mortem was needed. If an inquest was called for, this heightened the general distress level considerably: people were shattered by the suggestion that something untoward had happened.

Administrative procedures

There were a lot of complaints about inefficiency in the hospital's administration of the paperwork.

> My husband died on a Thursday. They insisted it had been a Wednesday, and put Wednesday's date on the death certificate. I now wonder if it really was my husband's funeral I paid for and attended.

People were frequently given little real guidance about 'what to do next' and too often this was done in a tactless, uncaring way. Several people suggested that a booklet about procedures would have been helpful, and one person said she would have valued this as soon as she knew her husband's condition was terminal.

Pointless journeys were often made to collect death certificates which were not available. One Jewish family, whose cultural preference is to bury their dead within 48 hours, found the administrative delays extremely inconvenient. They were also concerned about the large black and Asian community served by the hospital if different cultural practices were not being respected. One woman arrived to collect her husband's death certificate and was told: 'You were supposed to be here an hour ago'. She was then handed the certificate in a sealed envelope addressed to the registrar. She found this very offensive.

Collecting belongings

The issue of collecting the dead person's effects came up repeatedly. These items intrinsically had very poignant associations and were seen as part of the person. One relative was distressed because the clothes were blood-stained; one was upset because a watch had been put with a wet face cloth; one was offended because a wedding ring was described on the inventory as 'one brass ring'. The fact that items were bundled into black plastic bags was the final blow: the association with rubbish disposal was overwhelming. One woman said it was like going to a jumble sale; another that she felt like a prisoner leaving gaol with everything precious in a bin bag.

Follow-up support

Several practising Christians said they had derived some comfort from contact with the hospital chaplain at the time of their bereavement, and subsequently from their local church. Yet of those families who did not mention religion, very few said that the hospital had given them the name of an appropriate support organisation. It seems that, once the immediate issues relating to the death had been dealt with, the relatives were left to cope alone.

This, then, was the reality of hospital bereavement as recounted by people who had lived through the experience. Whatever official claims might be made about a supportive service, nearly a hundred people told us otherwise – and in terms which were direct and graphic and full of pain. Indeed, the strength of people's feelings was quite overwhelming. The very fact that so many people wrote long, detailed letters is in itself noteworthy.

> Thank you for taking the time to read this. It has taken me 3 hours to write my feelings down.

And there was a suggestion that, for many, their contact with us became therapeutic:

> Apologies for 'rambling on'. I have felt some reward from having, as it were, talked about it all.

From this, one is naturally led to ask questions about the way in which the bereavement was handled in hospital and about the apparent lack of follow-up support to which people had access.

We are aware of course that our sample is not entirely representative, and that in specific instances there may have been good reasons why things were done in a particular way. Yet the basic point remains: that the majority of people who wrote to us (and the number who wrote was itself striking) *perceived* their experience as unhelpful. Somewhere, communication was lacking. More fundamentally, even when practical details were administered smoothly, people felt that the attitude of staff was insensitive and uncaring, and it was this, above all else, which was most frequently the source of extra distress and pain to the relatives.

The practical improvements which our consumer survey suggests would probably be straightforward to implement. However, attitudinal changes are notoriously more difficult to bring about. At this level, something very odd indeed seems to be going on in hospitals. We know that many times a day people all over the country are facing one of the most profound of all human experiences: the death of someone they love. Yet our evidence (which is *their* evidence) suggests that, for many people, the health service is failing them at this critical time. It is failing not because death in hospital is a rare occurrence which 'throws' the system; nor because resources (in this instance) are lacking; nor because hospital personnel are intrinsically any less humane than the rest of us. It is failing because staff have not been properly equipped to cope with this aspect of their job.

Firstly, it would seem that sometimes staff had had little guidance about how people react under great stress, or about some common forms of grief reaction. For example, that a straightforward piece of information may not be 'heard' correctly; that people may say or do things out of character; that they might interpret a word or gesture wrongly; that they might indeed complain 'unreasonably'. All of this needs skilled handling by staff who are properly trained in this specialised area.

But, secondly, it would appear that some staff are not coping well at a much more personal level. It is not easy to be confronted daily with the death and grief of others. It reminds us of the fundamental threat to our own well-being from which none of us is exempt. So it is understandable that we develop ways of protecting ourselves from that threat and that sometimes these mechanisms become enshrined in practice: the mythology, for example, that nurses or doctors are more 'professional' if they show little emotion at such times (a time which may anyway be perceived as one of professional 'failure'). Developing a shell may prevent us from connecting too closely with people's pain and may protect us from our own latent fears; but it can also prevent us from offering the emotional support which many people yearn for at this point in their lives and which we are best placed to give.

It is, therefore, clearly important that this complex issue of staff attitude towards death and the bereaved should be addressed. The training implications are obvious, not only at the basic pre-practice stage, but also in the form of ongoing in-service support for staff at all levels. With an overall heightened awareness among staff, improvements would naturally follow in a whole range of related spheres.

We hope that the testimony of these 119 people will at least do something to provide the necessary inspiration for such changes.

4 What health authorities told us

As the previous section demonstrates, we received a wealth of graphic detail about people's experiences of bereavement in hospital. This amply corroborated the evidence which the Health Service Commissioner presented in his 1985 report and which inspired a series of recommendations within the subsequent DHSS circular, *Patients Dying in Hospital* (DHSS 1985). While primarily instructing district health authorities to draw up written guidelines about the care of the dying, this circular therefore addressed to some extent the needs of bereaved relatives. It was the response of DHAs to this element that we decided to seek to throw some light on.

In order to do this, we drew up a brief questionnaire asking a number of questions about the way in which death is managed, from the relatives' point of view. This questionnaire was then sent with a covering letter to all DHAs in England in November 1986, with copies to CHCs for information. We initially received 75 replies from health authorities, of which for various reasons we were able to analyse 57. Further replies eventually produced a grand total of 104 responses of some kind. The figures we cite below are based on the 57 DHAs, but the other material received has been referred to in our commentary where appropriate.

The extent of the problem

The scale of the task of responding to the DHSS circular clearly fell more heavily on some DHAs than on others, primarily because of the differing nature of the districts. Some administer more hospitals than others (East Birmingham has one hospital, Somerset has 28); and some have many more beds (Kidderminster has 408, North Staffs has 3,500). This fact may partly help to explain the variety of official responses to the circular, and perhaps the patchy nature of the response to us. What did surprise us, however, was that just over half the DHAs were evidently unable to calculate their own hospitals' deaths in relation to the total deaths in the district, so they themselves did not know the scale of the problem. We had assumed that hospital deaths was an easy statistic to collect, even given the complexity of some districts, but discovered that many DHAs do not keep records of deaths as distinct from other discharges, and are therefore unable to do the basic calculation. From OPCS sources we knew that in overall terms 58 per cent of deaths occur in hospital. Those DHAs who were able to calculate their death rate revealed wide differences: from 23 per cent in North Staffs to 73 per cent in Warrington. It is clearly a major issue for all health districts and many of them need to develop a much better information base if they are to address it effectively.

Since more people are likely to experience a death in their family in a hospital rather than a home setting, the attitude of hospital staff will be an important part of their bereavement experience. It may indeed affect the way in which they adjust to their loss. Making sure that death in hospital is handled sensitively is therefore a matter of concern for a majority of the population.

Guidelines for staff

We were interested to know whether health authorities had responded to the DHSS circular *Patients Dying in Hospital* and, in particular, whether they had followed through its recommendations by drawing up guidelines of good practice for use on wards.

Some three-quarters (73 per cent) of DHAs said they had responded to the circular and slightly less (68 per cent) had already issued written instructions on the action to be taken when a patient dies in hospital. Many DHAs (40 per cent) claimed to be in the process of preparing revised guidelines. However, about a third (32 per cent) of districts had no written guidelines and gave no indication when they would be available. It was also disappointing that only a minority of DHAs (40 per cent) said their guidelines were available on hospital wards at all times.

The actual quality of the written instructions (which we had asked districts to send us) varied considerably. In the majority of districts the job of devising and updating these guidelines had fallen to administrative staff. Only five districts mentioned that a working party had been set up to perform this task, and although it is possible that these groups might have included lay people such as DHA or CHC members, no actual reference was made to accommodating the consumer or lay view. As for tapping the skills of people who might be experienced in bereavement work, there was reference to using some form of 'counsellor' in only a handful of cases.

We were pleased to receive copies of their guidelines from most (74 per cent) of the health authorities surveyed and, although many were simply nursing procedures drawn up in accordance with earlier DHSS instructions, we discovered some to be very helpful. The best were those which covered the necessary medical and administrative procedures but at the same time gave them a 'human touch'; or those which suggested ways in which staff might cope not only with bereaved relatives but also with their own distress at a patient's death. For example, City and Hackney's booklet, *Symptom Control and Supportive Care*, is an excellent document which would be of help to staff, relatives and perhaps even patients themselves; while Tower Hamlets has produced helpful guidance on *Principles of Breaking Bad News and Supporting Bereaved Relatives* for their accident and emergency staff. The Herefordshire guidelines covered all aspects of death and bereavement in a clear and comprehensive way, and Shropshire had usefully based its guidance on the King's Fund book (Henley 1986).

In general we became aware that good practice had mainly been developed in relation to neonatal deaths and terminal care, and could now usefully be extended to the whole range of patients. Unfortunately, over a quarter of DHAs (28 per cent) had no designated person responsible for updating and extending the guidelines.

Guidance for bereaved relatives

In conjunction with the guidelines produced for staff, we also requested copies of any information which hospitals gave to relatives to help them through this difficult time.

Many DHAs gave relatives a duplicated sheet with the necessary information. Sometimes too much was included, which could be confusing; sometimes the print was difficult to read; often the presentation was lamentably poor, which somehow seemed to diminish the sense of caring. The West Midlands RHA booklet is very useful but not entirely sympathetic in tone (as in its attribution to the 'Public Relations Department'!). The best examples we saw from a generally dispiriting bunch came from Milton Keynes, Plymouth and Worcester, whose carefully produced leaflets gave clear information in a sympathetic manner, and from Doncaster in the form of a good practical information pack. In terms of both content and presentation, it is clear that there is much room for improvement in the written material made available by hospitals to the bereaved.

Bereavement officer

One of the recommendations of the DHSS circular was that districts should consider appointing a bereavement officer to coordinate a more sensitive handling of death. Only 12 DHAs (21 per cent) had made such an appointment: some based in the hospitals, some based at district offices. The title of the post varied (for example, patient services officer, relatives' officer) but mostly they were filled by administrative staff at higher clerical or general administrative assistant level. Occasionally other staff such as a community nurse or a 'bereavement counsellor' performed the role. The other 45 DHAs (79 per cent) who had not appointed a bereavement officer said that the various tasks associated with helping relatives were undertaken by nurses, chaplains, social workers, administrators and clerks.

Training

We were interested to know whether DHAs were addressing the crucial issue of staff training in this sensitive area, and were dismayed to find that almost half the DHAs (47 per cent) do not specifically train their new staff in aspects of dying and the care of relatives, although many assumed these aspects to have been covered on basic nursing courses. Two-thirds (68 per cent) of the districts do, however, claim to offer some in-service training for existing staff, although there is somewhat more emphasis on the care of the terminally ill and their relatives than on other groups. It was also clear that there was considerable variation about what appropriate training meant and involved. Nevertheless it does appear that there is an increasing awareness of the need for a more sensitive approach, and many districts are developing specific training programmes which include titles such as 'bereavement', 'counselling skills', 'loss and grief' among their courses. These courses appear to look not only at the needs of bereaved people but also at the needs of staff who are regularly faced with the death of patients. However, in most cases 'staff' seemed to mean only 'nurses' as far as training in this area was concerned.

Counselling

In view of the great need which many people have at this time to 'talk through' the death with a skilled and receptive listener, we asked whether bereavement counselling was available to relatives within the hospital. Three-quarters of the DHAs (77 per cent) said that such a service was available (and slightly fewer that this was available to staff as well), although on scrutiny it transpired that, for the most part, what was meant was that this role was performed informally by nurses and clergymen. It would seem that the term 'counselling' is largely interpreted as meaning 'opportunity to talk' and, occasionally, as 'a chance to give information'. While being important, neither of these is counselling in a psychotherapeutic sense. Occasionally in-depth counselling may be provided by voluntary groups and specialist personnel (Macmillan nurses and hospice staff) who may also train and support other hospital staff, sometimes using a groupwork model.

People with a different religion, culture or language

If people who share the dominant language and culture were finding the hospital environment unsympathetic, how were the needs of ethnic and linguistic minorities being met? We asked DHAs about staff training in such matters and also about the provision of interpreters and non-English leaflets. To our consternation, only half (51 per cent) of the DHAs said they offered some training to staff in religious and cultural practices; some felt that in their catchment area it was entirely unnecessary. In relation to interpreters, it seems that many DHAs simply call in staff members who may happen to speak the required language; one in five districts (22 per cent), however, could offer no interpreting service at all. As far as written information was concerned, over three-quarters (81 per cent) of the authorities had no leaflets available in non-English languages. Those leaflets which were available in other languages tended to contain general information on the hospital rather than specific help about what to do following a death.

Accommodation

We were interested to discover what degree of privacy was available for relatives to be with the dead person, or with each other, or with hospital staff, immediately following a death. The majority of districts did allow people wherever possible to sit quietly on the ward with the dead person if they wished, although 24 per cent made no such provision; and over three-quarters (77 per cent) provided a quiet room for relatives. When people wanted subsequently to view the body, this usually occurred in the hospital chapel or the mortuary. Five DHAs we surveyed had a special 'viewing room' for this purpose.

Post-mortems

We knew from the relatives who contacted us that post-mortems can cause relatives considerable extra stress, and we wanted to find out to what extent these examinations were being carried out and whether relatives were being informed of the results. We discovered that some hospitals, especially teaching centres, undertake post-mortems on all patients who die, regardless of whether such an examination is necessary. Only half the DHAs said they had a policy on this issue. Given that post-mortems occasionally delay funeral arrangements (and that for some religions a swift funeral is important), this is a worrying finding. It would appear that occasionally, therefore, additional distress is being caused for no good reason. We were also surprised that only a third (35 per cent) of DHAs routinely made the results of post-mortems available to relatives, although others did so if this was requested; and that 42 per cent of districts reported that this information was not given to relatives. Since we had been made forcefully aware of people's need to know as much as possible about the death of someone they love, it is difficult to regard this failure to communicate as other than disturbing.

Follow-up support

We were concerned that once the immediate issues surrounding a death had been dealt with, the relatives were often left to deal with their grief alone. We asked, therefore, whether some form of follow-up support was available. Over half the DHAs (58 per cent) did claim that access to a variety of agencies and personnel (both statutory and voluntary) was available, although it seemed that often it was relatives themselves who had to request further support rather than it being offered by the hospital. Again, terminal illness and neonatal death attracted more after-care services for relatives than other groups, and it seems that many people in their distress finally look to their GPs. Unless they specifically request it, very few people seem likely to have a chance to seek support from the hospital staff who cared for their relative, and to whom they may have become very close during that time.

Good practice

The questionnaire which we sent to health authorities owed much to the excellent King's Fund book *Good Practice in Hospital Care for Dying Patients* (Henley 1986), which offers practical guidance to staff in the care of dying patients and their relatives. We were interested to know how many authorities knew of this book and used its checklist in their hospitals and in reviewing their procedures and guidelines. By asking this question we naturally also hoped to draw attention to this excellent resource. Over half (60 per cent) claimed to know of the paper, but only one in five were actually using the checklist (although some had evolved their own checklist). From the evidence sent to us, however, it seems that there is still more emphasis upon developing smooth practical procedures rather than upon recognising and meeting the emotional needs of those concerned with a death. Since this questionnaire was circulated, the National

Association of Health Authorities has published *Care of the Dying: a Guide for Health Authorities* (NAHA 1987), but this, too, pays scant attention to the needs of the bereaved.

We hope that our survey of health authorities may in itself have helped to raise awareness within and among them about the needs of bereaved relatives and encouraged them to review their current practices and procedures to meet these needs more effectively.

5 What we concluded

We began with a personal experience of bereavement, which first suggested to us that there might be serious and distressing inadequacies in the way in which hospitals handled the human dimension of death and bereavement. This initial impression was confirmed in the further inquiries we made, which have been reported here.

It was confirmed by our reading of the available literature and, in particular, by a series of cases reported by the Health Service Commissioner. These reports spoke of 'failures to give caring and sensitive attention to the bereaved relatives' and of 'serious shortcomings in the arrangements made for dealing with the bodies of deceased patients'. The Department of Health was sufficiently stung by such repeated indictments that it was prompted to issue its circular on *Patients Dying in Hospital* (DHSS 1985). Further confirmation that these were not isolated or untypical cases came when we invited bereaved relatives to contact us with their own experiences of hospital bereavements. The response was overwhelming and the evidence damning, as we described earlier. The fact that there really was a problem could not be in doubt.

Against this background, our survey of health authorities was designed to throw some light on the extent to which the problem was being identified and addressed within the hospital system. Prompted by the DHSS circular, most health districts seemed to be making some response and it should be acknowledged that our survey was carried out at a period when many districts could claim still to be working through their response to an issue that had been brought to their attention. Nevertheless, as the last section indicated, the survey findings gave grounds for considerable anxiety about the energy and imagination with which the hospital system as a whole was approaching this matter.

For example, it was disturbing that so many districts evidently did not know how many people were dying in their hospitals, and that districts frequently assumed that the issue of bereavement support was simply subsumed by policies for the terminally ill. The DHSS circular had asked health authorities to draw up written guidelines but, as a chief nursing officer and director of quality development put it to us, 'the issuing of guidance does not guarantee a change in practice'. The particular questions we asked of health authorities (on such matters as the availability of guidelines, staff training, the appointment of bereavement officers and follow-up support to relatives) revealed such a patchy picture that it was difficult to conclude that a coherent approach was being developed.

Where support of various kinds was available, it seemed generally to be the case (as with the giving of information) that it depended upon bereaved relatives asking for it. The written material available to relatives was often of poor and dispiriting quality. Moreover, many districts claimed to be distributing the DHSS leaflet *What to Do After a Death*, evidently unaware that this was so outdated (a new edition has now been produced, DHSS 1987) that several of the contact addresses given in it were wrong. The fact that the vast majority of districts had not appointed bereavement officers (surely not a happy title anyway – relatives' officer is much better) is less significant than the lack of coherent planning which this revealed. There was confusion about what such a post would involve and who would properly occupy it; several districts denied the need for a separate post of this kind on the grounds that all staff should be concerned with offering support to the bereaved; and it was rare to find a district like Eastbourne with a clear conception of the role of a bereavement officer (basically, to make sure that the system worked).

To argue the need for a coherent approach to bereavement support is not to argue for a single approach. There is plenty of scope for innovation, experiment and diversity. However, coherence is imperative, not least because in this matter – perhaps above all others – the nature of our hospital and health care system may make it especially difficult to achieve. It involves the integration of administrative and emotional support. It also involves a partnership between the different health care professionals, as well as communication skills, for which our hospitals are not noted. This means a concerted initiative on the training side, including a recognition that it is not unprofessional to grieve and that a death continues, not ends, the caring process. The opportunities and difficulties in all of this were well described to us by a member of staff trying to develop good practice in this field in a major London health district. She reported an increasing recognition that the period following a death had in the past been 'generally badly handled and considered unimportant' and that 'the initiative for improving care for dying patients and their relatives has achieved improvements in nursing and administration, but the doctors remain fairly untouched by it all'.

Much clearly remains to be done, then, even in those districts and hospitals where the issue is at least being identified and addressed. The scope for the development of good practice is enormous; and it was good to find some examples from around the country where promising initiatives were being actively pursued. Some districts, like Canterbury and Wandsworth, had produced reports and guidelines for staff which were often frank in their acknowledgment of the deficiencies in their service to bereaved relatives and vigorous in their identification of the range of improvements required. It was good to find a district like Herefordshire clearly rooting its comprehensive written guidance in a statement of basic philosophy of care, and even warning about the perils of the 'inflexible chain' of bureaucracy getting in the way of sympathy and sensitivity; and the South Hams community division of the Plymouth District rightly emphasised that the written information it produced for bereaved relatives was not to be seen as a substitute for individual care.

Our general conclusion is that so much still needs to be done in terms of the management of bereavement and support for the bereaved, and it is important to identify where promising initiatives are taking place. For example, there is the work being done in Doncaster, where a relatives' room, supported by a team of volunteers, has been developed to ease the bereaved through both the emotional and administrative problems they inevitably face. There is the development of bereavement support services linked to hospitals, as in the London Hospital Bereavement Service and other examples elsewhere, which would seem to be a particularly promising initiative. There is the example from Cornwall and the Isles of Scilly, where nursing staff are encouraged to attend funerals and where they routinely make follow-up telephone contact with the bereaved. Our survey produced examples of thoughtful and promising staff training programmes. There is, as might be expected, the example of the hospices to learn from, in the care of the bereaved no less than in the care of the dying. In their integration of the continuing care of the bereaved with the care of the dying (see, for example, the follow-up letter to bereaved relatives sent by St Mary's Hospice in Birmingham – Appendix A), the hospices offer a reservoir of good practices. Because we were impressed by the critical and vigorous way in which (at least on paper) particular districts were addressing this whole area of care, we have also included reports produced for two DHAs (Eastbourne and Cantebury – Appendix B and C). These are not a blueprint, but they may serve to encourage others.

Such examples are not exhaustive. Indeed, there is further work to be done – building upon our preliminary study here – in looking in detail at the service provided to the bereaved in particular areas and in individual hospitals. It is very much to be hoped that such further work can be undertaken. Moreover, although our focus has been on the hospitals (where over half the population dies), there is a need also to look at the service being provided in the community. We hope we have done enough here, though, to show that there is a major problem to be tackled and one which in many ways is a test of the human quality of our health care services. As one health authority rightly observed, this is an issue where a small investment is capable of producing a dramatic improvement in the quality of service offered. In these hard pressed times, that may be the most appropriate note on which to end.

6 What next? – a checklist

What we offer here is a brief checklist to identify and encourage good practice in hospital management of bereavement and support for the bereaved. The focus here is only on bereavement support, from the perspective of relatives, and it does not cover wider administrative or medical issues. Nor is it designed to be comprehensive but it does (we hope) cover most of the essential ground.

Written statement

1 a. Does every health authority, and every hospital, have a clear written statement of the procedures to be followed after the death of a patient?

b. Does this statement include details not only of the administrative and medical procedures to be followed but also of the support and consideration to be shown to the bereaved?

c. Do these procedures reflect the need to be sensitive to different kinds of death (for example, of children) and of the different circumstances in which they occur (for example, in accident and emergency settings)?

d. Is the statement of procedures widely available throughout the hospital?

Staff

2 a. Are all staff familiar with the statement of procedures to be followed after a death?

b. Is there satisfactory training provision for all staff (nurses, doctors, administrators, ambulancemen, porters and clerical staff) about bereavement and the needs of the newly bereaved?

c. Is there support and counselling always available to staff who have to cope with bereavement and the bereaved?

d. Do staff have permission to grieve?

Immediately after death

3 a. During the initial few hours following a death, are the immediate needs of the bereaved met in as caring a way as possible?

b. Is there support and counselling available to the bereaved and is it always made available?

c. Are relatives offered as much time as they need to sit in privacy with the dead person and with each other in a quiet room?

d. Are they given a cup of tea and is a telephone made available to them?

e. Is a senior doctor available to see the relatives and answer immediate questions they may have?

f. Is the body of the dead person treated with dignity at all times, including the time when it is removed from the ward?

g. If a post-mortem or organ transplant is to be discussed with relatives, is this done sensitively by a person skilled at handling such situations, with full information and without pressure?

h. Are relatives given clear information and helpful guidance about what to do next, especially concerning the necessary administrative procedures associated with a death?

i. Are the community and caring services alerted to provide immediate support where necessary to bereaved relatives (especially when they are going back to an empty house) and are GPs informed at once by telephone as well as by letter?

The next step

4 a. Are all the necessary administrative procedures following a death organised in such a way that bereaved relatives receive the maximum of consideration and support and the minimum of distress, delay and inconvenience?

b. Is someone responsible for ensuring that this happens, and do the staff involved have enough time and support?

c. Do the administrative arrangements ensure that relatives only have to see one person in one place, at a convenient time and without undue waiting, and that all the documentation and belongings are ready?

d. Is the room where relatives wait, and where they are seen by an administrator, private and pleasant?

e. Are the personal belongings of the dead person collected and presented with dignity?

f. Are the practical arrangements for viewing the dead person handled in a sensitive and supportive way, even down to the smallest detail, and is the opportunity to view always made clear?

g. Is the mortuary chapel or viewing room decent and dignified, and is the body of the dead person suitably presented?

h. Does an appropriate person always accompany relatives to view the body?

Information

5 a. Is all relevant information explained clearly and fully to relatives?

b. Are relatives given supporting leaflets which are clear, informative and suitably presented?

c. Does this information include details of bereavement support that is available as well as administrative matters, and does it give specific local details?

d. Are relatives fully informed when a post-mortem is required or requested, and are they informed of the results of a post-mortem and offered opportunities to discuss these?

e. Is verbal information interpreted, and written information translated, into minority languages where necessary, to ensure that relatives fully understand what is happening?

Follow up

6 a. Are relatives offered a future opportunity to return to the hospital to discuss the death with a senior doctor and others involved in the care of the patient?

b. Who has to initiate this subsequent contact?

c. Are relatives put into contact with bereavement support groups and other support services?

d. Who has to initiate this contact?

e. Does the hospital initiate any follow-up contact with bereaved relatives to find out how they are coping or what help they might need?

f. Does the hospital ensure that no future communications are sent to the deceased person?

g. If relatives have agreed to organ donation are they subsequently thanked by letter, informed about the use of the donated organ(s), and offered further contact if this is wanted?

Miscellaneous

7 a. How well do the administrative and support arrangements work 'out of hours', and can the body of a dead person be viewed in the evening or at weekends?

b. Are the arrangements for handling death and bereavement sensitive to the cultural and religious practices of different groups?

c. Is there a bereavement officer or relatives' officer, suitably qualified and with adequate support, to coordinate all aspects of the care of the bereaved within the hospital setting?

d. Is there a relatives' room in the hospital where bereaved relatives can be offered support and taken through the necessary administrative procedures?

e. Does the hospital take any steps (for example, by sending a letter or card) formally to express its sympathy with the bereaved relatives of those who have died in its care?

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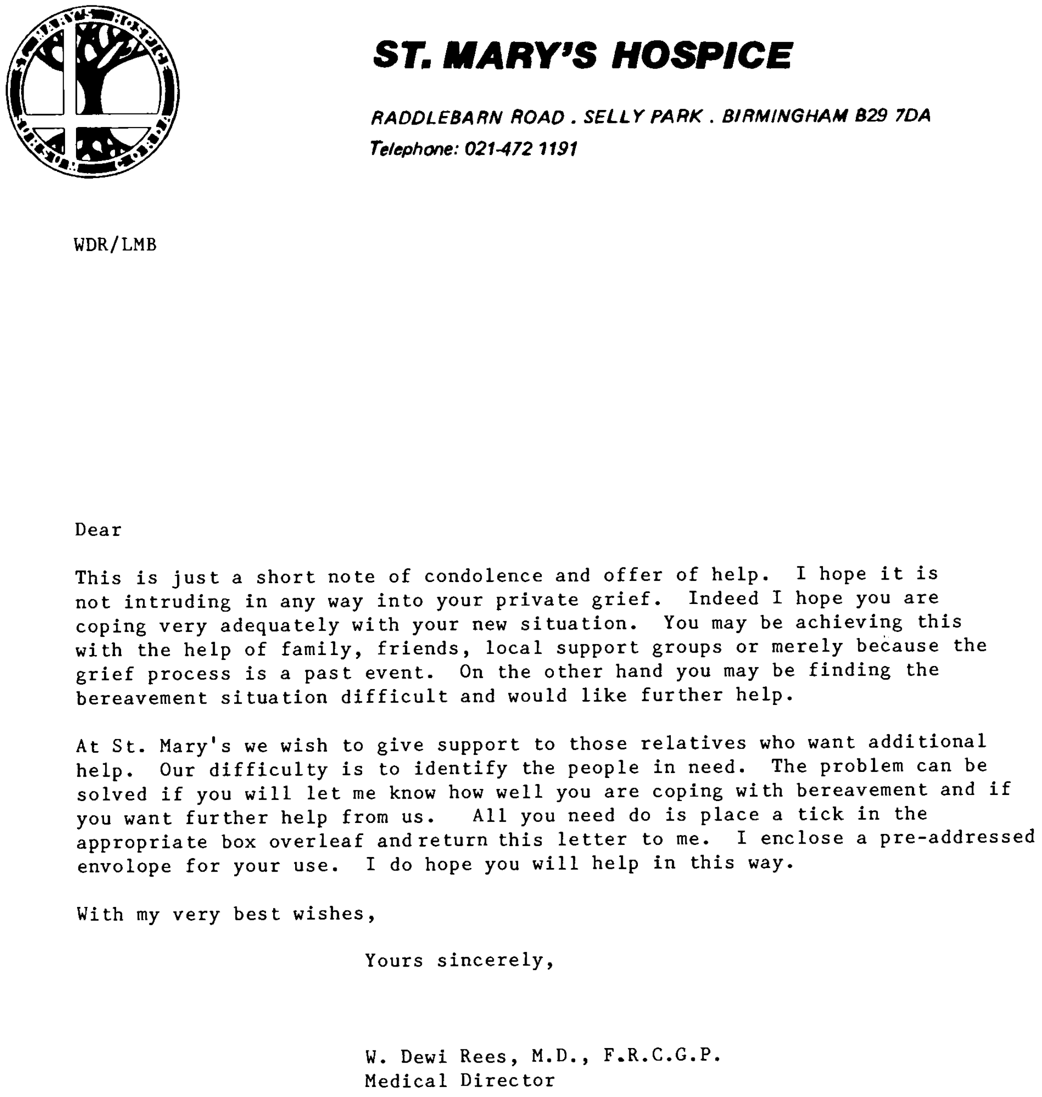
Appendix A



ST. MARY'S HOSPICE

RADDLEBARN ROAD . SELLY PARK . BIRMINGHAM B29 7DA
Telephone: 021-472 1191

WDR/LMB

Dear

This is just a short note of condolence and offer of help. I hope it is not intruding in any way into your private grief. Indeed I hope you are coping very adequately with your new situation. You may be achieving this with the help of family, friends, local support groups or merely because the grief process is a past event. On the other hand you may be finding the bereavement situation difficult and would like further help.

At St. Mary's we wish to give support to those relatives who want additional help. Our difficulty is to identify the people in need. The problem can be solved if you will let me know how well you are coping with bereavement and if you want further help from us. All you need do is place a tick in the appropriate box overleaf and return this letter to me. I enclose a pre-addressed envolope for your use. I do hope you will help in this way.

With my very best wishes,

Yours sincerely,

W. Dewi Rees, M.D., F.R.C.G.P.
Medical Director

☐ I am managing adequately and need no further help

☐ I am not managing as well as I would like but am receiving all the help I need from relatives, friends or local support groups

☐ I need further help and would be glad if you would contact me

Please place a tick in the appropriate box and return this letter to Dr. Rees at St. Mary's Hospice.

If you think another relative needs our help, please write the name and address below.

Appendix B

July 1986. Agenda Item 13

EASTBOURNE HEALTH AUTHORITY

REPORT OF THE WORKING PARTY ON THE CARE OF THE DYING IN HOSPITAL

Terms of Reference

1. To review the way we care for patients dying in hospital, using as a starting point HN(85)31.

2. To advise the Authority on immediate and longer term measures that should be taken to improve the services to this needs group.

3. To identify and advise the Authority on any other areas relating to the care of the dying, that should be the subject of further study or review.

Acknowledgements

4. The Working Party appreciate all the help and assistance afforded them by the various members of staff who made time within their busy work schedules to talk with us.

5. The District already does much to support the dying and their relatives. Following the research carried-out by the various members of the Working Party, the following is a description of current practice and, where considered appropriate, the recommendations for change or improvement:-

Ambulance Services

Frequently the ambulance service is the first ambassador of the Health Authority involved in the death of a patient and in the care of distraught newly bereaved members of the public.

7. Attempted resuscitation of the patient is their first concern. There is a need for written procedural guidelines clarifying the role and responsibilities of ambulance and other staff. The need for adequate training programmes is highlighted.

8. The reception of, distraught relatives upon arrival at hospital, the facilities and arrangements for receiving and identifying the body out of office hours and the administrative procedures for dealing with the effects of the deceased require review and consideration.

Hospital Services

9. To facilitate a dignified, peaceful and pain free death should be seen as an achievement by the whole caring team. This should be reflected in the written aims and objectives of ward policy documents; it is important to counteract feelings of failure that often exists amongst staff dealing with the dying.

10. The need for privacy both for the dying patient and for relatives, who maybe involved with his care, may properly call for the physical provision of a private area. In the absence of family or friends, a member of staff should remain with the patient.

11. The needs of the dying patient and of bereaved relatives impose their own types of emotional stress upon staff. This is compounded by ungenerous staffing levels. It is further compounded by lack of adequate consideration at the planning and commissioning of Units.

12. The necessary administrative procedures following the death of a patient are often unfamiliar and a source of worry to bereaved relatives. Distraught people are not always receptive to verbal instructions and advice. The need for an information brochure detailing such items as local undertakers, address and office hours of registry office, local DHSS, Social Services and local Voluntary Support Groups etc., was identified.

13. Relatives may request to see the body of a deceased patient. Facilities and procedures differ throughout the District. The Working Party made the following observations:-

    13.1 Viewing facilities need to be made to look less austere and ideally should be adjacent to, but separate from, the mortuary.

    13.2 Accompanying bereaved relatives to view the deceased is a task for a properly and appropriately trained member of staff.

14. Each hospital throughout the District should prepare written guidelines for staff, covering the various points mentioned in HN(85)31, which is attached.

15. The Working Party supports the recommendations of the appointment of a bereavement officer. This appointment should be part of the role of an existing staff member.

16. The bereavement officer should: Review the facilities and arrangements with each hospital, update policies and procedures, act as consultant to planning and commissioning teams, revise and maintain registers of relevant people who may need to be contacted, and advise on and participate in education and training initiatives for all disciplines.

17. Staff who deal with dying patients and bereavement need preparation. The Working Party commends the work that is already done within the District and recommends that an educational package be designed on a multi-professional basis for all staff.

18. There is a complexity of problems associated with the care of the dying involving, as it does, many different departments and people of different disciplines. Dealing with newly bereaved relatives is an important interface with the consumer of the National Health Service. The grief, anger, fear and guilt experienced by bereaved people often makes them hypersensitive and hypercritical. To enhance and maintain the quality of the service and the confidence of the general public, calls for investment of time, effort and resources. Limited resources are the cause of some existing problems. Others are attributed to poor communication. It is strongly recommended that quality circles are set-up in each hospital. Thereby, achieving a focused multi-disciplinary approach, minimising communication difficulties and leading to an enhanced quality of care. It is suggested that these quality circles be led and facilitated by bereavement officers.

Recommendations

19. It is recommended:

19.1 Written policies and procedures should be provided to clarify the role and responsibilities of ambulance and other staff dealing with sudden death and newly bereaved relatives.

19.2 Written ward policies should include the achievement of a dignified, peaceful and pain free death as a valid goal.

19.3 The needs of the dying patient and bereaved relatives should be reflected in the planning and commissioning of Units.

19.4 Facilities enabling relatives to view the body of a deceased patient need to be reviewed and upgraded in all existing Units and particularly in those with potential development.

19.5 Written guidelines covering the points made in HN(85)31 should be provided in each hospital for all staff dealing with death of a patient and bereavement

19.6 Brochures containing local information for bereaved relatives should be provided throughout the District.

19.7 Each hospital should identify an existing member of staff to take on the role and responsibilities of a bereavement officer.

19.8 Existing educational programmes require review in the light of the need to provide effective and sensitive multi-disciplinary responses to the needs of the dying and their relatives.

19.9 Quality circles should be set-up in each hospital with the express purpose of enhancing the service offered to dying patients and bereaved relatives.

19.10 Services to patients dying in their homes and their relatives, invite further research and review. It is suggested that appropriate members of the existing Working Party form the core of the subsequent group designated to undertake this work. Such a group may also wish to consider the follow-up of bereaved relatives of patients dying in hospital.

VERA DARLING
Chairperson to the Working Party

Appendix C

A REPORT RELATED TO PATIENTS DYING IN THE CANTERBURY GENERAL UNIT, OCTOBER 1986

Dying patients and their relatives are as important and require as much care, both practical and emotional as patients who will survive.

Throughout this report "relatives" relate to the person designated as closest to the patient in our care.

GOOD PRACTICES WHICH SHOULD BE ACHIEVED	EXISTING ARRANGEMENTS	REMEDIAL ACTION
Communications		
BEFORE DEATH		
Establish and record what the patient knows	Not always recorded	More emphasis during nurse training
and what the relative knows	Not always recorded	More emphasis during nurse training. Director of Nurse Education and Director of Nursing Services to be informed.
Was an opportunity given for patients to have a private one-to-one conversation with a senior doctor?	This opportunity is rare	Discussion with Consultant Staff to achieve an agreement.
When was an opportunity arranged for relatives to meet the medical staff?	This is a usual occurence.	To ensure this always happens. Discussion with Consultant Staff to achieve an agreement.
All doctors and nurses, however junior, should feel able to talk to patients about their condition and know where to get help if they feel out of their depth.	Usually undertaken satisfactorily.	More emphasis during training of both disciplines to ensure it is entirely satisfactory. Director of Nurse Education and Director of Nursing Services to be informed. To be included in discussions with consultant staff.
Non-professional staff should be advised how to deal with patients' questions.	Very recently Portering staff have been advised during a discussion period.	Inclusion in regular planned training sessions with Portering staff. Inclusion in orientation training of Domestic Assistants.
Patients and their relatives should be aware of the services of the Chaplaincy at this time. It is helpful for the Chaplaincy to be advised early in order that a natural meeting will take place. Both between Chaplain and patient and Chaplain and relative. This not only offers support at this time, but can offer continuing support through local clergy and ministers.	Referrals are only occasionally made. Either at the discretion of the ward nursing staff or at the request of relatives. It has been noted that some wards are more aware of the support offered than others, and regularly advise the Chaplaincy.	Inclusion in guidelines which should be available and which should state a basic standard of care which must be reached. Director of Nursing Services to be informed in order to ensure this happens as soon as possible.
Relatives including children if wished, should be made welcome as part of the caring team at all times. Allowed to remain as long as they wish.	Usually undertaken satisfactorily, but children not always considered.	More emphasis during nurse training. Director of Nurse Education and Director of Nursing Services to be informed. Include in guidelines.
To be involved in the care if they wish.	Some wards do feel able to include relatives in the care if they wish.	Again include in nurse training and guidelines in order that all wards participate.
Facilities available must be offered to relatives:		
The overnight room and	Usually offered. Cleaning irregular and unplanned.	Include in guidelines. Domestic services to be reminded of expected standard.
Restaurant availability	Usually offered satisfactory.	
If relatives leave the hospital their wishes regarding telephone messages at night must be sought and noted.	Some wards more consistently thoughtful than others.	Include in guidelines.

GOOD PRACTICES WHICH SHOULD BE ACHIEVED	EXISTING ARRANGEMENTS	REMEDIAL ACTION
All staff involved must be supportive and flexible.	Nursing and medical staff usually supportive. Not always maximum flexibility.	Include in guidelines.
Communications must be updated as frequently as necessary during this period.	Not always recorded as accurately as necessary	More emphasis in nurse training. Director of Nurse Education to be informed. Director of Nursing Services to be informed. Inclusion in guidelines.
Organ Donation		
The most appropriate time to approach relatives is usually after the first brain death criteria have been fulfilled.	Not always undertaken at this stage.	Discussion with consultant staff to achieve a general agreement.
The interview must be in private and carried out by the doctor in charge of the patient's care.	Normally undertaken by the most senior doctor in private.	
There must be a good deal of time available, both for discussion and for consideration.	Time for consideration can be curtailed if not discussed early enough.	If agreement regarding timing is reached this point will be resolved.
Relatives should be thanked by letter and offered the opportunity for further contact if they wish.	Relatives of kidney donors are thanked by Regional Officer. Further contact is offered in certain circumstances.	To ensure all donor relatives including corneal donors are thanked by an individual letter. Further contact should be routinely offered. Include in guidelines.
AT THE TIME OF DEATH		
Relatives need to be assured that good care will continue.		
Expected Deaths		
As much time as necessary must be given.	Usually accomplished.	
If relatives are present an opportunity should be made to speak to a doctor in private.	Not always arranged in privacy.	Each ward should have available a notice stating "Engaged, please do not enter", in order to isolate the most suitable room.
If relatives are not present, a message by telephone must be sensitively and accurately given, stating the true facts and giving the date and time to meet the Administrator concerned.	Telephone messages are accurate at this time, but not always as sensitively as possible. At present relatives are asked to ring the Administrator after 10.00am.	Nurse training required. An appointment system to be initiated.
Sudden Deaths		
In either the Accident and Emergency Department or a ward:		
Information to relatives must be sensitive, truthful and given as soon as possible.	Some wards have felt unable to be truthful when using the telephone.	Training in both the reasons for truth and how to do this sensitvely to be given to trained nurses as necessary and as soon as possible.
As much time and support as necessary must be given.	This is a usual occurence.	
An opportunity must be made for relatives to speak to a doctor.	This opportunity is always given if relatives are present at the time.	
The facilities available should include a pleasant waiting area with a window.	The waiting room in Accident and Emergency Department is unsuitable. Each ward can arrange a suitable room when necessary.	Privacy could be ensured if each ward had a notice available, "Engaged, please do not enter". It could be used for the most suitable room available. New accommodation in A & E required.
A telephone should be available.	This facility is available.	
Relatives should be always be made aware of the services of the Chaplain and the Chaplain advised accordingly.	This information is not always given. It depends entirely on the discretion of the nurse in charge at the time.	Training given to trained nurses and include in the guidelines.

GOOD PRACTICES WHICH SHOULD BE ACHIEVED	EXISTING ARRANGEMENTS	REMEDICAL ACTION
Sudden Deaths (Continued)		
All stillbirths should be notified to the Chaplain. In most cases funeral arrangements are involved.	Currently stillbirths appear to be advised.	Director of Nursing Services, Midwifery to be informed in order to ensure this continues if there is a change in Senior Nurses.
Relatives who are present when a patient's condition is critical should be allowed to visit immediately if they wish.	This is rarely considered and offered if resuscitation is in progress.	Education of both nursing and medical staff to achieve this. Discussion with consultant staff particularly in A & E Department in order to achieve agreement.
Careful preparation of relatives should be made regarding the activity and technology in progress as well as notification of their arrival to all personnel at the scene.		Education of trained nurses.
AFTER DEATH		
The facts must be given sensitively and truthfully. Idioms must not be used.	If the death is expected information is truthful. This is not always so if death unexpected. Some nurses have more skill than others in undertaking this sensitively.	Training given to inexperienced trained nurses as soon as possible.
Relatives may wish to visit the deceased patient after death.	Always arranged.	
The patient should look as normal as possible.	This is always attempted.	
Head uncovered resting on a pillow.	This is usually arranged.	Include in any education or training.
A hand exposed in order to make touching easier. The identiband should be on the other hand.	Only very recently considered.	Include in any training arranged for trained nurses and include in guidelines.
An opportunity for privacy should be offered and relatives allowed to remain as long as they wish.	Usually offered.	Include in any education or training.
If the death has occured in a general ward other patients should be sensitively informed. If this is not done furtive conversations will take place.	This is not generally undertaken. It is noted that some units have undertaken this for a few years.	Training given to trained nurses and included in guidelines.
Other patients should be consulted about whether they wish to be screened when the deceased patients is moved. Many wish to be involved. To pay their respects and to be assured of good care continuing. Their wishes must be followed.	As above.	Training given to trained nurses and included in guidelines.
At the time of transfer the demeanour and appearance of everyone involved must demonstrate on-going care.	Not every member of the portering staff has worn uniform to a satisfactory standard. Very recently an improvement has been noted.	Included in Terms of Employment and accepted on appointment. To form part of the disciplinary procedure.
Curtains do not exclude sound.		
The bed is the ideal vehicle in which to transfer the deceased patient. The difficulty in deciding whether or not to cover the face is well recognised.	Beds are only used if it is impossible to use the Mortuary trolley.	When the trolley is being assembled by Medical Physics is ready a decision about that and the prototype should be made by Senior Nurses together with Portering personnel.
The Mortuary trolley should be silent, easily manouvered and of acceptable appearance.	Present trolleys and new prototype do not fill the requirements.	
All members of the caring team, including Domestic Assistants should be informed of the death.	This is not undertaken.	Include in training for trained nurses as well as in the guidelines and included in orientation of Domestic Assistants.
Relatives may wish to visit whilst the patient remains in the hospital mortuary. During the normal working day the mortuary technician is informed. At other times the Senior Porter on duty.		
The deceased patient again should look as normal as possible.	This is always attempted.	
Head uncovered resting on a clean pillow.	This is arranged.	
A Hand exposed to make touching easier.	This is not done	Include in training and guidelines.
The identiband on the other hand.		

GOOD PRACTICES WHICH SHOULD BE ACHIEVED	EXISTING ARRANGEMENTS	REMEDIAL ACTION
A check within the Mortuary Chapel will be made before the visit takes place.	Usually undertaken.	
The waiting room should be welcoming, pleasantly furnished and decorated with adequate seating.	Seating adequate. Decorative state could be improved.	Redecoration and provision of a floral arrangement after discussion with Hospital Chaplain.
Flowers and plants regularly changed. Information leaflets available.	No flowers or plants until a plant moved from the Board Room last week. No leaflets available.	
The Chapel should also be welcoming, pleasantly decorated and appropriately furnished.	Redecoration required.	Redecoration after discussion with Hospital Chaplain.
Three sets of alter and trolley drapes.	No spare sets.	Provision of two sets of alter and trolley drapes as well as a spare set of curtains.
Two sets of curtains behind the alter.	No spare set	
Flowers on the alter changed regularly.	No flowers on alter until two weeks ago.	After discussion with Hospital Chaplain.
Relatives should be accompanied either by the Hospital Chaplain or a nurse. Sometimes the Coroner's Officer, or a Police Officer will fill this role.	Relatives are always accompanied but the Hospital Chaplain is never involved.	Include in training for trained nurses as soon as possible.
THE ADMINISTRATIVE PROCEDURE		
Relatives should be made welcome by name and a feeling of individual care ensured.	A warm welcome is given but not always by name.	Include in training.
An opportunity to meet medical staff should be offered if not already taken place.	This is not current practice.	Include in training.
An appointment diary giving half-hour appointments should be available out of hours at the Porters' reception desk.	Not in use	Instigate an appointment system available throughout 24 hours.
Appointments are made by name in order that there is no queue and that relatives are greeted by name when shaking hands.	Some queuing occurs. Efforts are made to reduce this as much as possible.	Appointments made by name. Relatives asked to report to the Porters' Desk.
A waiting area and interview room (without a telephone) should be pleasantly decorated and separate from the office accommodation.	Present room unsatisfactory. Relatives wait in main corridor.	Arrange a private waiting area and interview room.
Adequate cupboard space provided in order that only one set of property is on view at a time.	Not possible in existing location.	
Appointments cards should be available in wards and A & E Department and should include some information as well as the appointment date and time.	Not available. A typed slip of information gives very bare information.	Provide appointment cards to be given to relatives. Sample attached.
A mature and experienced administrator should be involved in order that the responsibility is dealt with sensitively and not seen as low priority.	This is achieved normally, though fails at times of sickness or annual leave.	
Meet junior medical staff on first day of appointment.	This opportunity not currently arranged.	Discuss with consultant staff in order to achieve cooperation.
The administrator should be on duty when night nursing staff leave in order to be available if necessary and to prepare to see the House Officers before they begin normal duties at 9am. This ensures that all paper work is ready before the relatives arrive.	The administrator commences at 9am.	Arrange for the administrator's day to begin at 07.45 hours and finish at 15.45 hours if possible.
Two property books should be available, one for property and one for valuables.	This is current practice.	
An offer should be made to dispose of unwanted articles.	This facility is not offered, but any such requests are arranged.	

GOOD PRACTICES WHICH SHOULD BE ACHIEVED	EXISTING ARRANGEMENTS	REMEDIAL ACTION
An explanation should always be given regarding terminology used when jewellery is described.	This is not current practice.	
An information leaflet of helpful addresses as well as a map giving directions to the Registrar should be made available.	Not available A map is available.	Produce an appropriate information leaflet including addresses and telephone numbers which may be helpful.
A message should be sent to the general practitioner.	General practitioners are informed.	
TRAINING		
Training must be given to everyone closely involved: Medical staff Nursing staff Administrators	Training details unavailable and possible inadequate Some training is given but not in sufficient detail	Ensure that appropriate training is given to all. Discuss with consultant staff to achieve cooperation. Provide guidelines, the contents of which will alter for each discipline involved. (Guidelines for nursing staff should be written by a Senior Nurse in order to relate to the nursing procedures.)
Portering staff	Recent discussions have included veiled mention of basic standards to be considered.	Training of portering staff should be on more formal basis.
as well as: Para-Medical staff Non Professional personnel and all supporting staff.	Training details unavailable and possibly omitted. Training probably inadequate	
The subject should be included in multi-disciplinary induction study days.	Not included up to the present time.	Include a broad reference during the induction study day which could appropriately be undertaken by the Senior Nurse who discusses the Role of the Nurse during this day.
FACILITIES AVAILABLE FOR VISITING THE DECEASED		
Kent and Canterbury Hospital		
Chapel	Available and satisfactorily placed.	
Visitors Room	Available and satisfactorily placed.	
Nunnery Fields Hospital		
Chapel	Available and satisfactorily placed.	
Visitors Interview Room	Available and satisfactorily placed.	
Mount Hospital		
Chapel	No Chapel available. Relatives wishing to visit deceased patients would be encouraged to do this at the undertakers though no requests have been made in the past 12 months. If essential arrangements to visit could be made in the ward area.	

Miss P Morley
Senior Nurse (Medical)

Mrs A M Grimsdell
Senior Assistant Unit Administrator

PM/JMK/D3a
23.10.86

Appendix D: Useful contacts

There are a number of groups and organisations concerned with bereavement support in different ways. The following are the main ones.

British Organ Donor Society
(for families of organ donors)
Balsham
Cambridge CB1 6DL
Telephone: 0223 893636

The Compassionate Friends
(for bereaved parents)
6 Denmark Street
Bristol BS1 5DQ
Telephone: 0272 292778

The Cot Death Society
4 Mansell Drive
Wash Common
Newbury
Berkshire RG11 6TE
Telephone: 0635 523756

CRUSE (bereavement care)
Cruse House
126 Sheen Road
Richmond
Surrey TW9 1UR
Telephone: 01–940 4818

The Family Welfare Association
(general bereavement counselling)
21 Kempson Road
London SW6 4PX
Telephone: 01–736 2127

The Foundation for the Study of
Infant Deaths (cot death)
15 Belgrave Square
London SW1 8PS
Telephone: 01–235 1721

Gay Bereavement Project
(for bereaved homosexuals)
Gay Switchboard
London WC1N 3XX
Telephone: 01–837 7324

The London Bereavement Project
c/o Hilary Lock
London Voluntary Services Council
68 Charlton Street
London NW1 1JR
Telephone: 01–278 5195
(home: 01–863 3571)

The Miscarriage Association
18 Stoneybrook Close
West Bretton
Wakefield WF4 4TP
Telephone: 0924 264579

National Association of Widows
1st Floor
Neville House
14 Waterloo Street
Birmingham B2 5TX
Telephone: 021–643 8348

The Stillbirth and Neonatal
Death Society (for bereaved parents)
28 Portland Place
London W1N 4DE
Telephone: 01–436 5881

Also there are local bereavement support groups in some areas and a number of the organisations listed here have local branches.

£2.75

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