

# STEP BY STEP GUIDE



**Baby's Breath**  
**Souffle de bébé**

## SIDS/SUDC

When an infant or child dies unexpectedly, the death is investigated by a team of professionals including coroners/medical examiners, police officers, first responders, and pathologists. This can feel overwhelming and this brochure is meant to provide some information to help you and your family by providing an outline of what to expect and who to contact.

## LANGUAGE USED

Sudden Infant Death Syndrome or SIDS, refers to the unexpected death of an apparently healthy baby during sleep. Sudden Unexpected Death in Infancy (SUDI) includes SIDS but also refers to infants who are later deemed to have died as a result of infectious metabolic or cardiac disorders, suffocation, trauma and other causes. Sudden Unexplained Death in Childhood (SUDC) refers to the unexpected death of a child over the age of 3, that may occur while the child is sleeping or awake and engaged in normal activities.

## WHAT IS SIDS/SUDI?

By definition, SIDS is a diagnosis of exclusion. This means that if a cause of death is identified, that is given as the diagnosis and the child's death then no longer falls into the category diagnosed as SIDS. The goal of autopsy examination, conducted by the specialist physician, the pathologist, is to determine whether there are any medical conditions that can now be diagnosed and might provide more specific information. If, after a complete autopsy, no other cause of death or diagnosis can be made, this would be considered a SIDS-type death. Coroners and medical examiners classify deaths by manner of death and so a SIDS-type of case may be classified as "undetermined" cause of death. This means that a specific cause of death has not been identified; it does not mean that there is no need for further medical assessment and follow up.

# AUTOPSY REPORT

Autopsies take time to complete because they have to incorporate results of special testing and examinations. Many coroner/medical examiner systems have a formal review process which can prolong the wait for the autopsy report by the family and their care providers.

From a medical perspective, in Pediatric autopsies, a final report should be available to the family by 3 months after the death of their child; no report should be delayed beyond 6 months.

It is important for families and their care providers to have access to the pathologist's detailed final autopsy report, not just the diagnosis, so an MD can assess the conditions that have been evaluated and can arrange for appropriate referral and follow up. This timeframe is important as conditions that can lead to SIDS/SUDI maybe inherited and so other family members may be at risk.

To obtain a copy of the autopsy report on your child, the offices of the coroners/medical examiners for each province are listed at the Appendix (See Figure: 1) .

When you call, have your child's full name, date of birth, name of attending coroner and your child's coroner case number, if you have the latter. If you prefer that your family physician receive the autopsy report, then you can give permission for that. A template for request of an autopsy report may be helpful.



## **MEDICAL REFERRAL & FOLLOW-UP**

When a baby or a child has died unexpectedly, and a specific diagnosis has not been made after a detailed and complete autopsy, this should be considered an undiagnosed medical condition and all families should ask for and receive a copy of the autopsy report on their child so they can take that to their medical community care provider.

The care provider can use the complete autopsy report to explain to the family what was found and to determine how best to follow up medically with the family and make referrals to other specialists so that the parents and other family members can be assessed and counselled.

Care providers may find the separate Information for Care Providers brochure helpful. It has been suggested that many of the cases of apparent SIDS/SUDI may be due to undiagnosed cardiac arrhythmias - abnormal heart rhythm - and for this reason, it may be important to be seen in follow up by a pediatric cardiologist or a cardiologist specializing in cardiac arrhythmias - some provinces even have inherited arrhythmia clinics (See Figure: 2).

Your care provider can make this referral for you. If the final autopsy report suggests a possible cause of death, such as an infection or metabolic condition, your medical doctor can discuss this with you, and if there are concerns for an inherited condition, refer you and your family as appropriate.

## **GRIEF & BEREAVEMENT SUPPORT**

The loss of a child is one of the most difficult challenges a parent can face. Grief is intense and can lead to depression and anxiety. It is important to stay in contact with your family doctor so he/she can be a support.

Your doctor may recommend other grief and bereavement resources and can make referrals as needed. Some people prefer to find their own sources of support and a link to lists of resources, some SIDS/SUDI-specific and others not, is provided at Figure 3.

## APPENDIX

Figure 1:

### **Coroner's Office Provincial Links**

[Ontario Chief Coroner's office](#)

[Alberta Chief Coroner's Office](#)

[British Columbia Coroner's Office](#)

[Manitoba Coroner's Office](#)

[New Brunswick Coroner's Office](#)

[Newfoundland and Labrador Coroner's Office](#)

[Nova Scotia Coroner's Office](#)

[PEI Coroner's Office](#)

[Quebec Coroner's Office](#)

[Saskatchewan Coroner's Office](#)

## APPENDIX

Figure 2:

### **Provincial Arrhythmia Clinics Lookup**

Figure 3:

### **Bereavement Support Links**

Baby's Breath Canada

PAIL Network



GET THE HELP AND  
SUPPORT YOU  
NEED.

Contact Us

(888) 688-8884

PO Box 5005, St. Catharines, ON  
L2R 7T4

[info@babysbreathcanada.ca](mailto:info@babysbreathcanada.ca)

[www.babysbreathcanada.ca](http://www.babysbreathcanada.ca)



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