The Removal, Retention & use of Human organs & Tissue from Post-mortem Examination.

Social Issues & Resources Committee

Introduction

In recent years there has been much controversy and hurt surrounding the revelations about post-mortem practice in N. Ireland and throughout the United Kingdom. The Human Organs Enquiry Report 2003 shows, 'there was a gulf between what the public knew and was told about procedures and practices on the one hand and what was actually happening on the other hand. This has created a legacy of distress and anger among some members of the public even if other people do not share their concern.' (Report: Ch. 1; Para. 1.1)

For the bereaved and those involved with pastoral care the distress and anger has been all too real. The matter has raised issues such as renewed grief, burial of remains, and feelings of having betrayed or failed the deceased. For Christians it has raised issues regarding wholeness in the next life and about what will happen at the resurrection?

These feelings have been particularly acute in regard to the loss of children.

Medical practice

The Report is to be welcomed and has dealt with both legal matters and medical practices including the care of the bereaved in hospitals. While pointing out the enormous benefits to medical science in being able to retain tissue and organs the report acknowledges the need for consent and a greater degree of openness in procedures. It recommends, for example -

1. The tightening up of legal requirements to be met by medical professionals in regard to the removal, duration of retention and use of human organs and tissue;
2. More adequate information to be given on the nature of post-mortem procedures;
3. Fuller and better explained consent procedures;
4. Additional bereavement training for medical and nursing staff;
5. The offer of counselling for the bereaved.

In the Report covering England and Wales the Chief Medical Officer stated that good practice should be based on the following 'Guiding principles':

1. Respect treating the person who has died and their families with dignity and respect;

2. Understanding - realising that to many parents and families their love and feelings of responsibility for the person who has died are as strong as they were in life;
3. Informed consent - ensuring that permission is sought and given on the basis that a person is exercising fully informed choice; consent is a process not a ‘one off’ event;
4. Time and space - recognising that a family member may need time to consider whether to agree to a post-mortem examination and to consider donation of tissue and organs and will not wish to feel under pressure to agree in the moments after death;
5. Skill and sensitivity - NHS staff must be sensitive to the needs of the relatives of someone who has died and sufficient staff skilled in bereavement counselling must be available;
6. Information - much better information is required, both generally by the public and specifically for relatives who are recently bereaved, about post-mortems and the use of tissue after death. Relatives may also require information about the progress of research involving donated material;
7. Cultural competence - attitudes to post-mortem examination, burial, and the use of organs and tissues after death differ greatly between different religions and cultural groups; health professionals need to be aware of these factors and respond to them with sensitivity;
8. A gift relationship - the emphasis in all present legislation and guidance is on ‘taking’ and ‘retaining’. The balance should be shifted to ‘donation’, so that tissue or organs are given as a gift to help others and recognised as deserving of gratitude to those making donations.

Such guidelines are to be welcomed and if practiced consistently should greatly reduce the kind of distress caused in recent years.

Pastoral Approach -Sensitivity

As in all sensitive pastoral situations there is the need to listen and seek understanding, to show compassion and allow time and space for the expression of strongly felt emotions. There is also the need to allow difficult questions to be asked, and to provide appropriate means to help families through their shock and grief to bring dignified closure. Part of the pastoral care offered by hospitals should in the future include providing families with dignified options regarding the disposal of retained organs and tissue. For some this may include some form of burial/cremation service to enable them to bring closure to the matter.

Balance

It is important to help the family to a position of balance.

On one side every family will want a dignified closure to the life of a loved one through burial or cremation. The body, after all, for Christians is a "temple of the Holy Spirit," (1 Cor. 6:19) and to be treated with dignity. Few people, however, would want returned to them a removed appendix, ovary, or hip joint. Nor would they count a loved one who died without one these somehow lacking in wholeness.

As Christians we believe that the soul departs the body at death. It is 'remains' that are buried or cremated not the person. The body given at the resurrection will be new, glorified and free from sickness, decay and death. (1 Cor. 15) With regard to the person and the resurrection therefore what happens to organs and tissue is not important. Indeed a resolute belief in the resurrection can, and should, encourage Christians to donate organs and tissue both for transplant and medical research.

Such balance is important in the pastoral setting to help the family steer away from superstition and towards a positive perspective.

Justice

Emotions surrounding organ retention are often fuelled by a sense of injustice. The matter of permission is not unimportant but it is a procedural matter. There is no indignity in tissues or organs being retained and used to further medical science. From a Christian perspective it is perfectly valid for a family to seek the implementation of better procedures regarding organ retention yet not to seek to retrieve any such organs or tissue that may have been retained. This is especially true when a funeral and fitting farewell has already taken place. Again, a strong belief in the new resurrection body should encourage Christian people to accept that the person has gone but will be made new and perfect at the resurrection.

Guilt

In the Chief Medical Officer's (GB) guidelines above he mentions that, 'to many parents and families their love and feelings of responsibility for the person who has died are as strong as they were in life.'

Feelings of guilt and having failed the loved one may need to be acknowledged and verbalised. It may be helpful to point the family to their care for the person while he/she was still alive. Families who lose a loved one at sea or on a battlefield may never have the opportunity to bury their remains in a dignified way.

Anger

Feelings of anger need also to be respected. However, as with all anger, if allowed to simmer it can turn to bitterness, which will neither benefit the angry person nor honour the dead. (Eph. 4:26) It may be helpful to point out that from their pain is likely to come positive benefits for other families. Although their suffering has been for a time it has led to an enquiry, as a result of which such circumstances should not arise for other families in the future. At an appropriate time it may be helpful to gently lead the family in a prayer of forgiveness encouraging them to move on.

Help

As part of the new Post-Mortem consent procedures hospitals will offer parents various options with regard to the burial/cremation of remains. If the parents wish the hospital will make necessary arrangements. Helpful material for those in a position of pastoral care may be found on the hospital chaplains web-site, address below.

Some helpful passages of Scripture

Psalm 62:1,5

Psalm 90:3

Hosea 13:14

Matthew 10:28

John 5:25

2 Corinthians 5:1-10

Philippians 3:21

Helpful Materials

Post Mortem Examinations and the Human Organs Enquiry – Information leaflet published by the Department of Health, Social Services and Public Safety and delivered to all homes in N. Ireland.

Post Mortem Examinations – Good practice in consent and the care of the bereaved. A consultation document produced by the Department of Health, Social Services and Public Safety. January 2004

Helpful Contacts and Web-Sites

The Relatives Reference Group
Supports relatives in liasing with hospitals and organisations.
Tel. 028 9032 5250

Parents Advice Centre (NI)_
Support and guidance to individual family members with family difficulties. Tel. 028 9031 0891

Stillbirth & Neonatal Death Society (SANDS)
Support for those whose baby has died at or near birth.

Tel. 020 7436 5881 (Helpline)
or 020 7436 7940 (Admin)
www.uk-sands.org/index.html

CRUSE – Bereavement Care
Tel. 028 9079 2419
www.crusebereavementcare.org.uk/

www.hospitalchaplain.com/
For hospital chaplains offering resources in spiritual and pastoral care. Useful for suggestions for funeral services especially regarding stillbirth.

Care for the Family (General Christian family issues)
3 Wallace Avenue, Lisburn BT27 4AA
Tel. 028 9262 8050

Christian Guidelines (General Christian counselling)
7 Queen Street, Belfast BT1 6EA
Tel. 028 90230 005

Presbyterian Church in Ireland Counselling Service
Contact through the Board of Social Witness
Tel. 028 9032 2284

Presbyterian
CHURCH IN IRELAND
Board of Social Witness
Assembly Buildings, Belfast BT1 6DW
www.presbyterianireland.org/bsw