

Autopsy Information for Parents

Information About Autopsy

To simplify wording in this booklet, 'child' refers to your fetus, baby, child or teen and 'parent' is parent or guardian.

What is an autopsy?

An autopsy is a careful examination of your child's body after death.

Who is asked to consent to an autopsy?

Doctors at our hospital ask all parents whose child died at the hospital to consent to autopsy. This includes those whose child died during pregnancy or at childbirth. Having an autopsy is always the parent's decision except when the coroner is involved. (See pg. 4)

If your child died at home or another hospital and was cared for by a BC Children's & Women's Hospital doctor, your consent may be required for autopsy at the Oak Street site in Vancouver.

Why do you need to decide now?

Right now, it may be hard for you to think about whether or not you want an autopsy. This request is made now because an autopsy is most helpful when it is done soon after death.

If your child has a fatal illness, you may be asked about an autopsy before your child dies so that you have more time to think about it. Your decision will not change the care your child receives.

How can an autopsy help our family?

An autopsy may...

- **provide details about the cause of death.**
You may have talked with your doctor about your child's cause of death. An autopsy is a way of being more certain about the cause and about seeing how therapy and treatment worked, but it may not answer all the questions about the death.

- **help explain an unexpected death**
Having answers about an unexpected death can be comforting and help everyone cope better.

"When our baby was stillborn, the heartbreak was so over-whelming. We did not expect it at all. I had to know why. It helped to find out, through the autopsy, that many of our daughter's organs were affected. She wouldn't have survived long if she had been born alive. It still hurts, but at least we know what happened."

- **help answer questions you may have later**
After awhile, you may have other questions. Reading about the cause(s) of your child's death may help you understand what happened and why, which may be the reason your doctor requested that you consent to the autopsy.

- **help explain what may have happened during your pregnancy**

If your child died during pregnancy, you may need to know what happened and if it could happen again, especially when deciding about having another baby. Knowing the facts may also help to guide your pregnancy and newborn care.

- **find out about something you may have inherited**

It may not be clear if a genetic disease or a hidden birth defect was the cause of your child's death. An autopsy can help figure that out.

Making Your Decision

The information you need

Before you decide, you can ask to know just basics or about all the details on how the autopsy is done and what happens after.

Your spirituality and death beliefs

You may want to talk with your spiritual advisor before making the decision. Share your beliefs and feelings with others in your life.

Your cultural beliefs

Tell the doctor or team member about your cultural needs. Often it's possible to make arrangements so that your needs are met.

“Our tradition is to have the funeral immediately. We told the doctor that we would like an autopsy, but that we did not want to delay the funeral for 2 or 3 days. He made special arrangements to have the autopsy done early the next morning.”

Your plans

Talk with your spiritual advisor or funeral director about funeral timing or how an autopsy may affect your plans. Don't rush to plan events.

Your child's body

Once your child's body is dressed, you usually can't tell that an autopsy was done so you could have an open casket at the funeral if you wish. Sometimes, with damage during pregnancy or in an accident, your spiritual advisor or other team member may advise you that it's better not to view the body or have an open casket.

The location

All autopsies for Children's & Women's Health Centre of BC and Sunny Hill Centre for Children are done at the Oak Street site in Vancouver in a secure location.

Helping other families

What is learned from this autopsy may help find better ways to treat others and could help prevent future illness and disability.

“We thought long and hard about whether to go ahead with the autopsy. In the end, we decided that it was one way to honour our son's life. He was always helping others. We wanted to give him a way to continue helping.”

Restricting the autopsy

You can agree to autopsy but limit what can and can't be done. Your specific wishes will be clearly shown on the consent form. If retained tissues &/or organs need to be returned for burial or cremation later, there may be additional funeral home charges

“In our religion it is important for the body to be whole. But we really wanted to help others dealing with this rare heart condition. We decided to go ahead with the autopsy, but we didn't allow them to keep any tissues. Joel was buried according to our traditions and we felt that we helped other families a little bit by allowing the doctors to do an autopsy and take photographs”

Refusing the autopsy

You can say 'no' in the autopsy discussions. Don't agree to an autopsy if you don't want to. Your decision will be respected unless the coroner requests an autopsy (see page 4 for more information). You will need to sign if you refuse the autopsy. Make sure you keep a copy of the signed Autopsy form.

“I just couldn’t agree to the autopsy. I knew that it could help others, but it was out of the question. Our daughter had been through so much with her cancer treatment. I just wanted her to be left alone in peace. Our whole family needed that too.”

Frequently Asked Questions

When do I have to decide?

It’s important that you make this decision as soon as you can. A few hours, an afternoon or a day is what is suggested.

A family member, friend, or spiritual advisor can be with you as you decide. If it’s easier for you to use your home language, ask for an interpreter. Your doctor can ask the pathologist about special needs and/or get specific answers to your questions.

Do I have to sign to give permission?

Yes. A parent of the child who died must sign a consent form before an autopsy can be done and will receive a copy of the signed consent form to keep. Before signing, make sure you:

- understand the reasons for the autopsy
- know what will be done in as much detail as you want
- have all of your concerns answered
- have had time to talk to others about your decision
- feel comfortable with your decision

When will the autopsy be done?

Once you have consented, the autopsy is done in 2-3 working days. Some types of autopsy must be done very soon after death but your doctor will tell you if this is the case with your child.

Will the autopsy delay the funeral?

After the Autopsy Department gets the consent forms, every effort is made to do the autopsy right away so your child’s body can be transferred by the funeral home.

If, in your culture or religion, the body must be buried right away, tell your doctor or other team member. They will do what they can to help make

any special arrangements so your traditions are honoured.

Can we see our child after the autopsy?

Yes. The social worker can help you to see your child’s body before &/or after autopsy. Staff dresses your child’s body and takes him/her to a private Family Viewing Room where your family can be with and hold your child if you want to. Tell staff how long you will need.

You can also wait to see your child’s body at the funeral home. The funeral home can arrange a viewing before the funeral.

Who does the autopsy?

A doctor, called a pathologist, is trained in the nature and cause of disease and is in charge of the autopsy. A specially trained assistant or resident (doctor-in-training) may help. The pathologist supervises these helpers closely.

What is done in an autopsy?

(Caution: These details are graphic.)

There are clear rules to make sure that all staff are respectful in an autopsy. First, they check the outside of your child’s body and may take photographs and x-rays. They then carefully look at internal organs through a surgical cut. Organs, thin tissue samples and body fluid may be taken for testing. In most cases, the cuts are then carefully stitched.

Why keep some organs and tissues?

Organs and tissues are sometimes kept so:

- a detailed organ examination taking more time can be done
- health professionals and students can learn more
- researchers can use samples to find better treatments

The consent asks if organs or tissues can be kept. Your choices are:

- tell the hospital which organs may be kept
- say ‘no’ to organs being kept but still allow an autopsy
- agree that organs may be kept longer and/or used for educational or research purposes

What happens to organs that are kept?

All organs/tissues are kept in locked storage. Small tissue samples or slides may be kept for a long time. The identity and diagnosis are kept private.

When tests are finished or after 2 years, the organs are respectfully disposed of by the hospital or you can have the organs sent to your chosen funeral home for cremation or burial. The consent form has a section where you can say what you would like the hospital to do when the tissue or organs are no longer needed.

When do we get the autopsy results?

The final report is ready in 3-6 months but some brief results may be ready within 30 days. The final report is sent to the doctor who cared for your child. To discuss the results, make an appointment with your doctor, Medical Genetics counselor, or the pathologist.

It helps to talk over the report with a doctor because it's written in medical language. Also, reading the autopsy description may be upsetting so it may be better to hear the information from someone you know. Once you have talked to the doctor about the report, you can ask for a copy of it.

What if my child died somewhere else?

Babies or children who have died at local hospitals in the province, but who were cared for by C&W staff, may be brought to the Oak Street site for autopsy if a signed consent comes with the child.

Is consent for autopsy always needed?

No. When the Coroner orders an autopsy, parents' consent isn't needed. The law guides the Coroner to have the autopsy done.

What's a Coroner?

A coroner is a community member, appointed by the government, who must review certain types of deaths.

What deaths does the Coroner review?

The Coroner is responsible for reviewing all unnatural, unexpected, unexplained or unattended deaths. The Coroner then decides when to order an autopsy.

Is a Coroner's review an autopsy?

No. The Coroner's examination is on the cause of death. You may be asked to sign an autopsy consent and Coroner's examination if you and the doctor want answers to questions about your child's death.

How can we get information about a Coroner's investigation?

The Coroner contacts the family, when able, to discuss reasons for the investigation. The investigation's results may be shared with you only if the Coroner gives permission.

How can I get support?

Your family doctor and/or your C&W doctor can help with answering questions so you can make your decision.

Your family's spiritual advisor can help you to understand your religious or cultural requirements.

Chaplains offer support and counseling for people of all denominations and religions. Ask the hospital operator to page Spiritual Care.

The Family Resource Library has books & videos on children's grief & talking with siblings about death. BC residents can borrow books free of charge. Some Cantonese, Spanish, Hindi, Punjabi and Vietnamese material is available.

Email: famreslib@cw.bc.ca

Your social worker can provide counseling, assist with special arrangements for cremation and help find community support.

The Recurrent Pregnancy Loss program supports those who have had many pregnancy losses. Ask the hospital operator to page them.

Griefworks BC is a C&W provincial resource and referral centre for bereavement.

Contact them through www.griefworksbc.com