The first 48 hours: after your child has died

An information book for families, friends and support networks



SA Health

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Introduction

The death of a child is a very emotional and difficult time for a family, it is one of life's toughest experiences. It may have been expected after an illness, or have been a sudden loss. This book has been written to provide you with information to get through the first 48 hours and also contains information about how to access support in the longer term.

We acknowledge that every family will be unique in their needs and we encourage you to make choices with as much information, time and support as you feel is right for you.

Rights and Entitlements

It is important that you feel comfortable to ask all the questions, as you need, of the teams around you. You can also ask other support networks to find out information on your behalf.

What is an autopsy/post mortem and why might we need one?

The medical team supporting you and your child will have discussed the likely causes of your child's death. Sometimes things are not clear and an autopsy may be suggested to help understand why your child died. Your written consent for an elective autopsy is required and will be explained carefully. It is important to note your personal preference and choices.

Can I donate my deceased child's organs or tissue?

Organ and tissue donation may be possible. You can ask the medical team involved in your child's care about this if you would like to know more about it.

How will I get a death certificate for my child?

Certification of death will be provided by a doctor, unless your child is referred to the Coroner. The Funeral Director (refer to section - Arranging a Funeral) will register your child's death at the Department of Births, Deaths and Marriages and a copy of the certificate will be posted to you.

What does it mean to have the Coroner involved?

Sometimes the law in South Australia requires that certain circumstances of death be notified to the State Coroner such as: when the cause of death is unknown, accidental or traumatic death, death occurred within 24 hours of hospital discharge or if a child is in the guardianship of the minister. In these instances the Coroner will ask the medical team further questions. If there is a reason for a Coroner's Investigation/Case then your rights of time and access with your child's body will be restricted. You will be guided by the Coroner's representatives and medical team as to what access is possible, and they will have contact numbers for you to call if you have any questions throughout the coronial process. When the process is complete your child's body will be released to your chosen Funeral Director and you will have the opportunity to have time with your child's body.

After my child dies can I spend time with them?

Being with your child after s/he has died is a very personal time and you may be able to choose how and where you can spend time with them. There is no need to rush. It is important that you have the privacy, support and flexibility to make this time what you need it to be. You may choose to wash and dress your child or leave this task to the Funeral Director. You may ask for memory-making items like a lock of hair, photographs, hand and foot prints. You may have family, friends, spiritual, religious or cultural support people with you if desire.

If your child dies in hospital you and your family can stay with your child's body in either a private room if available or in a viewing room in a separate section of the hospital.

Rights and Entitlements

Communication

You may decide to take your child's body home for a time. This can be arranged with the Funeral Director. At home, your child's body will need to be kept cool with air-conditioning, a cooling pad or ice packs.

When you are ready, there are a number of options in preparing for your child's funeral. Your child's body can remain at home, at the Funeral Home, or your child's body can go temporarily to a Funeral Home for embalming/preparing before returning to your home. Wherever you spend time with your child's body, you will need to prepare for the separation, which can be an intensely emotional experience. You may prefer not to be involved or ensure you have support, such as family and friends, around at this time.

Will my child's death affect my Centrelink payments?

Centrelink payments are altered when a child dies and may change to bereavement payments. It is important that you notify Centrelink of the death of your child within fourteen days, or there may be implications for your payments. You may like to have a family member or friend support you.

Important things to remember

- It is ok to ask questions if you don't understand why something is happening, how to do something or want further information
- If you need to, write questions down as they arise so you don't forget them
- Being with your child after they have died is a very personal time and there are many options regarding how you may spend time with them
- After you have gone home you may contact the hospital, clinical supports or Funeral Director any time.

Talking to people about the death of your child can be challenging when you are trying to deal with your own grief. Following are some tips on how to manage communication around your child's death.

How can I explain what is happening to my other children?

It is recommended that you inform your other children of their sibling's death as soon as you can. Find a quiet, private place to talk with them if possible. Use simple, easy-to-understand language. Try to use the words 'death' and 'dead' rather than using words such as 'passed away,' 'asleep,' 'lost,' or 'gone,' as these words may confuse the child about what death really means. Remind them that being alive means breathing, talking, walking, eating, etc., while being dead means that all of these things stop. While children may not understand or express their feelings about death in the same way as adults, they might still understand it and develop coping strategies that are consistent with their level of development. Trust in your abilities as a parent to use the wording that will be most age appropriate.

It is natural to try to protect your children from the pain of a sibling's death. However, children generally want to know the truth and to talk about it. Talking with them about it will help them process their grief. Children may frequently ask questions about the death of their sibling. Answer these questions in brief truthful terms that provide both the understanding they are looking for and reflect your personal beliefs and values. This will help them to grieve and cope in a healthy way. Your honesty also builds their trust in you and reduces the likelihood for misunderstandings in the future.

Communication

How do I manage communicating with family and friends?

Sharing information with people in your support network can sometimes be overwhelming. You may feel like you need to protect them and therefore might not express your true feelings, or you may simply feel unable to talk to others for a time. These feelings are normal after the death of a child. You might like to designate someone to provide regular updates to others in your network to avoid added stress on you. In selecting such a person you might look to someone you can trust and be honest with. It might also be helpful to share your immediate needs with these people, as often family and friends are wanting to help but are unsure how to assist you.

When someone has said something that is upsetting to me, how can I respond?

Many families report experiencing someone saying something to them that is hurtful or upsetting. It is important to remember that people generally are trying to be kind and usually have the very best intentions. What people say might be guided by their own beliefs, experiences or what they feel might be helpful to hear. Sometimes people just simply don't know what to say and might say something completely inappropriate. It is important not to take what people say personally and you do not need to take on board what is being said. If someone does say something inappropriate, have a plan for what you will do. Examples of what you may do include walking away or politely making people aware of what is and isn't helpful to hear, or specify what your needs may be.

How do I manage my social media pages following my child's death?

Many people use social media (e.g. Facebook, Twitter, blogs etc.) to stay in touch with family and friends. Although you might have used these sites to provide updates on your child's health, knowing how to manage them after their death can be difficult. While some people choose to avoid all social media immediately after their child's death, others use these sites to notify people about it. There is no right or wrong way to manage these sites. It is important to remember though that you are unable to control other people's comments on such sites and these may cause you additional distress. If you wish to maintain your social media presence, you could consider using your designated person to provide updates on your behalf.

Who do I need to contact?

It is important to decide who should be notified immediately following the death of your child (i.e. your main supports). You do not need to be responsible for informing everyone. As mentioned previously, you may like to arrange for someone in your support network to do this on your behalf. Some of the people/ organisations you may like to consider informing include:

- Family doctor or clinic
- Other health professionals involved in your child's care
- Your own Counsellor or Therapist
- School
- Recreation Clubs
- Work and colleagues
- Medicare/Private Health Fund
- Centrelink

Arranging a Funeral

Some people want to organise most of the funeral themselves, while others prefer a Funeral Director to guide and support them. Funeral Directors are there to carry out your wishes, so choose a provider you feel comfortable with. You can find Funeral Directors listed in the telephone directory or online. Hospital chaplains can also provide a list. Ask the Funeral Director about such matters as viewing your child's body, the location of preparation, service options of your child's body, and conducting the service. You may want a friend/relative to do this for you initially. Fees for a child's funeral can vary so it is important to make enquiries about this to suit your needs and financial circumstances.

What are the legal requirements around my child's funeral?

The Funeral Director or the Cemetery Authority will provide you with several forms that you must complete before the funeral. Generally the Funeral Director will assist you with completing the required forms to obtain a death certificate. The death certificate will then usually be sent to you in the mail. As previously mentioned, you may keep your child's body at home if there is no Coroner's process.

Can I take my deceased child in my car?

You can transport your child's body in your car, but regulations require that they be in a closed coffin or casket before entering burial grounds.

If I would like my child's body to be buried what do I need to know?

If you choose a burial, this generally takes place in an approved cemetery. You or your Funeral Director will need to ask the cemetery about the lease time for the plot, the cost for this and a headstone.

A burial can occur outside of a recognized cemetery under certain conditions. It is recommended that you check with your local Council that they permit burial outside of a cemetery, if you wish to explore this option.

What is a natural burial?

Natural burials are an environmentally sustainable alternative to the traditional burials. It involves preparing your child's body without the use of chemical preservatives (no embalming) and burying your child using eco-friendly materials.

If I would like my child's body to be cremated what do I need to know?

If you choose cremation there are no restrictions on what you do with the ashes. You might decide to scatter them in a significant place, place them at the cemetery or keep them at home.

What are some symbolic acts that I could include in my child's funeral?

You can create a service that meets you/your family's particular needs in honouring your child's life. It can be important to include siblings in this. Some bereaved families choose to engage in commemorative acts throughout the service such as:

- releasing of helium filled balloons, doves or butterflies
- including family and friends (by undertaking a reading, singing or playing music)
- lighting candles
- playing music that has a special meaning to you/your child/family
- decorating the coffin (e.g. with photos, painting, stickers)
- displaying photos and favourite items, recording names of those present in a decorated book
- asking people to wear a favourite colour.

Support

After the death of a child you may experience a broad range of emotions. In other circumstances these emotions might appear to be inappropriate or irrational. However, in this instance they are likely to be a completely appropriate emotional response to the loss of your child. If you are unsure in any way about your feelings or are struggling to cope, there are a range of professional support networks available to you.

What can I do if I or other family members are finding it difficult to cope?

If you already have a Counsellor or Therapist in your local community it might be a good time to re-engage their support. Alternatively, your GP can organise a Mental Health Care Plan, which entitles you to 6 sessions Medicare funded (which can be extended further if required) with a Psychologist or a registered Mental Health Practitioner.

You might also like to make contact with one of the relevant support agencies listed at the end of this book, with whom you may already have a relationship. If you have any worrying thoughts or thoughts of harming yourself or others, then you should seek help immediately.

Emergency support contact details

As mentioned previously if you have any worrying thoughts or thoughts of harming yourself or others, then you should seek help immediately. You can make contact with the following at anytime:

Lifeline on 131 144. This is a 24 hour emergency telephone service.

Mental Health Triage (formerly ACIS) on 131 465. This is a 24 hour mental health triage service which can link you in to the appropriate mental health service.

Your nearest hospital emergency department.

Closing Note

Remember, make sure that you look after yourself and allow others to support you during this time. Many decisions need to be made so it is important to be gentle with yourself and to take the rest, comfort and nourishment that you need.

Useful Resources

Support organisations who may be able to provide assistance within the first 48 hours

Anglicare SA

Provide grief and loss counselling to families affected by the loss of a loved one.

Ph: 08 8131 3400 9:00am – 5:00pm Monday – Friday www.anglicaresa.com.au

CanTeen

Counselling and youth support for young people affected by a personal or family cancer diagnosis. Ph: 1800 835 932 9:00am – 5:00pm Monday – Friday Phone counselling available 10:00am – 10:00pm AEST weekdays and 11:00am – 6:00pm AEST weekends www.canteen.org.au

Childhood Cancer Association

Bereavement support to families affected by the death of a child from cancer. Includes funeral financial assistance, counselling and support groups. Ph: 08 8239 2211 9:00am – 5:00pm Monday – Friday www.childhoodcancer.asn.au

HeartKids

Practical and peer support for families and young people affected by childhood heart disease. Ph: 08 8269 3122 9:00am – 5:00pm Monday – Friday www.heartkidssa.org.au

RedKite

Practical and emotional support for families affected by the death of a young person aged under 24 years by cancer. Ph: 1300 722 644 8:30am – 6:30pm Monday – Friday

www.redkite.org.au

Road Trauma Support Team of SA

Individual and group-based support for individuals affected by road trauma including bereavement. Ph: 1800 069 528 www.roadtraumasupportsa.com.au

SANDS

Miscarriage, stillbirth and newborn death support. Ph: 1300 072 637 Available 24 hours a day, seven days a week www.sands.org.au

SIDS and Kids SA

Crisis response, Counselling and bereavement support to families affected by the sudden and unexpected death of a baby or child up to the age of seven, during pregnancy, birth or infancy regardless of cause of death. General enquires: 08 8332 1066 Emergency Crisis response: 1300 799 656 (Available 24 hours a day, 7 days a week) www.sidssa.org

Women's and Children's Health Network

Online information regarding grief support following the death of a child. www.wch.sa.gov.au

If you feel you are in immediate danger and cannot keep yourself safe, present to the Emergency Department at your nearest hospital.

For crisis support please contact one of the following organisations

Beyond Blue

Telephone support. Ph: 1300 224 636 Available 24 hours a day, seven days a week

Kids Helpline

Telephone counselling for children aged 5-12 and young people 13-25 years.

Ph: 1800 55 1800 Available 24 hours a day, seven days a week

Lifeline

Telephone crisis support. Ph: 13 11 10 Available 24 hours a day, seven days a week

Mental Health Triage Service (formerly ACIS)

Main entry in accessing mental health services in South Australia.

Ph: 13 14 65

Available 24 hours a day, seven days a week

Notes	
INOLES	

For more information

Paediatric Palliative Care Service Women's and Children's Hospital 72 King William Road North Adelaide SA 5006 Telephone: 08 8161 7994 cywhs.pallcare@health.sa.gov.au www.wch.sa.gov.au

SA Health and the department will make every effort to Interpreter provide you with an interpreter in your language.



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