

L'Hôpital de Montréal pour enfants The Montreal Children's Hospital Centre universitaire de santé McGill McGill University Health Centre

Deciding about Autopsy A Guide for Parents and Legal Guardians



Perinatal, Neonatal and Pediatric Autopsy

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We are sorry for the loss of your child. We understand that this is a devastating time for you and it may be difficult for you to consider an autopsy. This booklet aims to help you to understand the reasons for doing an autopsy and gives details about what happens during the examination and the value it can have for you. Staff from your child's treating team (medical doctors and other professionals) will give you all the assistance and support they can while you take the time to make this important decision.

What is an autopsy?

An autopsy (also called a post-mortem examination) is a careful medical examination that is done after death. It is the best possible way to understand how and why your child died. Later in this booklet you will find details and explanations about the different types of autopsies.

Why should I consider an autopsy for my child?

An autopsy is the last possible way to find out how and why your child died. An autopsy can detect medical problems that other tests your child had were not able to show.

In cases where your child died after being sick or staying at the hospital:

- An autopsy is the best way to understand important details about the cause of your child's death
- · It may find medical problems that other tests cannot show
- It may find a genetic disease (a disease that comes from one or both parents, that you may not know about), which could affect your other children or future pregnancies
- It helps the treating team better understand your child's disease and may help other children with similar problems.

In cases where your child died during pregnancy or around birth:

- It may help explain what happened during your pregnancy
- It may help tell you about conditions that will guide your care for possible future pregnancies
- · It may tell you about a condition in your child that could affect your other children

In cases where your child was born in critical condition or admitted to the Intensive Care Unit (ICU):

- · It may tell you important details about your child's illness or cause of death
- · It may find a condition in your newborn child that could affect your other children
- It may help the treating team better understand and give better care to other children born with similar conditions

Sometimes the autopsy will not tell you the cause of your child's death but may still help the treating team rule out other medical conditions or inherited diseases that could affect other family members or future pregnancies.

Making your decision about an autopsy

Your spiritual and cultural beliefs

Families from many different cultural and religious backgrounds agree to autopsies. However, before deciding, you may want to talk with your spiritual advisor, share your feelings with your family or friends, or speak with your doctor or treating team about your concerns. In most cases, it is possible to make arrangements that meet your needs and help you understand what happened.

Your child's body after an autopsy

After the autopsy is completed, and your child is dressed, you usually cannot see any marks from the autopsy. You can plan for an open casket at the funeral or organize a family viewing. Autopsies do not affect the face and other body parts that you will be able to see during a viewing. In some cases, (especially if your child died after an accident or during pregnancy) your child's body may have marks that can make viewing more difficult.

Funeral planning

Generally, doing an autopsy will not delay funeral arrangements. Talk to your spiritual advisor or funeral director about the timing of the examination and how it may affect your plans for a funeral or a spiritual or religious ceremony.

Who will do the autopsy?

The autopsy will be done by a doctor from the Montreal Children's Hospital (MUHC Glen site) called a pediatric pathologist. Pathologists are fully qualified medical doctors with special training and expertise in diagnosing diseases in babies and children. The pediatric pathologist usually has help from one or more assistants like anatomical pathology technicians and residents.

Sometimes, medical students and other healthcare professionals may attend an autopsy as part of their medical school training.

Where is the autopsy done?

The autopsy is done in the post-mortem examination room of the Department of Pathology (MUHC Glen site).

When will the autopsy be done?

The autopsy will be done during office hours from Monday to Friday, excluding holidays, and usually within 1 to 2 (sometimes 3) working days after your child's death.

Consenting to an autopsy

Except in coroner cases, the parent or parents of the child who died can decide whether or not to have an autopsy done. You must sign a consent form before the examination takes place. You will have the power to decide on all the details of an autopsy for your child.

The options for types of autopsies are:

- Complete autopsy (also called an unrestricted or standard autopsy)
- Partial autopsy
- · External examination of your child (the team will only look at the outside of the body)
- No autopsy

You can find out more about what happens during an autopsy on page 6.

How long will it take to get the results?

Autopsies are very complex procedures. When the cause of death is very easy to see, the autopsy report may be available within 6 to 8 weeks. In more complex cases, the pathologists need more time and may ask for the expert opinion of other specialists or do other highly specialized tests. In that case, the report can take up to 6 months to finish. The pediatric pathologist who did the autopsy often discusses the results with your child's treating doctors and speaks regularly with your child's healthcare team.

Who will explain the results to me?

In most cases, the hospital doctor who cared for you or your child will go over the autopsy results with you after the autopsy report is ready. If you wish, you can also speak to the pediatric pathologist who did the examination.

What happens in an autopsy?

(Some details may shock you or be uncomfortable to read)

There are 3 types of autopsy:

Complete autopsy

The usual way to do an autopsy is a complete (unrestricted) autopsy. This type of examination gives the best chances to find out the cause of death. It starts with an external examination, like a physical exam of the body done by your doctor. It is followed by an internal examination with evaluation of all internal organs (body parts).

To do the internal examination, the pediatric pathologist needs to do surgical "cuts" of the skin, usually two or more. The pediatric pathologist will take small pieces (samples) of each organ to look at under a microscope. After taking samples, the pediatric pathologist puts the internal body parts back in the child's body right away. Some organs such as the brain and heart may be kept longer to do more detailed examinations.

After the autopsy, your child's body will be put back as it was before, and the cuts will be closed.

The pathologist takes pictures to record important findings. The complete autopsy may also include special tests, like medical imaging (for example, X-rays, CT scans or MRIs), genetic investigations and microbiology (to check for infections). Small amounts of tissue may be frozen and kept for future genetic testing if your medical team thinks it's necessary and only if you agree. These special tests are done to have a better chance of finding all the diseases affecting your child.

Partial autopsy

The partial autopsy (or limited autopsy) includes an external examination (outside of the body) and a partial internal examination (inside of the body). In the internal examination, the skin is cut to look at and take samples of only the organs that you agree the pathologist can look at more closely. Some examples are a single organ like the heart or the brain, a body system like the respiratory system (nose, throat, lungs) or one area like the chest or stomach. The partial autopsy may include different imaging tests like X-rays, CT scans or MRIs, and pictures.

Note: A limited autopsy may give less information than a complete one. However, depending on what happened around your child's death, it could give enough answers to specific questions about your child's illness. Your doctor is often able to help you make the right decision about which organs (internal body parts) are most important to look at to answer specific questions.

External examination only

If you choose this option, your child's body will be looked at and measured from the outside only. Medical pictures will be taken, as well as different medical imaging tests if needed, like X-rays, CT scans or MRIs. The pediatric pathologist will not cut the skin, and no organ inside your child's body will be touched or removed. There will be no examination of your child's organs with a microscope.

Note: This examination gives less information. It may help to answer specific questions, but only in a very small number of cases.

Why we might keep organs longer

Sometimes, certain organs are kept for a longer time. This is usually the case for organs like the brain, which needs many weeks before it can be properly examined by the specialized neuropathologist (a pathologist of the brain).

If you agree, organs we keep are disposed of by cremation according to our hospital policy, with dignity and respect to the law. They can also be returned to your funeral home once the examination by the specialist is completed.

You may also ask that after the samples are taken, all organs be put back in your child's body during the autopsy. Your specific wishes will be clearly shown on the consent form.

Note: Please tell your doctor if you do not want us to keep whole organs for detailed examination and write this on the consent form. You need to understand that this may limit the chance to get information about your child's illness. If your child had a disease that affected the brain, it is recommended to consent for the pathology team to keep the brain for longer.

What happens to tissue samples after the final autopsy report is completed?

In complete or partial autopsies, small pieces of tissue are kept and examined under a microscope by a pediatric pathologist. These small samples (in the form of pathology blocks and microscopic slides) are kept in a safe place in the pathology department in accordance with hospital policy and according to National guidelines from the Canadian Association of Pathologists. These blocks and slides will be available for you and your treating team if needed for future tests. If you decide that you want these blocks and slides back after the autopsy report is available, please tell the Department of Pathology so you can arrange to take them.

References

From the Canadian Association of Pathologists guidelines

A guide to the autopsy

 <u>https://cdn.ymaws.com/cap-</u> acp.org/resource/resmgr/guidelines/1 medical expert/1guide to the autopsy.pdf