

Chapter 2. The Parents

Contents

1.	Introduction	18
2.	Death of Child	21
3.	Post Mortem Examination	22
4.	Retention	23
5.	Funeral	23
6.	News of Organ Retention	23
7.	Overview	24
8.	Summary of Parents' Criticisms and Suggestions	25

1. Introduction

- 1.1 We spent considerable time assessing the written and oral evidence of the parents. The content is powerful and should be highlighted. The following quotations are indicative of the emotional force generated by organ retention and its subsequent revelation.
- 1.2 We can do no better than to let the parents describe their feelings in their own words.

On the death of their child and the issue of consenting to post mortem examination

- 1.3 'I just couldn't think... I felt so empty and helpless... they shouldn't be so quick... it's rude and they catch you at your most vulnerable moment.'

'Not a lot that was said actually went in ... I was told it had to be done to check on the surgeon ... I signed the paper through tears and just wanted to grieve at home. I feel I was rushed into signing ... I feel that I should have been there to protect her ... I do understand that these things need to be done but only with full permission and a full explanation.'

'When they ask you to sign the form you are in so much turmoil you could sign your life away and would not know it.'

'I wish they had explained things to us.'

Parents' reaction to learning of organ retention

- 1.4 'It feels like body snatching. The hospital stole something from me. They have taken us back 11 years in our healing process.'
- 'They gave me skin and bone back.'
- 'Alder Hey stole 90% of my child.'
- 'I feel devastated ... I am wondering how much of her body was left.'
- 'I have learnt to live with my daughter's death and now I have found out that they removed her heart. It is like losing her all over again.'
- 'Studying her brain would help explain why her brain did not form properly and it might help treat the next child born with a similar condition. Unfortunately her brain has not been studied. Instead it sits in a jar in a storeroom somewhere.'

Handling the news of organ retention

- 1.5 'We are left feeling that full details are being withheld.'
- 'Alder Hey gave the impression that as parents we had little or no right to know what happened to our children after death.'
- 'Alder Hey could not cope.'
- 'On a personal basis I have found the representatives of Alder Hey to be very helpful, available, open and honest when dealing with our individual situation.'
- 'They have been helpful and regretful.'
- 'We are suspicious of everything Alder Hey says.'
- 'They have been cold and it is all telephone calls.'
- 'I have not spoken to anybody face to face.'
- 'Inept and inconsiderate.'
- 'Staff... have been as courteous and helpful as they can in the circumstances.'
- 'We were surrounded by good people at Alder Hey and wish to extend our support for them.'
- 'There has been a huge lack of accuracy and secrecy.'
- 'These poor people who have had to deal with us over the telephone... should be given sympathy and counselling themselves.'
- 'There has been a catalogue of public relations disasters that have only upset parents more.'

On completing the preliminary evidence questionnaire

1.6 'I am remembering things from 10 years ago that my mind put into a little black box.'

Our Inquiry looked back over a period of more than 40 years. Parents said:

1.7 'The death of a child is traumatic enough without having to relive it ten years later.'

'Try to imagine having a second funeral 34 years after the first.'

'We cremated our son in two separate boxes 31 years apart.'

1.8 We considered whether the passage of time has impaired the quality of the parents' evidence. We also considered the distress and loneliness which many parents have experienced over the years. It is possible that some parents will have suffered an adverse psychological reaction because of the death of their child.

1.9 Even taking these matters into account each parent was recalling one of life's major events, namely the death of their child. It was a unique event for them and is liable to remain imprinted upon their minds forever. We are concerned with their perception of how their child was treated at death, how the issue of post mortem examination was dealt with, how they reacted to the news of organ retention, how they reacted on learning that they had not buried their child whole and of the need for a second or more funerals. We are aware that we have only heard from those parents who have responded to the Inquiry and to that extent they are self-selected. We are left to speculate about the reaction of those who have not responded to the Inquiry. We were recently informed of one parent who received a full list of retained organs relating to their deceased child despite their stated preference not to know. These matters are analysed in Chapter 3.

1.10 We have asked Alder Hey to devise and implement an effective handling strategy, to include psychological input, for additional parents who are likely to come forward following publication of our Report. These matters are again dealt with in Chapter 3.

1.11 We have subjected the parents' evidence to critical examination. There are likely to be areas where inaccuracy prevails, particularly in respect of detail which they cannot or subconsciously do not wish to remember. This might relate to the issue of whether or not they signed a consent form or the full detail of conversations they had with clinicians following the death. However, because of the unique circumstances of the death of their child and the events of September 1999, when the issue of organ retention became public, their evidence is entitled to respect and is worthy of very careful consideration. More particularly, those who have had second and third funerals have had no difficulty recalling such recent events.

1.12 Our overall impression of the evidence from parents is that the issues which confront us are no respecter of socio-economic group or manner of life. There has been a huge consistency of response with clearly recurring themes throughout. The love parents

showed for their children both in life and in death was plain to see. The care they lavished upon them in life and as far as they were allowed in death was apparent. The extent of their grief and distress was reflected in the eloquence and dignity with which they gave their evidence. On many occasions we were deeply moved. It was our privilege to share their evidence and in particular, photograph albums and baby books whenever produced. The age of the child was of no consequence to the parents. Whether stillborn or teenage, their children were deeply loved and valued as unique individuals and family members.

- 1.13 Each parent has posed individual questions for which they seek answers. We explained to those who gave evidence that it would be impossible to answer all questions individually but our Report should help them understand how the situation developed and how it should be prevented from recurring in the future.
- 1.14 The strength of the parents' evidence is such that the only way to do it justice is to include in a separate chapter (Chapter 14) faithful summaries of representative evidence. Wherever possible we have endeavoured to use the parents' own language in the narrative. We have adopted the simple strategy of marking each summary with the child's first name, age and year of death. We do this as a mark of respect and also as a permanent memory of their involvement in and contribution to the Inquiry, while preserving the anonymity of their family. We commend the summaries to all who read them for their compelling content, understandable and reasonable expression of emotion, consistency of response and identification of recurrent concerns.

2. Death of Child

- 2.1 Many of the deaths occurred around the time of birth. Later deaths usually resulted from malformation, disease, infection or accidents. Sometimes deaths occurred during surgery or shortly thereafter. There were cases of older children dying from Hodgkin's disease and leukaemia.
- 2.2 Whatever the circumstances, the universal consequence of death has been grief. Some parents were referred to a social worker but the majority spoke of a lack of bereavement advice or counselling. They identified a great need for such a service. Their evidence should lead to a better understanding of the consequences of death including the issue of lack of objection or, as we prefer, fully informed consent to post mortem examination.
- 2.3 Immediately following the death of their child many parents offered to donate organs to save the life of another child in immediate need. The majority of offers were refused on the basis that the organs had been damaged in the disease process which caused death. There were several parents who carried organ donor cards with them. We were told that

one or two teenagers involved in the organ retention issue had requested organ donor cards themselves when they were alive. Several parents destroyed their cards when they were told about organ retention and how it affected their child.

- 2.4 Parents described difficulty in understanding what was said to them by clinicians or hospital staff because of their grief. From the sample questionnaires commenting on hospital post mortems looked at by the Office of National Statistics, just 37 per cent of parents could remember reading the consent form, whilst 44 per cent said they had not read it. In the few cases where a pamphlet or booklet was made available to parents, they had found it hard to understand because of their grief and distress. Too many parents, 46 per cent, were asked for consent to a post mortem within minutes of the death of their child. There was little time for reflection, advice and counselling as appropriate.

3. Post Mortem Examination

- 3.1 The vast majority of parents were told that a post mortem examination was to be carried out. Surprisingly, few were told when or where it was to be carried out. Generally, parents were not told what was involved in a post mortem examination.
- 3.2 Parents were given little information when a Coroner's post mortem examination was to be performed. A Coroner's post mortem is demanded by law in certain circumstances and for which consent is not required (see Chapter 9). When the Coroner's process was complete they were not asked for consent to the retention of organs for medical education or research purposes.
- 3.3 When a hospital post mortem examination was to be performed, some 81 per cent of parents (sample as above) said they were not told specifically that they could object. A hospital post mortem requires consent or more properly 'lack of objection'. When they did consent almost all the parents thought it was to the taking of tissue sufficient for microscopic examination and not the retention of organs. Indeed, no parent could recall being advised that they could object to the retention of organs. There was no consistency as to who dealt with establishing consent or lack of objection with parents. It was sometimes the clinician, but more usually a junior doctor or even a member of the nursing staff who dealt with establishing consent or lack of objection.
- 3.4 Many parents described being placed under pressure to consent to a hospital post mortem. In several cases parents spoke of the prospect of a Coroner's post mortem being used to obtain consent to a hospital post mortem examination. There were instances where clinicians allowed one parent to sign the consent form although aware that the other parent's wishes were not known.

- 3.5 Following Coroner's post mortem examination there was little evidence of contact or discussion between the Coroner, parents, clinician or pathologist. Only a minority of parents were informed of the contents of the post mortem report. Few parents were referred for genetic counselling even if the need was established. Some parents had further children before the results of post mortem examination were made known to them. One family lost two children close together from the same congenital heart condition. They had never seen the post mortem report on their first child.

4. Retention

- 4.1 Many parents did not realise and were not told that the organs would be removed from the body, weighed and subjected to naked eye examination in the post mortem process. Those who were aware that organs were removed for this purpose were always reassured that they would be restored to the body prior to the funeral. It was rare for any parent to be told that an organ or organs would be retained.

5. Funeral

- 5.1 The parents described the first funeral as dignified and respectful. Each parent believed that they were laying their child to rest intact. In some cases, particularly with regard to stillbirths, parents were told that their child would be buried in a dignified and respectful manner within the hospital grounds. They were not told where or when.

6. News of Organ Retention

- 6.1 The realisation that many children had been buried without their organs caused their parents shock and distress. The parents' summaries in Chapter 14 contain accounts of personal reaction to the news.
- 6.2 Many parents were drip-fed information about what had or had not been retained. There was unacceptable delay between initial contact and the subsequent disclosure of what had been retained. There were too many instances of the initial information being inaccurate. Neither Alder Hey nor the University had an individual record of organs retained from each child following post mortem examination, nor did they have an individual record of organs used for research. They should have done.

- 6.3 Accordingly there were unnecessary delays, confusion and inaccuracies, the cumulative effect of which greatly added to the distress suffered by parents.
- 6.4 There was neither a proper system nor a uniform approach as to how to deal with parents. There does not appear to have been any handling strategy based upon psychological advice. Under these circumstances the telephone and correspondence were unsatisfactory means of communication. There should have been face to face meetings.
- 6.5 The attitude of Alder Hey has been described as insensitive and arrogant. Some parents who described Alder Hey's treatment of their children in life as 'outstanding' have changed their view because of organ retention and the handling issues. What is described is evidence of a system based upon poor crisis management.
- 6.6 Some parents have had to have three funerals, particularly those involved in the very recent revelation of the cerebellum (*part of the brain*) collection in August 2000. Some have had the further indignity of samples being taken from retained organs without consent immediately prior to their return. Parents wondered how such a situation could arise. They asked why organs were retained following Coroner's or hospital post mortem examinations without their consent or a record being kept of organs retained. They also asked why there was no record of organs used for research, and no regular stock-take or audit. In particular they could not understand why there was no current list of retained organs compiled before news of organ retention becoming public. This would have avoided the unacceptable delay between initial contact being established with Alder Hey and the later provision of details of organ retention, some of which were still inaccurate. Even this process was fraught with error.

7. Overview

- 7.1 Parents contrasted the very full information they received about the treatment of their children in life with the absence of information in death. Had the circumstances of death received equal attention then they would have understood the intended purpose of post mortem examination, as well as the benefits to society of retaining organs or tissue for medical education and research purposes. They would then have been more inclined to give proper informed consent.
- 7.2 Openness and transparency requires robust organisational procedures. The most important function of post mortem examination is diagnostic. All processes where tissues are examined are aimed at identifying underlying disease. The other functions of post mortem examination, including medical education, research and audit, are desirable for the purpose of improving the health of future generations.

- 7.3 There will always be parents who, for personal reasons, will refuse a request for post mortem examination. Nevertheless, if the death is within the parameters of the Coroner's jurisdiction, then post mortem examination will be carried out to establish the cause of death. On the evidence we feel that many more parents would be willing to consider consenting to their children's organs or tissue being retained for the purpose of medical education and research, if the matter were dealt with openly and respectfully.
- 7.4 There is clearly a social need for more post mortem examinations to encourage and assist improvements in the health of future generations. The majority of parents recognise this. The major impediment to its achievement has been the unnecessarily paternalistic attitude of the medical profession based on restricting information about post mortem procedure, organ retention, medical education and research. The parents have been systematically deprived of information which they had a right to know.

8. Summary of Parents' Criticisms and Suggestions

- 8.1 This is a summary of the concerns we heard from parents, together with some of their suggestions about how to address them. Parents feel they have the right to information about their child and his or her treatment in both life and death. They want to see systems in place which can help them make sense of their child's death and feel confident that they have the relevant information. They want the confidence to be able to put their children to rest.
- 8.2 **Concern:**
- That undue pressure was brought on parents to sign the consent form.
- Suggestions:**
- Allow time for parents to reflect after death before discussing the issue of post mortem consent.
 - Ask a psychologist to help develop a sensitive approach to giving parents the news about the death of their child, and then move on to the issue of consent.
- 8.3 **Concern:**
- Parents would like advice and support.
- Suggestions:**
- Offer bereavement advice and counselling following a child's death, addressing feelings such as guilt.

- Provide formal advice and support not only to parents but also to brothers, sisters and perhaps other close relatives.

8.4 **Concern:**

Parents need to know that when they give consent their wishes will be followed.

Suggestions:

- Parents will be told if there is need for retention of organs or tissue for microscopy.
- Organs will be reunited with the body after post mortem and before funeral.
- There are legal restrictions to prevent undisclosed retention without parental consent.
- Full details of organs and tissue retained will be recorded and put on a database.
- Parents are told what will be the purpose for retaining organs or tissue.

8.5 **Concern:**

Parents need to know that a checking procedure is in place, and to be confident that swift action will be taken to correct mistakes.

Suggestions:

- Clear systems should be set up to deal with this type of issue (avoiding the hospital being defensive and unco-operative, and over-concerned with damage limitation).
- Prevent delays in supply of information by putting in place a proper management structure and database.
- Train hospital personnel to deal with parents in this kind of crisis.
- Audit the post mortem examination procedure regularly.
- Keep careful control over research on human organs and tissue.
- Establish a clear line of responsibility for issues like this, and discipline individuals if necessary.

8.6 **Concern:**

Parents did not know their rights to refuse hospital post mortem examination.

Suggestions:

- Parents need to know of their right to limit post mortem examination and of their right to object/consent.

- Information given to parents should be in non-medical language and clearly state options and possible outcomes after the post mortem examination.
- There should be clear guidelines of post mortem examination and procedure, including the different types of post mortem examination and the process.
- Parents' instructions should be obtained and followed.
- Explain the meaning of tissue and organ.

8.7 **Concern:**

No system or procedure for informing parents of post mortem examination results.

Suggestions:

- Post mortem examination and reports should be part of the individual's medical record.
- If parents wish they should be kept informed at every stage.
- GPs should have responsibility to follow up a child's death with the parents.

8.8 Parents would like to be dealt with sensitively.

8.9 Parents want to know why the practice of organ retention has gone on for so long, without their knowledge.

8.10 We have paid particular regard to the parents' suggestions in considering our recommendations, particularly relating to the handling issues at the end of Chapter 3.