

# Report of the Working Group on Post Mortem Practice

## 1. Introduction:

1.1 The Madden Report into Post Mortem Practice and Procedure (2005)<sup>1</sup> stated that consideration should be given to the implementation of the recommendations made in the Report to other post mortems<sup>2</sup>, namely those carried out on babies who died before or during birth, minors and adults. It was acknowledged that while many of the recommendations in the Report may apply generically to all categories of post-mortem examinations, these post mortems also raise distinct legal and ethical issues that were not within the Terms of Reference of the Madden Report. The Report advised that a Working Group be established to ensure that appropriate adaptation in relation to those issues takes place. It was recommended that its membership should include relevant stakeholders and family representative organisations. This Working Group was established by the Minister for Health and Children, Mary Harney TD, in March 2006. The members are as follows:

Dr. Deirdre Madden, Faculty of Law, University College Cork, Chairperson

Ms Charlotte Yeates, Parents for Justice

Ms Breda Butler, Parents for Justice

Ms Ron Smith-Murphy, Irish Stillbirth and Neonatal Death Society

Ms Ann Canning, Irish Stillbirth and Neonatal Death Society

Ms Pauline Treanor, Joint Standing Committee of the Dublin Maternity Hospitals

Dr. Eoghan Mooney, Consultant Histopathologist, Faculty of Pathology RCPI

Prof. Elaine Kay, Consultant Histopathologist, Faculty of Pathology RCPI

Dr J. Conor O'Keane, Consultant Histopathologist, Faculty of Pathology RCPI

Prof. Fionnuala McAuliffe, Institute of Obstetricians and Gynaecologists, RCPI

Ms Nuala Harmey, Irish Association of Social Workers

Ms Loretto Reilly, Irish Association of Social Workers

Mr Tom O'Connor, Department of Health & Children, Secretary to the Group

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<sup>1</sup> Report of Dr. Deirdre Madden on Post Mortem Practice and Procedures (2005) Government Publications Office, Dublin. Available at [www.dohc.ie/publications/madden.html](http://www.dohc.ie/publications/madden.html)

<sup>2</sup> A post-mortem examination or autopsy is the dissection and examination of a body after death in order to determine the cause of death or the presence of disease process.

## **2. Terms of Reference**

To consider the application of the recommendations in the Madden Report on Post Mortem Practice and Procedure, to babies who died before or during birth, minors and adults.

To report and make recommendations within a six-month timeframe on policy and legislative modifications in relation to post mortems on babies who died before or during birth, minors and adults.

## **3. General summary**

3.1 The Working Group met on 7 occasions in Hawkins House, Dublin and maintained a website<sup>3</sup> through which minutes of meetings were made available to the public. The Working Group consulted with the Office of the Ombudsman for Children, and held meetings with representatives from the Coroners Society of Ireland, the Dublin Cemeteries Committee, and the Miscarriage Association. Submissions were sought from members of the public through the website and through ISANDS and Parents for Justice members. All submissions received were acknowledged and read by each member of the Working Group. This consultative process was very informative and beneficial to the Working Group in the formulation of its recommendations and the Working Group is very grateful to all those who contributed to this process.

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<sup>3</sup> [www.dohc.ie/working\\_groups/pmpp/](http://www.dohc.ie/working_groups/pmpp/)

3.2 The Working Group endorses the recommendations contained in the Madden Report in relation to the need for legislation to be introduced as soon as practicable to ensure that no post-mortem examination will be carried out on the body of a deceased person, and that no organ<sup>4</sup> or tissue<sup>5</sup> will be retained from a post-mortem examination for any purpose without knowledge and appropriate authorisation<sup>6</sup>.

3.3 The authorisation model put forward in the Madden Report facilitates those who are prepared to allow a post-mortem examination to take place but do not wish to be given further information about the process of carrying out a post-mortem examination. It enables them to authorise a post-mortem examination to be performed and the hospital to undertake any appropriate action during/following that examination. It also allows further information to be given at any future time should it be sought by the next-of-kin. This model ensures that next-of-kin are given as much information as *they* decide they wish to have and are given the opportunity to ask whatever questions they feel necessary. If they choose to refuse to authorise the post-mortem examination, they do not need to give reasons for their refusal.

The ISANDS representatives expressed concern in relation to the concept of authorisation.

3.4 Most people are unfamiliar with the practice and procedure of a post-mortem examination and, in the immediate aftermath of the death of a loved one, may not be best placed to take in detailed information at that time. The distressing circumstances present at such a time necessitates the sensitive and clear delivery of information by staff that are appropriately trained in bereavement counselling.

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<sup>4</sup> An organ is interpreted here as a part of the body composed of more than one tissue that forms a structural unit responsible for a particular function(s), for example, the brain, heart, lungs and liver.

<sup>5</sup> Organs contain tissue, collections of cells which give organs their special function. Samples of tissue (typically small slices about a quarter of an inch thick) are taken during a post-mortem examination for examination with a microscope.

<sup>6</sup> Authorisation refers to the granting of legal permission by an appropriate person.

3.5 Substantial changes have occurred in pathology practice in the last number of years. Since 2000, both the Faculty of Pathology and the Health Service Executive have introduced new protocols<sup>7</sup> and information leaflets to provide a developing support service to the bereaved. However, the Working Group was concerned that these changes do not appear to have been introduced consistently across all hospitals and the diversity in relation to information sharing, and liaison with relatives and next-of-kin is still problematic.

3.6 Clear and comprehensive information leaflets giving information relating to the purposes of a post-mortem examination, the requirements for authorisation, and the potential use of retained tissue and organs for medical education and research, should be distributed as widely as possible. The Working Group considers it important to achieve consistency in best practice through standardisation of national protocols and professional guidelines. As stated above, significant changes have been made to pathology and hospital practices since 2000 and much progress has been made by the Faculty of Pathology, the HSE, and bereaved parent representative groups, in putting in place the necessary support structures for bereaved families. As a result many information leaflets have already been devised and should currently be available in all hospitals. However, further development of these leaflets in light of the Madden Report and the Report of this Working Group should be carried out by a committee comprising of representatives from the Faculty of Pathology, clinicians<sup>8</sup>, social workers, the Health Service Executive, and family representative organisations. These leaflets should be standardised on a national basis and readily available to any person from whom authorisation for a post-mortem examination is sought.

3.7 The information leaflets should advocate that individuals who wish to authorise post-mortem examinations after their death should discuss this with their close relatives before death. It was not within the remit of this Group to recommend the means by which this may be achieved, as this is a health promotion matter properly dealt with by the Department of Health and Children and Health Services Executive.

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<sup>7</sup> A protocol is a policy or strategy which defines appropriate action in specific circumstances. It also covers the adoption by all staff of national or local guidelines to meet local requirements in a specified way.

<sup>8</sup> A clinician is an expert clinical practitioner who specialises in clinical work as opposed to laboratory-based studies. Clinical staff include all medical, midwifery and nursing staff who cared for the deceased during life and after death.

Information sheets dealing with the nomination of authorised representatives should be standardised and made available across all hospitals.

3.8 Authorisation forms for each category of post-mortem examination, i.e. adult, paediatric and perinatal<sup>9</sup> should also be standardised. In exceptional cases a facility should be made available for verbal authorisation to be given and witnessed.

3.9 Most of the difficulties described by parents and next-of-kin in recent years relate to lack of information, failure to ensure that families were aware of what was happening to their relatives, and a lack of sensitivity to the need of families to be involved in decision-making after death. Although the level of information made available to families has generally improved in recent years, it is also crucial that educational and training curricula should provide adequate training in communication skills as well as the legal and ethical issues that arise in end-of-life care and bereavement. A senior clinician, preferably a consultant who knows the family or treated the patient prior to death, should discuss the post-mortem examination with them. This doctor is best placed to gauge the depth of explanation that the family requires and answer any questions they have. Where possible prior to discussion with the next-of-kin, this clinician should liaise with the pathologist<sup>10</sup> so as to give guidance to the relatives as to what organs might be retained and for what purpose and period of time. Bereavement counselling should also be available to assist families if required. Pathologists should be available to speak with families, on request, after the post-mortem examination.

3.10 In the submissions made to the Working Group, summarised later in this report<sup>11</sup>, no distinction was drawn by the authors between coroners' post-mortems and hospital cases. Although there is a significant difference in law in relation to the procedural aspects of these examinations, this difference is not always apparent and relevant to grieving families. Under the Coroners Act 1962 a coroner may direct a pathologist to carry out a post-mortem examination in order to establish the cause of death of the deceased person. It is an inherent part of this procedure that the deceased

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<sup>9</sup> The post-mortem examination carried out on stillbirths and babies less than four weeks old.

<sup>10</sup> A pathologist is a doctor who identifies diseases by studying cells and tissues using a microscope and other techniques.

<sup>11</sup> Section 8

person be formally identified. The Garda Siochana act as officers for the coroner in relation to the formal identification, and their presence and role in this context must be explained to next-of-kin who may not otherwise understand the involvement of the Gardai at this time.

3.11 The remit of the coroner does not extend further than an investigation into the cause of death and therefore the coroner cannot authorise the retention of tissue or organs for any other purpose. Families must be informed of the retention of organs, the purpose of the retention, and the duration of retention. This would enable families to make informed decisions regarding burial.

3.12 In some circumstances retention of tissue or organs beyond the remit of the coroner may be desirable in order to gain further information on some aspect of the deceased's condition which had no bearing on the cause of death but may have a hereditary aspect of relevance to the deceased's family or may be of interest for educational or research purposes. Such retention can only take place with appropriate authorisation by next-of-kin. The possibility of such retention should be discussed with next-of-kin as part of the information given in the coronial process. Clear protocols must be put in place between pathologists and coroners in relation to tissue retention.

3.13 The Working Group also expressed concern regarding the storage of retained organs. It is important to bereaved families that the dignity and respect shown to their loved ones during life would be maintained after death. Where organs are retained following post-mortem examination, these organs must be appropriately stored according to international best practice guidelines.

## **General Recommendations:**

1. Legislation should be introduced as soon as practicable to ensure that no post-mortem examination will be carried out on the body of a deceased person, and that no organ or tissue will be retained from a post-mortem examination for any purpose without knowledge and appropriate authorisation.
2. Clear and comprehensive information leaflets giving information relating to the purposes of a post-mortem examination, what happens at a post-mortem examination, the requirements for authorisation, and the possibility of tissue and organ retention for medical education and research, should be standardised and distributed as widely as possible across all hospitals and other relevant clinical sites, such as GPs offices.
3. Information sheets dealing with the nomination of authorised representatives should be standardised and made available across all hospitals. Standardised authorisation forms for each category of post-mortem examination, i.e. adult, paediatric and perinatal should be signed by the appropriate person. In exceptional circumstances a facility should be made available for verbal authorisation to be given and witnessed.
4. Education and training curricula should provide adequate training in communication skills as well as the legal and ethical issues that arise in end-of-life care and bereavement.
5. Clear protocols must be put in place between pathologists and coroners in relation to tissue retention. Families must be informed of the retention of organs, the purpose of the retention, and the likely duration of retention.
6. Where organs are retained following post-mortem examination, these organs must be appropriately stored according to international best practice guidelines.

#### **4. Post-mortem examinations on babies who died before or during birth**

4.1 Practices in relation to histopathological examination and the care of women and other next of kin who have experienced the death of foetuses<sup>12</sup> below the age of viability (currently 24 weeks gestation<sup>13</sup>) raise a number of difficult issues. First trimester or early second trimester foetal death and spontaneous miscarriages occur in a very high proportion of pregnancies. Although in many cases the cause of the miscarriage may remain unknown, it is important for the tissue from the pregnancy to be examined in order to look for abnormalities that might affect future pregnancies. In most cases this tissue will be made up of placental and uterine tissue and blood clots which will be examined microscopically. Sometimes a tiny embryo or foetal parts are found amongst the tissue. With the increasing use of suction curettage (which reduces the risk of uterine perforation) embryonic/foetal tissue is seen less often on gross examination.

4.2 Attitudes towards foetal death in the first and second trimester of pregnancy vary considerably and the point at which prospective parents think of their foetus as a baby with its own identity is not the same for everyone. Sensitive and open discussion with the parents is important to enable them to come to terms with their loss and also to answer their questions regarding future pregnancies.

4.3 Difficulties may arise in the context of early miscarriage where no identifiable remains may exist for burial purposes. Where there are foetal remains, these remains are buried according to parental choice either in a family grave or in the hospital plot.

4.4 Where parents have not made their own arrangements for burial or cremation, the disposition of tissue following pregnancy loss is dealt with according to clinical protocols and gestational age. There appears to be diversity in practice between general and maternity hospitals in relation to disposition. In general hospitals,

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<sup>12</sup> The unborn child before the age of viable life, currently set as 24 weeks in gestation.

<sup>13</sup> The period during which a fertilised egg develops into a baby



products of conception where there are no identifiable foetal parts are generally handled and disposed of as surgical specimens<sup>14</sup>. Until recently, in some maternity hospitals products of conception over a number of consecutive months were placed in coffins and cremated, with the ashes being buried in a hospital plot. Recent changes in regulations relating to burial and cremation adopted by the Dublin Cemeteries Committee will have an impact on this practice and have therefore been taken into account in the formulation of the recommendations in this report.

4.5 Even where there is no identifiable body or foetal remains, some parents who have had an early pregnancy loss may wish to bury remains. Their wishes should be respected and appropriate options as to burial should be made available to them. If parents choose not to bury the remains themselves, these products of conception where there are no identifiable foetal parts may be handled and disposed of by the hospital as surgical specimens. Parents must be offered information as to the practice in the relevant hospital and should be asked to make their wishes known to the hospital within one month of their discharge from hospital. Appropriate resources need to be put in place in hospitals to support compliance with this recommendation.

4.6 There is no specific statutory regulation of examination of foetal remains in Ireland. It is unclear whether the foetus would come within the definition of a 'person' as it has not achieved independent existence. In *McGeehan v National Maternity Hospital, Stanley and Rafter*<sup>15</sup> the question arose as to whether the Plaintiff was entitled to take an action as a dependent under the Civil Liability Act 1961 on behalf of her child who was stillborn in the National Maternity Hospital in 1991. Section 48(1) of that Act provides that where the death of a person is caused by a wrongful act such that that person, if he had survived, would have been entitled to take an action, then the dependents can bring an action. Section 58 provides that the law relating to wrongs applies to an unborn child for his protection in the same way as if the child were born, provided the child is subsequently born alive. Kearns J held that the only interpretation of the Act is that 'no such wrongful action is deemed in law to take place where the child is not born alive'. However, he also stressed that he was not deciding the issue 'on the basis that the child was not a person and in any way

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<sup>14</sup> Samples of tissue

<sup>15</sup> (High Court 21/4/04 Kearns J.)

was to be regarded in any way less than any other citizen, whether born alive or, tragically in this case, as a still birth.’

4.7 The lack of clarity relating to this issue may lead to difficulties in relation to the authorisation of a post-mortem examination on a foetus. The jurisdiction of the coroner in relation to stillbirths<sup>16</sup> and miscarriages<sup>17</sup> is dealt with in the proposed Coroners Bill where ‘body’ is defined as including stillbirths and foetuses, thereby enabling a coroner to investigate the death. The Working Group expressed concern in relation to potential problems that may arise in this regard, such as where a foetus is returned to Ireland for burial from another jurisdiction. This proposed position differs from that taken in Northern Ireland where the coroner has no jurisdiction unless there has been a live birth. From discussions held with the representatives of the Coroners Society, the Working Group understands that coroners would not expect to be involved in such cases where the death took place outside of the jurisdiction. However, the Working Group agreed that specific provision should be made in legislation to define the circumstances in which a post mortem examination of a foetus or stillbirth may take place in both coroner’s and non-coroner’s cases.

4.8 The Stillbirths Registration Act 1994 defines a stillbirth as a child born weighing 500 grammes or more having a gestational age of 24 weeks or more who shows no sign of life. Maternity hospitals have policies in place to provide information and support to parents in such situations as well as where there has been a miscarriage. The issue arises as to whether both parents should be informed regarding the options about burial or cremation of foetal remains or whether it is sufficient to only seek the views of the woman. If the parents are married, both will be legal guardians of the child and it would generally be best practice for both parents to be informed regarding the options. If the parents are unmarried, the mother is the sole legal guardian. In these circumstances, rules of confidentiality<sup>18</sup> dictate that a man cannot be contacted in this regard without the permission of the woman.

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<sup>16</sup> A child born weighing 500 grammes or more having a gestational age of 24 weeks or more who shows no sign of life.

<sup>17</sup> Loss of pregnancy of less than 24 weeks gestation.

<sup>18</sup> Rules which govern limitation of disclosure of a patient’s medical information

4.9 In the past, infants and children who died in hospitals outside of the Dublin area were sometimes transferred to one of the Dublin paediatric hospitals for post-mortem examination. This is now a relatively infrequent occurrence but in some cases it could have an added value to have a specialist pathologist carry out the post mortem examination or it may be a referral from a coroner. This might include situations where the baby shows signs of abnormalities or complex cardiac problems, which are within the special expertise of a pathologist at a particular maternity or paediatric hospital. If only the organ is sent for examination, then the parents may choose to proceed with the funeral. Current practice indicates that due care and attention is paid to ensuring that parents are given the necessary information and choices in this regard, and that the body is transferred appropriately. However, there appear to be no written protocols in place for acceptance of bodies or organs by the receiving hospital.

**Recommendations:**

1. Where early pregnancies do not result in identifiable foetal remains, the products of conception are sent for examination to a pathology laboratory as part of the routine care of the mother. Some parents who have had an early pregnancy loss may wish to bury these remains. Their wishes should be respected and appropriate options as to burial should be made available to them. If parents choose not to bury the remains themselves, these products of conception where there are no identifiable foetal parts may be handled and disposed of by the hospital as surgical specimens. Parents must be offered information as to the practice in the relevant hospital and should be asked to make their wishes known within one month of their discharge from hospital. Appropriate resources need to be put in place in hospitals to support compliance with this recommendation.

2. Where miscarriage results in identifiable foetal remains, an examination of these remains requires authorisation. Parents must be given appropriate options in relation to burial/cremation of such remains. If the parents choose to have the burial/cremation carried out by the hospital, they must be offered information in relation to the burial/cremation practices in the relevant hospital. Parents may choose to be informed when the burial/cremation has taken place. All records must be maintained.

3. In cases of second trimester loss or stillbirth, identifiable baby remains are present in almost all cases and authorisation for hospital post-mortem examination is required. Where parents wish to make their own funeral arrangements, the hospital should facilitate this as far as possible by giving parents relevant information and contact numbers. Where parents choose a hospital burial, the hospital will make the necessary arrangements. Records must be maintained by the hospital, the funeral directors and the cemetery.

4. The preparation of tissue blocks<sup>19</sup> and slides<sup>20</sup> is an integral and important part of post-mortem examinations in both adult and perinatal cases. Current guidelines<sup>21</sup> from the Royal College of Pathologists list minimum blocks for histologic<sup>22</sup> sampling in examination of stillborn infants and neonatal<sup>23</sup> deaths.<sup>24</sup> Some families may object to the removal and retention of even the smallest amount of tissue. Unless they have indicated that they do not wish to receive information, it must be made clear to those from whom authorisation is sought that, in the absence of a specific objection, the preparation of blocks and slides will be regarded as part of the authorisation given. If there is an objection by the family to the preparation of blocks for histologic examination, the pathologist may decline to perform the post mortem examination. Provided a valid authorisation is given, these blocks and slides may be retained and subsequently used for legitimate educational and research purposes by the hospital.

5. The practice in relation to the transfer of infants between hospitals for post-mortem examination should be informed by and subject to written protocols to be put in place by any hospital to which bodies or organs are transferred.

6. Irrespective of the location of the parents, all necessary steps must be taken to ensure that no post-mortem examination takes place without valid authorisation.

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<sup>19</sup> Small pieces of tissue, usually measuring 2.5 x 2 x .75cm, are embedded in paraffin wax and stored in boxes.

<sup>20</sup> Shavings of tissue blocks about 1/100<sup>th</sup> mm thick, mounted on glass slides. The glass slides are stained in various ways and placed on the microscope for examination.

<sup>21</sup> Statements which help in deciding how to treat particular conditions

<sup>22</sup> Histology is the science concerned with the study of the structure, compositions and function of tissues under a microscope

<sup>23</sup> A term used to describe the first four weeks after birth

<sup>24</sup> Guidelines on Autopsy Practice – best practice scenarios 9 and 10 (June 2006) Royal College of Pathologists, London

7. All necessary steps must be taken to provide the parents with information as to the results of the post-mortem examination and a copy of the post-mortem report. This can be arranged locally if appropriate or the parents may wish to travel to meet the pathologist who carried out the examination.

8. Legislation should clearly set out the circumstances in which a post-mortem examination of a foetus or stillborn child may be carried out in both coroner's and non-coroner's cases.

### **5. Post-mortem examinations on adults**

5.1 A hospital post-mortem examination may be suggested by a doctor to confirm or clarify the nature and extent of the disease suffered by the deceased person, their response to medical treatment, and the detailed cause of death. The post-mortem examination may yield new information about the deceased's condition, which may be of benefit to family members as well as to future patients.

5.2 Current practice obliges doctors to seek consent from next-of-kin prior to carrying out a hospital post-mortem examination. The informed consent model mandates the disclosure of information to next-of-kin relating to the purpose of the post-mortem examination, details of the examination, retention of tissue samples and organs where necessary, and options for release of the body and organs. Some families may find this information disturbing.

5.3 The authorisation model put forward in the Madden Report facilitates those who are prepared to allow a post-mortem examination to take place but do not wish to be given further information about the process of carrying out a post-mortem examination. It enables them to authorise a post-mortem examination to be performed and the hospital to undertake any appropriate action during/following that examination. It also allows further information to be given at any future time should it be sought by the next-of-kin. This model ensures that next-of-kin are given as much information as *they* decide they wish to have and are given the opportunity to ask

whatever questions they feel necessary. If they choose to refuse to authorise the post-mortem examination, they do not need to give reasons for their refusal.

5.4 The preparation of tissue blocks and slides is an integral and important part of post-mortem examinations in both adult and perinatal cases. Current guidelines from the Royal College of Pathologists list minimum blocks for histologic sampling in post mortem examinations.<sup>25</sup> Some families may object to the removal and retention of even the smallest amount of tissue. Unless they have indicated that they do not wish to receive information, it should be made clear to those from whom authorisation is sought that, in the absence of a specific objection, the preparation of blocks and slides will be regarded as part of the authorisation given. If there is an objection by the family to the preparation of blocks for histologic examination, the pathologist may decline to perform the post mortem examination. Provided a valid authorisation is given, these blocks and slides may be retained and subsequently used for legitimate educational and research purposes by the hospital.

5.5 Authorisation should be given in writing. In exceptional cases authorisation may be given verbally in the presence of two witnesses.

### **Recommendations:**

1. The Working Group agreed that legislation must be enacted to ensure that no hospital post-mortem examination is carried out on the body of a deceased adult without valid authorisation.

2. There is no current legal provision that enables an adult to authorise a post mortem examination in advance of his or her own death. The policy of legislation in this context should be that a competent adult may while alive authorise the carrying out of the post-mortem examination. If the deceased has duly given such authorisation, there would be no legal obligation on the hospital to seek authorisation from next-of-kin. However, if next-of-kin of the deceased have strong objections to a post-mortem

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<sup>25</sup> Guidelines on Autopsy Practice – best practice scenario 1 (January 2005) Royal College of Pathologists, London

examination, the hospital should discuss this in detail with them and consider whether or not to proceed with the examination.

3. Authorisation should be given in writing. In exceptional cases a facility should be made available for authorisation to be given verbally in the presence of two witnesses.

4. The legislation should provide that the competent patient may nominate a representative who is authorised to make a decision in relation to post-mortem examination on their behalf in the event of their death. All competent adult patients should be asked to identify a nominated representative on admission to hospital. Patients and nominees should be made aware that this is not just for contact purposes but that this nominee may have important decision-making powers in the event of the patient's incapacity or death. The nominee does not have to be a relative or spouse but must be adequately informed and willing to undertake this responsibility. It is recommended that an information leaflet be made available to patients and nominated representatives on admission to hospital.

5. In the absence of a personal directive or a validly appointed representative to authorise a post-mortem examination to be carried out on the body of the deceased, the hospital must take all reasonable steps to locate relatives of the deceased. The legislation should provide that in such circumstances authorisation must be sought from the deceased's next-of-kin who should be ranked according to the following hierarchy:

Spouse/partner\*

Parent/child

Brother/sister

Grandparent/grandchild

Stepfather/stepmother

Half-brother/half-sister

Step-brother/step-sister

Child of brother/sister

Long standing friend

Relations in the same rank have equal rights. If there is disagreement amongst those of equal rank, the post-mortem examination should generally not be carried out.

\*Recognition of partners as of the same rank as spouses provides a means by which the reality of family relationships may be accorded due weight. If, for example, a deceased man is survived by an estranged wife and a current partner, the views of both should be taken into account though it is arguable that the view of the current partner should be given precedence as the person closest to the deceased. Legislation should be enacted to define and/or register appropriate partnerships within this category. Further specification on the definition of such relationships is part of a wider social debate and outside the remit of this Working Group.

6. Standardised information booklets and authorisation forms should be used in all hospitals in the State. The information available to next-of-kin must clearly state the following –

- The purpose of the post-mortem examination;
- The necessity to conduct an internal examination;
- Information as to the removal and examination of organs and tissue;
- Preparation of blocks and slides to be kept as part of the deceased's medical record;
- The necessity in some cases to retain organs for further examination;
- Retention in some cases of organs/tissue for medical research and educational purposes;
- Options in relation to delaying the funeral until the examination has been completed;
- Choice of means of burial or cremation of organs and tissue following examination.

7. For those who do not wish to discuss the information listed above, their choice must be respected. If they refuse authorisation with or without further discussion, their refusal must be respected. If they give authorisation, this is based on their



understanding that the hospital will carry out a post-mortem examination and will carry out any procedures it considers necessary and appropriate as part of that post-mortem examination. Next-of-kin must be given the information booklet to take away with them and must be told that they can return for discussion/further information at a future time.

## **6. Post-mortem examinations on minors**

6.1 In relation to medical treatment to be carried out on minors who have not reached the statutory age of consent, the question arises as to the extent to which their decision to give or withhold consent should be respected.

6.2 The Child Care Act 1991 defines a child as a person under the age of 18 other than a person who is or has been married. It does not specify the legal position in relation to medical consent but Section 24 provides that where there are court proceedings relating to the care and protection of a child, the court shall regard the welfare of the child as the first and paramount consideration and, insofar as is practicable, give due consideration, having regard to his age and understanding, to the wishes of the child. It is not clear how this might relate to medical treatment and the extent to which the wishes of the child might be considered in this regard, though it is possible that a court may take the view that it falls within the meaning of 'care and protection'. However, it is difficult to extend this interpretation to include a post-mortem examination after death of the child.

6.3 Section 23(1) of the Non-Fatal Offences against the Person Act 1997 states that a person of more than sixteen years can consent to 'surgical, medical or dental treatment' and that the consent of his parent or guardian is not necessary. 'Treatment' is defined in section 23(2) as including 'any procedure undertaken for the purposes of diagnosis<sup>26</sup>' and 'any procedure which is ancillary to any treatment as it applies to that treatment'. It is not clear from the Act whether persons under sixteen may also give a legal consent, as the language used in the section does not appear to be

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<sup>26</sup> Identification of an illness or health problem by means of its signs and symptoms. This involves ruling out other illnesses and causal factors for the symptoms.

prohibitive of this. There have been no reported cases on this point in Ireland to date. Again, it is difficult to interpret this section as including a post-mortem examination.

6.4 In an English case, *Gillick v West Norfolk and Wisbech AHA*<sup>27</sup>, a similarly worded provision was interpreted as meaning that a person aged less than sixteen years can give consent provided that s/he has ‘sufficient maturity to understand what is involved’. This means that, in the UK, in a situation where medical treatment is proposed for a young person under the age of sixteen years, the doctor must make an assessment of the competence and maturity of the patient. This assessment must look at the patient’s understanding of their condition, the proposed treatment, and the consequences of the decision that is made.

6.5 It is often presumed by medical practitioners in Ireland that the courts in this jurisdiction would adopt a similar interpretation of the comparable Irish statutory provision to that taken in the *Gillick* case. However, the provisions of *Bunreacht na hEireann* 1937 must be also considered in this regard. The personal rights of privacy and bodily integrity recognised by Article 40 of the Constitution apply equally to children as to adults. Thus a minor may argue that his or her consent to or refusal of treatment must be respected. However, the question of whether respect for the autonomy of the minor would interfere with the rights of the family under the Constitution has not been considered by the Irish courts in this context to date. In *North Western Health Board v W (H)*<sup>28</sup>, the Supreme Court upheld a decision by parents of a young child to refuse a screening test designed to discover whether the child might have a metabolic disorder. The majority of the Court took the view that where the constitutional family exists and is discharging its functions as such, and the parents have not failed in their duty towards their children, their decisions should not be overridden by the State other than in exceptional circumstances such as an immediate threat to life. The applicability of this case in the context of a conflict between a mature minor and his or her parents is difficult to assess.

6.6 Where it is proposed to carry out a post-mortem examination on a deceased child, this must be authorised by the child’s parents or by the coroner in an appropriate case.

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<sup>27</sup> [1986] AC 112

<sup>28</sup> [2001] IESC 90

The question arises however as to whether a person can give their own authorisation in advance of death, and how that might apply to mature minors. Although it is likely to be a rare occurrence, where a mature child/minor authorises a post-mortem examination to be carried out after their death, the Working Group agreed that in principle this decision should be respected by law. This would currently appear to fall outside of the statutory provisions described above and should be addressed in any legislation enacted in this area. Where no such decision is made by the minor, the authorisation of such an examination lies in the hands of the parents.

6.7 A further difficulty arises in the context of minors who have miscarried or given birth to a stillborn child or a baby who dies during birth. It may be considered advisable for a post-mortem examination to be carried out in order to provide further information in relation to the cause of death and future reproductive decisions of the mother. The question then arises as to whether or not the law recognises the minor as having legal capacity to authorise such an examination to be carried out on her child. As stated above, the Non-Fatal Offences against the Person Act 1997, section 23(1) states that a person of more than sixteen years can consent to ‘surgical, medical or dental treatment’ and that the consent of his parent or guardian is not necessary. ‘Treatment’ is defined in section 23(2) as including ‘any procedure undertaken for the purposes of diagnosis’ and ‘any procedure which is ancillary to any treatment as it applies to that treatment’. It does not state whether a person under sixteen can consent to their own medical treatment or a medical procedure to be carried out on their child. There is also the difficulty averted to above, that a post-mortem examination does not easily fit the definition of ‘medical treatment’ either as provided in the Act or as it is commonly understood in everyday language.

6.8 This area of the law has not been specifically addressed by legislation or case law but the Working Group is of the view that the minor who gives birth to a child would be considered under the Guardianship of Infants Act 1964 to be that child’s legal guardian, irrespective of her age. This would enable her to make decisions in relation to that child, subject to considerations of maturity and the welfare of the infant. It is not clear whether that status would be affected by the circumstances of a miscarriage or stillbirth, i.e. the fact that the infant had not achieved independent life.

6.9 The Working Group is of the view that by extension of the principle that mature minors should be enabled to make decisions in relation to a post-mortem examination to be carried out on their own bodies after death, a mature minor should also be enabled to authorise a post-mortem examination on her deceased child.

6.10 The Working Group was conscious that the law in this area is unclear and that best practice in most instances will be to include reference to the minor's parents where appropriate. However, this may not always be possible in circumstances where the minor is estranged from his/her parents or objects to their participation in the discussion and decision-making process.

### **Recommendations**

1. Legislation should provide that a person aged between 12 and 16 years may authorise a post-mortem examination of their own body after death and the removal and retention of organs for purposes of diagnosis, education and research. It should be presumed that the minor is competent to make such a decision unless there is evidence to the contrary.
2. Legislation should provide that where the mother from whom authorisation is sought for a post-mortem examination on a deceased child or stillbirth or miscarriage is below the age of sixteen, it should be presumed that she is competent to give such authorisation unless there is evidence to the contrary.
3. The Working group recommends that it should be considered best practice to include the young mother's parent/guardian in any discussion of post-mortem examination on herself or her deceased child.

### **7. Coroner's Post-Mortem Examinations**

7.1 The Working Group met with representatives of the Coroner's Society of Ireland in order to discuss issues of mutual interest. This meeting was very helpful in clarifying certain issues of concern to the Group and highlighting areas that require legislative change.

7.2. In a coroner's case the first contact with the family usually takes place in the hospital where the post-mortem examination is to take place on the body of the deceased person. There is a designated person, usually a senior member of the nursing staff or a social worker, in each hospital who will discuss the post-mortem examination with the family. A member of the Garda Siochana will also be present on behalf of the Coroner to receive formal identification of the deceased. The presence of the Garda for this purpose must be explained to next-of-kin. The coroner's service relies on the expertise and co-operation of pathologists who carry out post-mortem examinations and a good working relationship between both is essential.

7.3 Although the coronial jurisdiction in relation to post-mortem examinations does not require the authorisation of the next-of-kin of the deceased, it is important that information about the post-mortem examination be given to bereaved families. The provision of such information must be handled with sensitivity and respect. Although information booklets are generally provided by the coroner's service to hospitals, these booklets should be seen as supplementary to and not a replacement for personal interaction with appropriately trained support staff. The Working Group took the view that a family liaison officer should be available to bereaved families in the hospital where a coroner's post-mortem examination is to be carried out. Responsibility for the appointment and training of such officers must lie with the coroner's service, which must have oversight of protocols for the provision of information to families.

7.4 Families must be informed that a coroner's post-mortem examination has been directed, and the likely timeframe within which the body and any retained organs will be released for burial. Unless they indicate that they would prefer not to receive further information, they must be offered information in relation to the purpose and conduct of the examination, and tissue and organ retention practice. They must also be offered information as to the options available to them in relation to burial/cremation of the organs on completion of the examination.

7.5 The retention of organs for education or research purposes following a coroner's post-mortem examination is outside of the coroner's jurisdiction and can only be done with the authorisation of the deceased's next-of-kin. The possibility of retention for

such purposes should be included in information leaflets and relevant authorisation forms should be provided to bereaved families where appropriate.

7.6 The Coroner's service is of crucial importance to bereaved families as well as to the public at large.<sup>29</sup> The investigation of the cause of death is of critical value to families of the deceased, as well as being a fundamental element of our criminal justice system. Public awareness of the significance of the coroner's role should be improved by the provision of educational information on the functions of the coroner.

7.7 The Working Group strongly supports the necessity for reform of the coroner's service and recommends that the proposed Coroner's Bill be enacted as soon as practicable following consultation with relevant stakeholders.

### **Recommendations:**

1. Information leaflets must be available to all bereaved families where a coroner's post-mortem examination is to be carried out. These leaflets must explain the functions of the coroner, the conduct of a post-mortem examination, retention of tissue and organs for purposes of ascertaining the cause of death, release of the body to next-of-kin for burial, options in relation to the timing of the release of retained organs for burial, the possibility of retention of tissue and organs for education and research, and details of support services available to families in these circumstances. Such leaflets are already commonly available in most coroners' districts but their future revision would benefit from collaboration with family representative groups and social workers trained in bereavement counselling.

2. Family liaison officers should be available to all bereaved families where a coroner's post-mortem examination is to be carried out. These liaison officers must be trained in bereavement counselling and be able to provide information, advice and support to bereaved families in relation to the conduct of the post-mortem examination and the coroner's service. Responsibility for the appointment and

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<sup>29</sup> See Council of Europe Committee of Ministers Recommendation (99)3 on the harmonisation of medico-legal autopsy rules.

training of such officers must lie with the coroner's service, which must have oversight of protocols for the provision of information to families.

## **8. Submissions**

A total of 7 submissions were received by the Working Group. Not all submissions related to the Terms of Reference. All submissions related to deaths prior to 2000. A summary of each relevant submission is provided below with the anonymity of each family protected.

**Submission A:** This related to a twin pregnancy in which one of the babies was stillborn. The parents were told that the baby died because the umbilical cord was around the baby's neck and that there were otherwise no abnormalities. The baby was shown to the parents after birth and had a normal appearance. The parents felt that a post-mortem examination was unnecessary given that the cause of death was known. After the controversy surrounding organ retention broke, the parents contacted the relevant hospital and were told that a post-mortem examination had in fact been carried out on their child. They were later given a list of retained organs and tissue and the hospital apologised for the hurt and distress caused to the family. The parents sought and received the organs and blocks and slides retained at the post-mortem examination and reburied them with their child.

The parents did not suggest specific recommendations in relation to the drafting of legislation on this issue but wanted some measures to be put in place to ensure that the events they described would never happen again.

**Submission B:** This submission related to the death of an elderly man whose family subsequently discovered had his heart and brain retained at post-mortem examination. The submission states that the family were opposed to a post mortem but were informed that they had no choice as the deceased's doctor was not contactable. It is not clear from the submission whether this was a coroner's case. The author of the submission describes the distress and hurt experienced by the family when told some time subsequent to the death that the deceased's heart and brain had been retained.

The author seeks information relating to the purpose for which the deceased's brain was retained, whether it was used for education and/or research and how it was disposed of. No specific suggestions are made in relation to legislative action.

**Submission C:** This submission relates to a stillborn infant. The author submits that it should be a criminal offence to remove and retain organs without consent. The law should make clear reference to stillborn children as their position is otherwise ambiguous. Legislation should be enacted to ensure that the organ retention controversy cannot happen again.

The author submits that consent must be explicit and that parents must have the option of agreeing to whatever level of examination they are prepared to accept. Organs must remain the property of next of kin and their agreement must be necessary prior to any further use.

**Submission D:** This submission related to the death of the author's mother in the early 1960s. The deceased's husband reported having felt coerced into consenting to a post-mortem examination. The author assumes that organs were retained but was never given any further information as records appear to be unavailable for that time.

The author submits that the recommendations in the Madden Report should be applicable to all categories of post-mortem examinations. Babies not born alive should be treated in the same way as those born alive who subsequently die. It is submitted that minors (described as 18 year olds) should be treated the same as adults as regards making decisions. The author queries what happens when deceased person has no next-of-kin.

It is submitted that it is necessary to have protocols and legislation in place prohibiting the use of human body parts for any purpose without informed consent by deceased themselves or their next of kin or representative. The main point of this submission is in relation to ownership of the body and decision making. Legislation should make clear that we own our bodies prior to death, and subsequently our representatives own them. The State or doctors should not have any right in relation to



the body for post-mortem examination or use for research purposes. The same principle applies to pituitary glands.

The author submits that the consent process should not begin on the same day as death. The importance of post mortems should be promoted as a public health education topic by dissemination of leaflets, posters in waiting rooms and other appropriate public places. There should be a similar system of request as is used for organ donation, particularly if the deceased's wishes are known.

It is submitted that coroners' legislation must prohibit retention for any purpose other than establishing cause of death. Next of kin must be informed in lay language and invited to choose means of burial, even of blocks and slides. The author does not believe that medical students should be enabled to attend post mortems as this is undignified for the deceased and his/her family. However, a family representative should be allowed to attend along with another qualified person to act as informant for the family.

**Submission E:** This submission related to a stillbirth. The mother recalls signing a consent form for post-mortem examination but was later told there were no forms used at that time. She was given the opportunity to hold the baby prior to post mortem and was asked to bring in a bonnet to the hospital. She was given the result of the examination verbally. Some years later she contacted the hospital in relation to the possibility of organ retention; it confirmed that organs were retained. She met a social worker and pathologist at the hospital and was given a list of retained organs and the post mortem findings. She was informed that photographs and footprints had been taken. She collected the organs from the hospital for burial as well as photos and footprints.

The author remains dissatisfied with the answers she received. She does not make any specific suggestions in relation to legislative change.