ORGAN RETENTION: HELPLINE EXPERIENCES

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The following article arises out of an interview with Fred Coutts from the chaplaincy department of the Grampian University Hospitals, which includes Aberdeen Royal Infirmary, Aberdeen Maternity Hospital and the Royal Aberdeen Children's Hospital. Fred describes a recent period of crisis in the life of the hospital, and how during this period, the chaplaincy department was able to provide a service to both hospital and community. By the nature of their training and day to day work, the chaplains were perhaps uniquely well able to provide this service.

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The Helpline

The story of the helpline unfolds against the background of unease and distress caused to bereaved relatives by the revelations concerning organ retention both at Bristol and more recently at Alder Hey. Those whose loved ones had undergone post mortem were left feeling in many cases that their consent to the retention, use and disposal of organs had not been properly sought and given, and this in turn engendered a climate of fear, anger and mistrust. One of the consequences of this proved to be that in some centres in the UK, pathologists were being placed under extreme stress, as they attempted to deal with enquiries from relatives concerning post mortem procedures. Pathologists felt very exposed to the strong emotions of those whose need was not only for information, but for the venting of strong emotion, and in some cases, the apportioning of blame. The fact that correct procedure has been followed does not always give protection from a feeling of guilt, when confronted with the raw emotions of a bereaved relative. Consequently, the advice from the paediatric pathologists' professional body was that measures should be taken by Trusts to protect pathology staff from such exposure.

After consultation, the decision was taken that at Aberdeen Royal Infirmary, the chaplaincy should be the point of contact for the public, as it was anticipated that there would be a number of enquiries in the wake of the publication of the AlderHey Independent External Enquiry, and the Report of the Independent Review Group on the Retention of Organs at Post Mortem (the McLean Report). The plan was that the chaplains, of whom there are six working whole time in the Trust, would deal with initial enquiries, pass requests for information on to a nominated person in the pathology department, and facilitate the relay of this information to callers, either by telephone or by letter.

So far, so prepared. Events, however, took us by surprise, before the above reports had appeared in the public domain. Events, in the shape of a splashed headline in a local evening paper. Shock Horror! a story of how a number of organs was being retained following post mortem at Aberdeen Royal Infirmary. Reporters had garnered information from a website which contained verbatim reports gathered for the ongoing work of the McLean review group, and had splashed statistics without regard for context, or for the likely effect on relatives. As every chaplain knows, the way in which news is broken can have a profound effect on the way in which that news is received and handled by those affected.

That same night, the helpline began to flood with calls from angry, sad, bewildered people; the chaplains were thrown in at the deep end, as relatives demanded information about the fate of their loved ones' bodies. The calls concerned children, babies and adults. And so it continued right through February; the chaplaincy office at times resembled a call centre.

Issues and Themes

Callers of course wanted to know if their relative's organs had been retained, and in some cases wanted to see the post mortem report. If such was the case, then how had the organ been used, and for what purpose? And if the organ had been retained and subsequently disposed of, in what manner had that disposal taken place? In many cases we were able to reassure people that nothing had been retained after post mortem except small tissue samples, retained for microscopic diagnosis and future reference, and really forming part of the patient's medical records. On the matter of the retention of brains, the chaplains were able to explain that it is sometimes necessary to retain the brain for a time, in order to establish a clear cause of death. As to the matter of disposal, the chaplains were able to say that organs would have been disposed of according to current guidelines on the disposal of human tissue. However, McLean has subsequently highlighted the need to look again at the guidelines, which up till now have classified human tissue as clinical waste.

There has also been concern expressed by some of those who had agreed that a particular organ from a loved one should be used for transplant; in such cases, the question was raised as to whether the interference with the body had stopped at that. Had other organs been taken, without relatives' knowledge or consent? This, for some, was a most distressing fear.

Relatives raised also the issues around post mortem carried out not by the hospital but, in the cases of sudden, traumatic or unexplained death, on the instructions of the procurator fiscal. They complained of the difficulties of extracting information, and generally about poor communication. In such cases we had to direct people to the appropriate fiscal, while at the same time offering ongoing pastoral support, should they wish to call back and talk things through.

The chaplains' role

If it had been a matter of the mere relaying of information, then it is arguable that it would not have been necessary to have a team of chaplains at the end of the telephones. Certainly, information giving was part of it, and sometimes information alone proved to be enough to satisfy callers' anxieties. In that sense, we were hospital spokespersons. But in such a situation as this, more was often demanded of us, and we needed to call upon our listening and pastoral skills to meet the needs that we discerned. In some cases we were also able to give practical help to those who were still mourning a loss. In the case of one family, who had lost a baby more that twenty years previously, it proved helpful to suggest that the baby's hitherto unmarked grave could now be marked by kerbstones placed beside it, and that the name could be recorded in the hospital memorial book, an option which was not available at the time of the death.

A pastoral response has involved members of the chaplaincy team in creating simple liturgies for the disposal of organs. There has been a felt need on the part of some families, not for a second funeral as such, but for a form of words or ritual which would mark a final closure, and constitute a respectful and dignified disposal of part of a precious person's body.

What have we offered callers?

Apart from information giving, we can offer families the opportunity to meet with the Director of Nursing and a consultant pathologist, to talk through the issues which trouble them, and we are willing to be there in a kind of advocacy role. Many of those who have taken up this offer have had some of their concerns allayed by a face to face encounter conducted in an atmosphere of openness and mutual respect.

The Trust felt it appropriate that we should offer formal counselling to those who expressed a need for this. One of the chaplains is a trained counsellor, and has been seconded to do this work on three half-days per week for the next six weeks. It is not anticipated that long term counselling will be offered, and in cases where it seems appropriate, clients will be referred on.

We have also been able to arrange to have post mortem reports sent out to GP's, so that families who wish to know the details can learn these from someone who is able to interpret the technical language, and hopefully provide a reassuring sense of support while doing so. But of course it must be borne in mind that even today, not everyone wants to know everything. Perhaps a danger in too strong a reaction

to the alleged paternalism of the past, in which clinicians saw themselves as protecting relatives from details which might upset them, is that clinicians will feel pressured into giving too much information to those who don't really need or want it. As the McLean report points out, great discretion and sensitivity will be demanded, if a culture of too much openness is not to prove as damaging as a culture of too little openness. A related danger is that fewer hospital post mortems will be carried out in future, thus making it in some cases impossible to determine the exact cause of death.

Spiritual issues

It seems to me that there has been something of a spiritual shift in our society over the past few decades. During my ministry in the fishing town of Buckie in the seventies, the community on several occasions had to cope with the loss at sea of a the entire crew of a fishing boat. The grieving was deep and terrible; the whole community owned and felt it, and supported the bereaved families. Awful as it was, there was somehow at a profound level a kind of acceptance that this was the way of things sometimes, among those so closely thirled to the sea. People seemed to respond to death much as their ancestors had responded. Never was there any question of trying to recover bodies or raise boats. But nowadays, two things seem to have changed.

1. The technology to raise vessels now exists.
2. There is a sense abroad that, as grief counselling theory tells us, in order for mourning to be proper and complete ideally bodies should be recovered.

Does this mark a spiritual shift? I think so.

It seems to me that nowadays, fewer people have a theology or a philosophy of death, nor a considered understanding of the proper significance of the body. It's as if, in the absence of any thoughtful faith in the resurrection, or in the soul if you like, then the body, as a material object, and the fate of the body, is of ultimate significance, just as the loss of the body is the ultimate tragedy. This is not in any way to make light of the sufferings of the bereaved relatives affected by the scandal over organ retention; the very depth of their anguish speaks volumes about our culture. In a previous era, there would perhaps have been a response of prayer, of trust in God, even in the face of profound grief; a sense that the body, though the temple of the holy spirit, was also only the earthly tent. We live in a materialistic age. Perhaps this spiritual shift accounts at least in part for the intensity of outrage which has resulted in some families even demanding to reclaim for burial the most minuscule of tissue samples, mounted on slides and kept as part of the deceased person's medical records.

On the other hand, there is, even among people of religious faith, at times a fear of returning to one's Maker incomplete, as it were. One lady asked for reassurance from us that God would accept her daughter, even though the child's brain had been removed from her body. This, while not a rational response (which of us goes to his or her Maker complete?), is nevertheless deeply felt. And it could be that this sense of a need for the integrity of the body to be preserved, links those distressed over organ retention with those now reluctant to agree to organ donation; there is no logical link between the two.

Conclusion

The team of chaplains at Aberdeen has been heavily committed to the helpline for the past few weeks. We have seen this commitment as part of our pastoral role; a service which we are well placed to give to staff and to patients, and also to the wider community. Staff at all levels have been affected by this crisis in the life of the hospital community, from receptionists and secretaries faced with irate callers, to pathologists feeling themselves in danger of being cast in the role of villains of the piece, to senior managers having to cope with the stress of adverse publicity. It has been a testing time for all the staff, not least for the chaplains themselves; many calls have come from people whose distress has wider and deeper roots even than the upset over the retention of parts of their loved one's body. Pastoral care has been exacting and time consuming, and we have been grateful for the support of one another.

The helpline is open ended, and we now anticipate a slowing down, a gradual diminution in calls. There will be a natural ending to it. One of the hardest things has been to hear people say to us, 'but how can I believe what you are telling me?' The McLean report talks about the need for rebuilding trust, and I am sure that chaplains will do all they can to foster

and to further that trust which is so vital to the practice of health care in the twenty first century.

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