A little lifetime

A Booklet for parents and families whose babies have died around the time of birth

ISANDS
Irish Stillbirth & Neonatal Death Society
 Printed 1984

Reprinted 1997

Published by ISANDS

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ISANDS 1997

ACKNOWLEDGMENTS

ISANDS would like to thank the many parents who have shared their experiences with us and
without whom "A Little Lifetime" would not have been possible.

We would particularly like to acknowledge the work of the founding committee of ISANDS and
Dr Kevin Connolly who put together "A Little Lifetime" in its original form.

We have endeavoured to ensure that this revised edition has maintained the high standard set in
the first publication while incorporating the advances which have taken place in the last 13 years.

We are grateful to the professionals and members of ISANDS who read the text and offered many
helpful suggestions. We acknowledge the assistance of the Health Promotion Unit, in the
Department of Health, in funding the printing of A Little Lifetime'.

Finally we would like to remember our babies whose little lifetimes was inspirational to us in our
task of revising this booklet.

"Grieving After The Death of Your Baby"
Jenni Thomas & Nancy Kehner
A little lifetime

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whose babies have died
around the time of birth

DEDICATION

This booklet is dedicated to Cassandra, Catherine, Frances,
Jenny, John, Megan, Sarah, Stephen, Susan
and all other babies who died around the time of birth
Each year in Ireland approximately 500 babies die around the time of birth. As a result a large number of parents, brothers and sisters, grandparents and friends are bereaved.

In recent years there has been much better realisation of the trauma caused by these deaths. There have been major improvements in the care given in hospitals to families bereaved by such a death. We are more aware that everyone's grief is different. However, there are still problems. Parents find it very difficult to make any sense out of the death of their baby. Not only has their baby died, their future child has also died. Most of us feel uncomfortable when faced by a crying parent. We find it hard to know what to say to children when their baby brother or sister has died. One parent said recently “I want to talk and talk and talk about it but no one wants to listen”.

This booklet will be a great help not only for grieving families but also for anyone who comes in contact with these families. It will help us realise that the death of a baby is a huge tragedy, that grief has to be worked through, that there is no time scale for this work to be completed and that everyone's grief is different.

Kevin Connolly
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Co. Galway
"A Little Lifetime" is a booklet written and produced by the Irish Stillbirth and Neonatal Death Society (ISANDS). The Booklet came about as a result of the sharing of the experience of grief and loss by a number of parents whose babies had died either through stillbirth or neonatal death. Using the knowledge they gained from their experiences, they put together "A Little Lifetime" to help other parents in a practical way and to guide them through the days, weeks and months ahead.

"A Little Lifetime" is distributed mainly through hospitals and is given to parents who have been told that their baby has died before birth or is not expected to live for very long after birth. Very often when parents receive "A Little Lifetime" they are still in the initial stage of shock and it may all seem a little unreal but it is essential that they have the information available to them as soon as possible.

ISANDS (The Irish Stillbirth and Neonatal Death Society) is a voluntary support group for parents set up in Ireland in 1983. Since that time ISANDS has grown and continues to increase understanding and initiate improvements in the care and support given to parents whose baby dies around the time of birth. We have contacts who give help and support to parents by telephone and through our network of branches we organise Parents Support Meetings, Information Talks and Memorial Services. One of the original aims of the group was to introduce a Stillbirth Register to Ireland to bring it into line with other European countries. Following years of campaigning, this was finally achieved by ISANDS in 1994 and became law in 1995.

"A Little Lifetime" was first published in 1984. At that time there was little understanding of the needs of grieving parents. This Booklet has proved to be a valuable source of information and support to both grieving families and those caring for them. Many changes have come about since then, this is a tribute not only to the work of ISANDS but also to those who have made the changes possible.
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Part 1
Part One

A NOTE TO PARENTS

Everyone feels grief when someone who is very special dies. Grief is a process that a person must go through in order to adjust to a death. You have spent months forming a relationship with your baby during your pregnancy and now your hopes for the future will not be fulfilled.

Nothing will take away the pain and hurt you are feeling- nothing anyone can say will do that. We would like to share with you what we have learned from other bereaved parents about how they felt physically and emotionally, how they coped with practical details and what helped them.

You will have to deal with many feelings that are probably new to you. You will need to make decisions about naming and holding your baby, about funeral and burial arrangements, etc. It is important to take your time; the decisions to be made are yours.

The time you have to spend with your baby is short, remember you will have to create a lifetime of memories. We hope this booklet will help you make the most of this time.

This booklet has been written to help you now and in the difficult days, weeks and months ahead. It may be hard to read it all at once, we recommend that you read the sections you need at this time. Other sections may be of more interest and relevance to you later.

When you are told the news that your baby has died you feel that all your hopes, plans and dreams for this little baby have been lost. It is important to remember that your baby will always be part of your family, even if those plans and dreams cannot be fulfilled. This is still your son or daughter and nothing can ever change that.
HEARING THE SAD NEWS.

Nothing can prepare you for the nightmare of being told that your baby has died or will die shortly after birth. The plans and preparations for the birth of your baby are all shattered with a few words telling you the sad news. You may feel afraid or angry, frustrated or shocked. It is also common to feel emotionally frozen as hundreds of questions go through your head, the main one being very simply "WHY?".

There are many reasons why babies die either before or shortly after birth. The baby may be incapable of life outside the womb, there may be a congenital abnormality causing death before or after delivery or other complications such as eclampsia or lack of oxygen.

MISCARRIAGE

The death of a baby at any stage of pregnancy can be a very real loss to its parents and family. From the very start of your pregnancy you will have begun to include this new baby in your future plans. A precious life has been lost to parents whether you lose the baby through early or late miscarriage. This booklet has been written mainly for parents whose babies were stillborn or died shortly after birth - however if you have had a miscarriage, even if seeing your baby was not possible, you may identify with much of this booklet.

CONGENITAL ABNORMALITIES

You may have been told that your baby has a serious abnormality and will die during pregnancy or after birth. Conditions such as Anencephaly, Spina Bifida, Hydrocephalus and certain heart defects or Potters Syndrome may be detected by scan. It may help to find out more about your baby’s condition to prepare you for what to expect. When you are given such news it is normal to feel totally shocked. You may begin to ‘grieve’ for your baby even though he or she is still alive. You will have to consider telling family and friends the sad news and preparing for the birth and death of your baby. You
may need extra support for the duration of the pregnancy. Many parents have found that being aware of their choices and making some plans before the birth allowed them to spend as much time as possible with their baby when he or she was born.

**INTRA UTERINE DEATH/STILLBIRTH - when a baby dies before birth.**

You may have found out from a routine scan that your baby has died. You may have been worried and hoped that the scan would reassure you that your baby was alright. Very often the bad news is written on the faces of staff long before they say anything. Being told that there is no heartbeat confirms your worst fears. It is very hard to accept that the son or daughter that you have been expecting, the baby whom you already know, who has lived inside you for many months has died.

Your immediate reaction may be to want the baby delivered as soon as possible. The question of how and when your baby will be born is something which you should discuss with your doctor. It is usually safer to wait until you go into labour naturally. This may take some time and it may be difficult to accept but it will give you an opportunity to prepare for your baby’s birth.

Going home from hospital knowing that your baby has died and that you still have to give birth can be a very frightening time. Physically you may not feel or look any different at all, and it may be hard to accept that the scan machines were right. You will miss your baby kicking but you will still have gentle movements which can be confusing for you.

If you have other children and they knew of the pregnancy, try to explain what has happened. It is best to tell family and close friends about the baby so that they are aware of the situation. You may feel very sad and isolated, you may want to have somebody to talk to or you may want to be alone. It can help to talk to somebody who has been through a similar experience. You can contact I.S.A.N.D.S. at the telephone number listed at the back of this booklet.
In some cases labour has already begun and it is during a routine examination that it is discovered that your baby has died. Even with new technology and close monitoring by hospital staff there are babies who die during labour, just before or during delivery.

It is a very confusing time emotionally, trying to cope with the birth of your baby and the death of your baby at the same time. The fear of not knowing what to expect and what your baby will look like is normal. Don't be afraid to express your fears. When the baby is born you can ask one of the nurses to describe him/her to you (you might like to see a photograph first) and when you are ready you can hold your baby. When you see your baby for the first time, you will realise that you have given birth to your son or daughter. You will be able to see who he/she looks like and you may even experience joy at having given birth.

The time you have with your baby shortly after delivery is very precious. Hold your baby for as long as you like, look at every little detail. Although it may seem like an intrusion at this time, it is lovely to have some photographs of your baby shortly after birth. This is your baby, a baby that will never be replaced and will have a special place in your heart.

**NEONATAL DEATH - a baby who dies after birth**

It is very difficult to accept, in spite of advanced medical knowledge and modern technology, that babies are born with conditions which cannot be cured. Your baby's condition may be diagnosed during pregnancy or immediately after birth. Sometimes everything may seem normal for a time and you may be celebrating the birth only to be told that your baby will not survive.

**When your baby dies within minutes or hours of birth**

Some babies only live for minutes or hours after birth, giving you little or no time with your baby. Nothing can prepare you to face
the birth and death of your baby so close together. Disbelief, shock and a feeling of numbness cloud what you hear and feel. Even though you may not have had the opportunity to do all that you would have liked to care for your baby while he/she was alive, there is still time before the baby’s funeral to involve your family and other children to create some special memories.

THE INTENSIVE CARE UNIT
Seriously ill babies will be rushed to the Special Care Baby Unit and you may only get a glimpse of your baby before he or she is taken away. The staff will usually take a photograph of your baby and bring it to you as quickly as possible. It may be necessary to transfer your baby to another hospital. It is very distressing being separated from your baby, you may feel very isolated and helpless knowing your baby is so ill. The doctors and nurses will tell you what is happening and explain your baby’s condition. They will prepare you for what to expect when you first visit the unit - what your baby looks like, if he or she is attached to monitors and/or a ventilator and how his or her condition is being treated.

When you are ready to visit the unit you may feel very nervous and detached in such strange surroundings. It will be very warm and you may feel weak. The staff will explain the functions of the equipment and this can ease your fears. You may not be able to hold your baby straight away but you will be able to touch and talk to him or her. Where it is possible, you will be gently encouraged to hold your baby and help in his or her care. You may be nervous or afraid of hurting your baby and feel it is better left to the professionals. This is a normal reaction, however helping to care for your baby now will be an important memory for you in the future.

Sometimes, one parent may want to be in the unit with the baby all of the time, while the other is reluctant to see and get to know the baby. These are both normal reactions but this may be the only time you can share as a family while your baby is alive. Parents also worry about the effect on other children of bringing them to see their
brother or sister in the intensive care unit. Most children will not find the unit as frightening as adults. The staff will help you to explain to them about their brother or sister’s condition and answer their questions. Involving your children is very important. Their memories are precious too and they will always remember you wanting and helping them to be included. Spend as much time as you can with your baby and if possible include other family members so they too can take part in your baby’s short life. Try to have photographs taken of all the family together.

Going home while your baby is in the Unit
Going home without your baby, knowing that he or she could die at any time will be very difficult. The staff in the intensive care unit or nursery will assure you that they will contact you immediately should your baby show signs of deterioration. You can always contact them by telephone for a report or for reassurance day or night.

Your baby’s death
You may be anxious about how your baby’s death will occur, the doctor will explain to you what will happen. You may not have been able to hold your baby before because of the tubes and monitors connected to him or her, now some or all of the support systems may be removed so that you can hold your baby as he or she dies. You may want to be alone with your baby or you may wish to have family members present.

Unfortunately, if your baby’s condition deteriorates very quickly you may not have time to get to the hospital. Be reassured that your baby will not be alone, as the staff who have nursed him or her will be there. They too will be upset when your baby dies as they also got to know him or her. You might find it helpful to talk to them again at a later stage.

Bringing your baby home while he or she is alive
In some cases it is possible to take your baby home for a day, a weekend or for whatever time there is left. This needs to be given a lot
of thought as your baby may have special needs for his or her care. The staff in the unit will show you how to manage this special care. It is also helpful if you contact your public health nurse, who may be able to help in a practical way with the baby’s care and these visits will be a support to you.

Caring at home for a baby who is going to die is very hard and the isolation from all the support systems in the hospital may make it difficult to cope. The compensations on the other hand are very real, having your baby at home gives you the opportunity to do everything you can as a family. It gives you a chance to take photographs (and videos) in your own home making a little lifetime of memories to treasure afterwards.

Let family and friends know if you would like them to visit, they may be unsure of what to do and may appreciate knowing how they can help.

You may realise that your baby’s condition is deteriorating and want to take him or her back to the hospital, this is entirely up to you. If your baby dies at home it may be frightening, but it will be a very special memory for you to have. It may be possible, if there is time, to have someone that was part of his or her care there with you. When your baby dies you will need to notify the hospital or your family doctor. If you choose your doctor, he or she will need to certify that your baby is dead. A post-mortem may also be requested. You may still take your baby back to the hospital at this stage to help you with preparations for the funeral or you may decide to do this at home.

Take your time in making these decisions.
TWINS (and other multiple pregnancies)
Unfortunately, the risks attached to a multiple pregnancy are higher than those of a single pregnancy. The risk of early miscarriage of one or more babies is increased. The risk of premature birth is high, sometimes resulting in the death of one or more babies. Complications can arise very suddenly during a normal delivery resulting in the loss of one baby. There is also the possibility that one of the babies will die in-utero due to a variety of reasons. If this happens it can create a very distressing situation, where the mother will have to give birth to the baby who has died as well as a live baby at the same time.

If you have experienced the death of twins you may have the added difficulty of both twins having died at separate times. There may have been days or even weeks when one baby was critically ill and did not survive.

Death of one twin
Being told that one of your twins is dead is one of the most heart-breaking situations you will ever have to face. This may have happened, before, during or after the birth. You will feel a great sense of disbelief with a mixture of conflicting emotions being experienced all at the same time - relief for your surviving baby and immense sadness for the baby who has died. While you are caught up in the sadness of this event, you still have to face making plans for your baby's funeral - a task which may seem unreal, while your mind may be focused on the baby who has survived.

Think carefully about what has to be done. This is a very precious time and will be the only time that you will have with both twins. Remember to take photographs of both twins together if at all possible. This may seem unimportant to you at this precise moment, but in years to come it will be very important, not only to you, but also to the surviving twin.

Leaving hospital and facing home may bring added difficulties. Even though you have been through a funeral service and said
goodbye, this could be the first time that the whole extent of what has happened begins to sink in.

During your pregnancy you were expecting to bring home two babies and now, sadly, only one will have made that journey. Trying to cope with a new-born baby and grieve for your other baby may seem impossible. You may have a strong fear that this baby will die too. You may also have to cope with the situation where your surviving twin has special needs and will require long term care. Your loneliness and sense of isolation may also be increased by what others may say. Family and friends may think that you were “lucky” to have one baby or that “perhaps it was for the best”. But you know that having one twin alive and healthy doesn’t mean that you have no feelings for the baby who has died. Your emotions are real and it is important for your own sake to express them as often as you want.

On the other hand, because you have a surviving baby, you may find yourself blocking out these emotions completely. This may be possible for some time but you may find your grief will surface in the future. After all, you do have a constant reminder - a surviving twin. You will have to face situations in the future which will emphasise your loss i.e. birthdays, first day at school, etc. These occasions will always be tinged with some sadness. Seeing other twins may also remind you of what could have been.

If the anniversary of the baby’s death falls on the same date as birthdays, it is advisable to leave that day for your surviving twin. Perhaps you could visit the grave a day in advance. Your surviving twin should be made aware from an early age that he/she is a twin. Details should be given gradually over the years. Answer questions truthfully in a language that they will understand.

When both twins die
When both twins die you have suffered a double tragedy. They may have died at the same time or one twin may have lived longer. Your
feelings of grief for your baby who has died may have been sup­pressed while you hoped that your second twin would survive. Sadly he or she has died and your grief is further complicated. You may have had to go through two separate funerals and this will cause your pain to be more drawn out. Although you may have the added difficulty of two separate anniversaries it may help to remem­ber them together in a special way on their birthday.

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Whatever the reason for your baby's death, you will want to ask "why did it happen?", "could we have done anything differently?", "is it likely to happen again?". Your doctor will be able to answer some of these questions. If unsure don't be afraid to repeat ques­tions or to arrange another appointment as it is often difficult to take in all the information given. Preferably both parents should talk to the doctor.

You may feel less alone if you talk to parents who have lost a baby in a similar way. You can get in touch with them through ISANDS.

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**YOUR STAY IN HOSPITAL**

Your present situation probably seems very unreal. You were get­ting ready to welcome your new baby into the family, but now the baby will not be going home with you. Being on a ward surround­ed by healthy crying babies and happy parents can be very hard to deal with. You may feel very isolated. Hospital is a difficult place in which to feel at home, but do not be afraid to ask the staff for any assistance you may need. Although hospital staff will want to help, they may not always be sure how to go about it. Some staff may have difficulties in knowing how to communicate with you. They too are saddened by the death of your baby.
You should talk about your feelings as much as possible and inform a member of staff of any particular need that might help you through this very difficult time.

If you have had a normal delivery, you will probably be allowed home within a short time, possibly within 48 hours. If you have had a complicated delivery or surgery, your stay will be more prolonged. Discuss visiting arrangements with the staff, as you may not want to see anyone other than your immediate family for a few days.

**Seeing and holding your baby**

In the long term, it will help you both if you see and hold your baby because these memories are so precious. If you don’t wish to see your baby initially and afterwards change your mind, it is still possible for this to be arranged. If you finally decide not to see your baby, ask the nurse or doctor to describe him/her to you, or better still to obtain a photograph for you. It may also help if you have other children that they see the baby - ask them if they’d like to. Giving them a photograph to look at may help them to decide.

**Naming your baby**

Names are important. You will use the name as you talk about your baby to others. You will use it as you tell your other children about this special baby. You will find it easier to connect your memories to this baby if you can refer to him or her by name. Most people will have chosen a name beforehand. It is best to keep this name and not to pass it on to another baby.

**The Family; Sharing the Experience.**

The whole family was preparing for the baby’s birth and it is the whole family that experiences the baby’s death. These short few days will be the only time you will have together - so it is important that family members are encouraged to see and hold your baby and family photographs are taken.

You will also need time to be alone with your partner to make the necessary arrangements and to discuss your feelings with each other.
You may have already arranged a nursery or a special place for the baby, a placed filled with toys and clothes. Family and friends may offer to put these away before you get home, but this is a task you should save for yourself - for when you are ready. There is no ‘right’ time for tending to this. You will know yourself when it is time.

Telling your Children
Many parents worry about what to tell their children and how to help them when their baby brother or sister dies. Children should be told the news as soon as possible, otherwise they might feel excluded and rejected and there is always the possibility that they will hear from somebody else. Their imagination of what is being kept from them can be far worse than the reality. Try to give clear simple explanations of the baby’s death, appropriate to the child’s age - even the youngest child can understand some aspects of death. You don’t have to give all the details at once, they will ask more questions in their own time. It helps children if you are open and honest. That includes saying, ‘I don’t know’ when that is the honest answer to one of their questions. If children discover that they have been told something that is untrue, they become confused.

It is better not to say that God wanted the baby for Himself, as the child may think that God will want them or you too. To say “the baby has gone to sleep” can cause children to fear sleep. Children don’t necessarily show how they feel immediately. It may take them a while to begin to express their feelings, and they may still be talking about the baby and about what happened some months or years later.

Involving your children
It is particularly important that your children come to see you in hospital and assure themselves that you are alright. They may have been worried about you - all children sense sadness and tension and they usually know when something is wrong. It helps your children if you involve them in everything that is happening, this includes bringing them to see their brother or sister. This may be a
difficult decision for you but it will help them to understand what has happened. Every family is different. The choice of how you involve your children when your baby dies is yours alone, but the following are some points for you to consider:

* Children of all ages should be given the choice to see or hold the baby if they want to
* If the child does not want to see the baby ask if they would like to see a photograph,
* Children who have spent time with their baby brother or sister will have tangible memories to help them through their grief.
* Your child might have a toy or gift to give to the baby - this helps them to feel part of what is happening,
* Children can help pick flowers for the baby's funeral,
* Older children may like to take an active part in the funeral by participating in readings, music and poetry.

Fathers

While your partner is still in hospital you may feel very isolated and lonely. You will have to break the sad news to your family and friends and deal with many of the practical arrangements. Perhaps you could ask a close friend or relative to help you with these. There will be difficult decisions to make, if possible make them with your partner and take time to think about them. Decisions made together may prevent misunderstanding and resentment later. Initially you may find yourself suppressing your grief to a certain extent, however it is important that you express your own feelings of sadness and loss. Sharing your feelings with your partner will help her rather than make her feel worse.

You may also have to resume work within a few days and be expected to carry on as normal. You may be asked "How is your wife/partner?" and never asked how you are feeling or coping. This may be difficult for you but it is important to explain that you too are grieving. Spend as much time with your partner and baby as possible.
Lone Parents
Most of the information and suggestions in this book are given to help all parents but we are aware that you as a lone parent are on your own and have an even greater need of support.

Your feelings are not any different from parents who have a supportive partner but you may feel more alone and isolated. You may have to make decisions on your own - Take your time - don’t be afraid to ask for any help from the hospital staff; (social worker, chaplain or nurses) on creating some precious memories of your baby for you to treasure. Perhaps a family member or close friend could help you by taking photographs or buying something special for the baby to wear. They could also help you with decisions and arrangements for your baby’s funeral.

If your relationship with your partner ended during the pregnancy you may feel very lonely. You may feel a sense of despair that you will not be able to have another baby in the future. Talking to a social worker or counsellor can be vital to help you cope with the double loss - your relationship and now your baby.

Sometimes, during pregnancy expectant fathers opt out. Then when they hear of the loss they may wish to return to be involved in seeing the baby and in the funeral. This raises many complex emotions for women.

Young couples who do not live together can feel very strained, because they cannot be as close as they might have been if they were a married couple - talking to each other can help you understand the emotions you are experiencing and may ease the strain.

You may need to share your feelings as the days and months go by after your baby’s death. It can be very helpful to find support and someone you can confide in, maybe a close friend or family member, even if they did not initially welcome your pregnancy, may feel very sad now and want to help.
You will need to be able to talk about your baby and what you are going through. You can contact ISANDS for support, we can put you in touch with someone who has had a similar experience.

Photographs and Keepsakes
We cannot stress enough the importance of photographs as tangible reminders of your baby. These are best taken soon after birth. A member of the hospital staff will take Polaroid photographs of your baby as soon as possible after birth. It is advisable to have copies made as Polaroid photographs fade, (a photographer will be able to do this).

Later there will be more time to take your own photographs. Take some of your baby on his/her own - close ups, lying on side, being held in your arms, with brothers and sisters, all the family together. Ask a friend to have the film developed immediately, then if you are not satisfied with the quality of the photographs you can take some more. Black and white copies of these may be made later.

You can also take a close up photograph of your baby's hand being held in yours.

If your baby has an abnormality or has been dead for some time before birth you may feel unsure about taking photographs, the hospital staff will help you with this.

It may not always be possible, or you may choose not to take additional photographs, the following suggestions may help you to gather memories which will mean so much in the future;

* Scan photographs and/or fetal heart tracings (if available),
* Footprints and handprints of your baby/twins
* Your baby's identification bracelet,
* The weight and other measurements of your baby,
* Birth, death or stillbirth certificate(s),
* A baptismal certificate - if your baby has been baptised,
* A lock of hair,
* Something your baby may have worn or been wrapped in.
Stillbirth Registration
If your baby is stillborn and has a gestational age of 24 weeks or more or weighs 500g or more the birth will be registered in the Stillbirth Register. **You have the option to register the birth yourself, however you must do so within 42 days of the birth.** If you choose not to register the stillbirth the hospital is obliged to do so. Once your baby’s birth has been registered you are entitled to a stillbirth certificate.

Ask for the leaflet “How Parents can Register a Stillborn Child”

Post-mortem
Your doctor may request that a post-mortem be performed on your baby.

This is a careful examination of the internal tissue and organs of the baby with the hope of a better understanding of the cause of death. Sometimes babies look perfectly healthy and their appearance offers no clue to the cause of death. It is hoped that the internal examination would provide some information as to the cause of death, although in many cases it may not. The procedure may clear up uncertainties in your own mind and provide helpful information for you in planning future pregnancies. It may also help the medical profession to prevent similar deaths in other new-borns.

A post-mortem is usually done at the hospital by a pathologist. Most parents feel better if they know where the baby is being kept or taken for post-mortem, so don’t be afraid to ask. In some cases your baby may be transferred to another hospital for a post-mortem. You may need to sign a form granting your permission. If hospital personnel do not suggest a post-mortem, you have the right to request one.

The preliminary results of the post-mortem will be available within a short time. The final report may take a few weeks. Ask your doc-
tor to go over the results with you and if you have questions later on, don’t be afraid to ask for another appointment.

It is normally possible for you to see and hold your baby after the post-mortem.

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**SPIRITUAL AND RELIGIOUS CONCERNS**

Most parents, even those with no strong or particular religious affiliations, find it helpful to have some spiritual input. As soon as the staff are aware that your baby has died or is very ill, they will notify the pastoral care team. If you belong to a religion which does not have a chaplain attached to the hospital, a member of staff will offer to contact the appropriate minister or religious representative.

**BAPTISM**

For most Christian parents baptism is important. If your baby dies around the time of delivery you may like to baptise your baby or ask a member of the hospital staff or chaplain to do so. If it is clear that your baby has been dead for some time baptism is not necessary as the Christian Churches believe that baptism is only necessary for the living. However, there is a special service of blessing and naming a baby who has died before baptism.

**FUNERAL AND BURIAL ARRANGEMENTS**

You probably do not want to think about practical arrangements at this time, but unfortunately there are some things which have to be done, the most important of them being your baby’s funeral.

Usually a member of staff will discuss the various options with you. It is better if both partners can take part in these discussions. Lone parents might benefit from discussing arrangements with a family member or friend. Do not feel pressurised - if you are not sure what to do, leave the decision for a day or two. It is important that you
do not feel rushed into any particular arrangement. You may feel it is easier to make your arrangements when you go home, and you can then let the hospital know your decision. It may be possible to bring your baby home for a while before the funeral. Some hospitals give parents a list of choices available to them.

Prayer Service
A service can be held in the hospital chapel, local church or your own home. You may wish to hold your baby during the service, or you may lay your baby in the coffin or Moses basket. You may wish to include family and friends by asking them to read prayers, play music or arrange flowers. Your wishes, particular needs and customs will help you make these decisions. ISANDS have a leaflet available with suggested readings, hymns and reflections.

Burial Arrangements
You can purchase a coffin directly from the undertaker if you wish, although most hospitals will arrange this for you. Parents are often unsure of what arrangements to make to transport their baby’s coffin to the cemetery/crematorium. Funeral cars are not generally used. Perhaps you could ask a close family member or friend to drive you and your baby’s coffin can be held or placed with you in the back seat.

When making any of the following arrangements, you must let the relevant hospital staff know your plans and the time you or the undertaker will be collecting your baby. They will generally give you a mortuary certificate at this time.

1. Existing family grave
If there is a family grave, i.e. one used for parents or grandparents, you might consider using it. If the grave is full, it may be possible to place the baby’s coffin at the head or foot of it. You will, of course, have to get the family’s permission. You can make arrangements either with the cemetery staff yourselves or through an funeral
director or clergyman. It is necessary to get written permission from the cemetery and to arrange to have the grave opened.

2. New family grave
You may decide to buy a new family grave. A funeral director will be able to inform you about the availability of graves and the costs involved.

3. Cremation
It is possible to arrange for cremation at Glasnevin Cemetery in Dublin. As a baby’s bones are soft there are no remains following cremation. It may be helpful to discuss this with the hospital staff or a funeral director.

4. Holy Angels Plot
It may be possible to make arrangements through the hospital for you to bury your baby in one of the graves designated for babies who die around the time of birth.
A number of coffins are placed in each grave. It may be possible to have the baby’s name and date of birth added to the existing headstone for that grave. However, check with your local cemetery to see if it is possible to erect a personal headstone on the grave. The hospital arranges the burial with the undertaker and your baby is buried in what is usually called “The Holy Angels Plot”. The hospital will send you the bill for this service.

Personal involvement in preparing your baby’s funeral can be very significant. You may like to consider the following ideas that other parents have found helpful:

* wash and dress your baby
* use a special outfit or blanket for your baby
* remember your keepsakes - a lock of hair, footprints and handprints, photographs
* you may like to bring your baby home, for the prayer service, or overnight before the funeral
* consider putting birth/death notice in the newspaper

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* hold your baby one last time
* place your baby in the coffin yourself
* put a special toy or family photograph with your baby
* write a letter or poem to be placed with your baby
* carry your baby’s coffin yourself

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**MOTHERS: PHYSICAL SYMPTOMS AFTER BIRTH**

It seems very cruel that, although your baby has died, nature will take you through the same physical symptoms common to all women who have just given birth.

You will have a discharge called ‘lochia’ which can last for several weeks. At first, it will require a pad change every few hours. Each day the discharge should lessen and appear more brownish rather than the original red. If you attempt too much activity before your body has been given adequate time to heal, you will notice your flow increasing. Slow down and put your feet up. If it continues to get heavy and changes to a brighter colour after several hours rest, call your doctor.

If you had an episiotomy, i.e. a cut enlarging the opening of the vagina, you will be very sore for a few days while the stitches heal. A warm salt bath can be soothing.

Your breasts may fill with milk. Your body is preparing itself for nursing. The best way to stop the manufacture of milk is to prevent stimulation of the nipples. When you take a shower don’t let the water strike the nipples. You may find it helps to wear a tight fitting bra. If you have nursed a baby before, you may experience aching in your breasts, especially when you are around other babies. Engorgement of the breasts is painful so do ask the medical staff for advice.

Another problem common to many mothers is feeling the baby kick long after the baby has been born. A mother grows used to this feeling
throughout her pregnancy. Don’t be afraid of these lingering sensations.

If you have had a Caesarean section your hospital stay will be longer. You will feel stiff and sore for a while and will need to rest more.

Should you have any other physical problems and are not sure how to cope with them, contact your G.P. or the hospital.

Post-Natal Visit
You will be asked to see your doctor within six to eight weeks of going home. Ask for your visit at a time when you will not have to wait with expectant mothers or young babies. It is helpful if both parents attend this visit. Writing down your questions in advance will help you to remember them.

There are several reasons why it is important to have a post-natal check-up:
* Your physical progress will need to be checked. This is a normal procedure after any birth.
* You may want to go over the details of your pregnancy and delivery to try and understand the reasons why your baby died.
* If your baby had a post-mortem you will want to know the result, and if the same problem could occur in any future pregnancy.
* If your baby was born with a congenital abnormality you may wish to arrange to see the paediatrician.
* You may wish for advice on contraception.
* You may want to know how soon you can start another pregnancy.

There is, therefore, quite a lot to be accomplished by your follow-up visit. It may be difficult for you to go back to the hospital, but it is well worth going back and you may feel better after the visit, and if necessary it should be possible to make a further appointment. You may also like to talk to some of the staff who were involved in your baby’s care or to visit the Social Worker or the Chaplain.
Part 2
When your baby dies you will experience a number of confusing feelings. These feelings are the basis of grief, a normal process which you must go through following the death of your baby. You will have both physical and emotional symptoms. Though these symptoms are distressing and painful, they do not indicate that you are ‘going out of your mind’.

Always remember that there is a purpose behind the process of grief - to help you to come to terms with the death of your baby. This is not to say that the process will encourage you to forget. Rather it will help you to reach the stage where you can remember this experience, accept it, and then look to the future.

There is no ‘normal’ response to the death of your baby. Do not feel that you have to experience all the emotions and symptoms that are described. Do not worry that something is wrong with you just because you don’t behave in a certain way or experience a particular emotion. Though your emotions at this time may be more intense than any you have ever felt before, don’t be afraid of them. There is no particular time frame, for most people the process will take longer than they ever would have expected.

No one can ever measure one person’s pain against that of another, and yet the death of a baby can be the deepest loss that any person can experience. There are good reasons for this. You expect your parents to die, but you do not expect, in this day and age, that your baby will die. Your baby is an extension of yourself. Your role as a parent - to provide for, to protect, to nurture - has been left unfulfilled.
One big problem you will face with the death of your baby is the loneliness in your grief. No one else knew this person but you, the parents. Other people may think you had not got time to know the baby’s personality and character so you have nothing to grieve for. They may soon forget your baby’s impact on your life, while you will continue to remember.

**Emotions**

You will experience a whole series of emotions. They will not always occur in the order listed here: they will not always be felt with the same intensity; and sometimes they will be missing altogether. Some days you will feel quite well and other days you will find yourself down again. But it is important to realise that these feelings are normal.

The immediate reaction to being told that your baby is dead or will die is **Shock** - you may be numbed and it can take hours or days before the reality of the tragedy sinks in. During this stage you may not remember all you have been told - but do ask the doctor to go over details again until you are able to take it all in.

You may feel **Anger** - angry with the doctor who gave you the bad news, angry with God, angry with the baby who seems to have caused all the distress. You may also feel angry with yourself or your partner. This anger is a normal part of mourning and it is important to work through it.

You may feel **Guilt** when your baby dies. Many mothers blame themselves and go over and over their pregnancy wondering if something they did contributed to their baby’s death. You may worry that you did not initially welcome the pregnancy and this may have affected the outcome, but this, in fact, is not so. There was probably nothing you did or didn’t do that was any different from many other women whose babies did not die.
The next phase is usually one of Sadness and emptiness. The sadness may be very intense and you may cry and cry. This may not occur until after the baby is buried or for some time after you go home. It may hit you out of the blue, or may happen when you see or hear another baby, when someone asks how you are, when you see baby clothes or toys. The crying that occurs is an important way of releasing your sadness. Initially, you will cry a lot. With time, the sad phases and the crying episodes occur less often. But they may continue to occur for months. Don’t be afraid to cry. If you hold it all in, it will come out at a later stage.

Your family and friends may not know what to do when you cry. They may feel self-conscious being with you while you are crying and may not mention the baby for fear this may cause you to cry. You may feel self-conscious too, especially when the tears come without warning. But crying is okay. You can help them understand your need to cry and let them know that you are glad they are with you.

It is also good to cry with your partner and your children as they need to release their sadness.

Physical Symptoms of Grief
You may feel physically exhausted and have difficulty in concentrating. You may feel a heaviness in your chest, a need to take deep sighing breaths, palpitations, ‘butterflies in the stomach’ and aching arms. You may lose your appetite and have difficulty in sleeping, or be disturbed by bad dreams and nightmares. Most, if not all, of these symptoms are a part of the initial grief process and they will disappear with time.

You may be worried that your grief is too intense, that you are crying continuously and feel unable to cope with your day to day life. Talk to your doctor about your worries, you may be reassured that what you are feeling is normal, you may be prescribed medication to help in the short term or be referred for counselling.
Children and grief

Children’s reaction to death depends on their age and stage of development. Even very young children often understand much more than adults may realise, they will be aware of your sadness and distress even if you try to hide it. Older children will have a clearer understanding of what death means and their experience of grief is similar to that of an adult. It is important for parents to realise that sometimes their own grief leaves them unavailable to help and support their children. It may help them to talk to a relative or friend.

* Many children feel guilty that their brother’s or sister’s death must somehow have been their fault. Sometimes children don’t say that they feel responsible but may become very anxious and unhappy. It’s hard for them to explain the death to themselves in any other way. They may remember saying at some time, “I don’t want this baby”, or “I wish the baby would go away”. They need to know that thoughts like these cannot cause a baby’s death. They may need a lot of reassurance about this.

* It will help if you can talk to them about why your baby died, and if there is no known reason, explain this honestly.

* Children need reassurance that they are not going to die, that you are not going to die and that their normal, everyday life can go on. Some think that death may be ‘catching’ and become very fearful, especially if they get something like a cold or a stomach upset.

* Children can switch their feelings on and off. They can be sad one minute, happy the next but that doesn’t mean their feelings are not genuine or just as intense as yours.
* Children need to be able to show their feelings when they want to, talk when they feel like it, and ask questions (and get answers) when the questions come into their heads. Talking when you think there is a need to talk does not usually work so well.

* Older children will sometimes be reluctant to talk about the baby. They can understand the full extent of the death of their brother or sister and they will be going through their own grief. They may not want to upset their parents by talking about the baby. It is good for them to express their feelings and sometimes they may prefer to talk to a close relative or friend.

* Some children want to care for you as well as be cared for. Try to accept their love and support without asking them to be brave or grown up.

* Children need to understand how you are feeling (sad, upset, angry, irritable) and why. They need to know that you loved the baby, that you are missing the baby, and that the baby won’t come back. They also need to know that you love them, and that you are not sad, upset, angry or irritable because of them.

* Many parents find it extremely hard to support and care for their children while they are feeling so low and in need of support themselves. Grandparents, aunts and uncles and family friends could all help.

* It’s important to talk to your child’s teacher. It can help if children have the chance to talk in school about what has happened and if other children are helped to understand. There may also be times at school when your child needs someone to turn to - a close friend or teacher.

* Sometimes parents don’t get the chance or perhaps decide not to bring their other children to see the baby. These children will still
have feelings of grief and they may feel angry because they were not included. Try to explain why it was not possible for them to see the baby and help them to express their feelings.

* Even after some time has past you may help your child to make some memories. You could do something special together as a way of remembering. Perhaps you could both make up an album of photographs, flowers, cards, or drawings your child has done. You could assist them in planting a tree or flowers for the baby. Including them in this way can help them in their grief.

Grandparents
As a grandparent of a baby who dies, you will be grieving too. Not only for the grandchild that you will never be able to play with and watch grow, but also for your own child. Most parents never get over the desire to protect their children. There is probably nothing you would rather do for your child right now than to take away the suffering. It will be difficult for you to watch them take the death of their baby so hard and you will want to do everything possible to help ease the pain for them.

We have learned more about the grieving process in the last few years and you may find that things have changed a lot, especially if you or someone close to you experienced the death of a baby many years ago. Parents today, as well as grandparents and extended family, get the chance to see and hold the baby who has died. In the case where the baby is in a special care baby unit, grandparents are encouraged to see the baby in the unit. Being part of the baby’s life, no matter how short, is very important. Let the parents know that you are there for them if they need any help. Knowing that you are there to support them in any way will mean a lot to them at this time.

Talking about the baby is an important part of the grieving process and although it may be painful for you, it will mean a lot to the parents. In the years to come always remember to count the grandchild
who has died when talking about the number of grandchildren you have. Remember the baby’s birthday/anniversary just as you would if the child had lived. A card or a few words can mean a lot. Be aware that family occasions such as Christenings may be difficult for the parents of the baby that has died. Although you may feel helpless, your support will be appreciated now and in the future.

If you have experienced the death of one of your own children, and now the death of your grandchild is bringing back painful memories, you can contact ISANDS for support.

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**HOME, FRIENDS AND THE MONTHS AHEAD**

What about after you get home? The hospital environment may have contributed to a sense of unreality regarding your baby’s death. The reality of the situation will hit you hard when you get back to the familiar surroundings of home. The sense of loss will be more real, the pain of loss more acute, the reminders that your baby is ‘missing’ will be more obvious. You may have gathered together some baby things or even set up a nursery, and sometime later you may need to put these away. There is no right time for tending to this. You will know yourself when it is time. You may still feel somewhat distant or remote and you may find it difficult to settle back into your usual routine. Don’t worry about this. This adjustment will take time and it is neither wise nor helpful to burden yourself with tasks that you are not interested in.

Your family and friends will react in different ways. Ideally, a time of grief, such as this, is when the love and support of the family circle really come through and you will receive the benefit of that support. However, don’t be surprised at some responses from your family. They may feel embarrassed or uncomfortable when you talk about the baby. They may become impatient when you don’t ‘get over it’ quickly. They may suggest that you forget about the tragedy and start planning for your next child. All of these attitudes can be hurtful to you because they imply a lack of acceptance of your baby.
as a real person. They have not formed the attachment to your baby that you had, their grief will be less intense and therefore some of their actions and words will seem thoughtless and cruel.

It will be difficult to face going out for the first time as many people will be curious to know how you got on and may not know what has happened. It is difficult to know what to say and you can find yourself comforting them. You may find some people avoiding you and pretending nothing has happened for fear of upsetting you. They don’t know what to say to you and that can compound the feeling of isolation.

You may feel restless, lacking in energy or you may find it hard to concentrate. You may find yourself dreading your friends talking about their pregnancies or seeing their new babies. You may find it difficult to look at another baby or you may long to hold another baby. You may want to be alone or want to be with other people. Try to explain to your friends how you are feeling.

One of the sad realities is that you will continue to feel emotionally fragile for quite some time and this may affect your relationship with family and friends. Communication may be difficult and things that are important to them may seem trivial and frustrating to you, and vice versa. Though it may be difficult, it is important to maintain friendships. As time goes on, you will want to resume activities and interests with them.

If you are returning to work outside the home after the birth, you may find this another traumatic experience. It is a good idea, if possible, to arrange to resume work towards the end of a week or to contact some of your colleagues beforehand. You may also feel a bit strange for a while but gradually you will feel more at ease as you get back into your work.

In the months ahead you may experience many difficulties. Your G.P. is there for you as a source of medical advice and ongoing support as he/she has a continuous relationship with the family.
Anniversaries/Special Occasions

Each anniversary of your baby's birth/death will bring many painful and sad memories. The first birthday/anniversary is usually a particularly difficult time. Remembering your pregnancy, delivery or your baby's short life can be distressing. It is quite normal to find yourself reliving the whole experience.

Often the weeks before the actual day are worse. You anticipate the day with pain and dread. It may seem that friends or even some family members have forgotten and are unaware of your anguish. It might help to talk about your baby - especially to those who have been supportive and understanding of your grief over the past year. Don't try to block the pain or the tears, look over your baby's photographs and keepsakes and allow yourself to grieve. Your baby's birthday/anniversary is and always will be a very special day.

Some parents have found that it helps to plan the day in advance and they make a point of doing something special, such as:
* doing something together as a family
* planting a tree or shrub in memory of the baby
* visiting the place where the baby is buried
* having a prayer or other religious service
* sending a contribution to a charity in the baby's name.

Some parents anticipate the sense of sorrow and depression that can come, especially at Christmas, and make special ornaments for their Christmas tree that remind them and others about their baby. In this way, your baby is included in the festivities.

Your feelings will come and go like waves for some time. Everything will seem fine and you will feel you're coping and suddenly something, possibly quite trivial, will bring your deepest emotions to the surface again. With time these episodes of sadness will get further apart.
Family Occasions
It probably won’t occur to your family and friends that you may be
sensitive and hesitant about taking part in family reunions following
the death of your baby or that such occasions can magnify your feel­
ings of sadness. You can help in such situations by reminding your
friends and family ahead of time so that they can prepare to be sup­
portive to you when you need them to be.
Christenings can be especially difficult, you may be asked to be a
Godparent, you may find this helpful or you may not feel emotion­
ally able at this particular time. Explain this to your family and
friends.

GRIEVING TOGETHER

Relationships are so individual and personal that it is very hard, at
a time like this, to describe the normal experience. Some parents are
drawn closer together, yet grief can strain the closest, most loving
relationship and a lot of parents can feel isolated from each other.

When you’re going through something so intense and overwhelm­
ing it can be difficult to go on caring and thinking about each other.
You are both grieving - both caught up in your own thoughts and
feelings - neither able to find the strength to tend to each others
needs or even be fully aware of them.

Two people, no matter how close, will grieve in different ways.
Each partner has different strengths and different needs. One par­
ent might want and need to talk about the baby’s death, while the
other may not, or one might be trying to protect the other. You
might be afraid to share your feelings with your partner and yet you
expect them to know and understand how you feel. If one partner
is trying to be strong and seems to be getting on with life - the other
can feel they are carrying the burden of grief alone.

It’s not unusual to feel angry with each other. Minor issues can irri­
tate you, and you find yourselves arguing at the very time you need
each other most. There can be a lot of strain and tension. Although anger is a normal part of grieving, unresolved anger can have a destructive effect on your relationship. It can help to find some ways of sharing your grief.

Talking
Talking to each other comes easily for some couples, but for others it is much harder. Some people prefer to grieve on their own. Also, some people, particularly fathers, are worried that talking might make it harder for their partner to cope, yet usually it is the talking that makes it bearable.

Talking can help you both to understand your emotions more clearly and make them seem less overwhelming. Keep in mind that each of you grieve differently and try to accept the others feelings.

Great effort is needed in the months ahead to take the time to talk and to listen to each other. However, if you need to talk and your partner doesn’t you may have a close relative or friend who understands. Many parents also find that attending a support group meeting can help.

Caring For Yourself
Grieving is very tiring so it is important to give some time and attention to yourself. Taking some exercise, such as going for a walk, may help you to feel less tired and tense. Try to make a little time to do something that you enjoy - listening to your favourite music or something as simple as taking a hot relaxing bath.

Sexual Relations
Some couples find it difficult to re-establish the sexual side of their relationship after their baby’s death, even though they are very loving towards one another. There is a lot of stress following your baby’s death. Don’t expect too much of yourself or your partner. You will need to be patient and understanding with each other and show your love in other ways. Take things at your own pace and
talk about your concerns with each other. Often just talking about anxieties can ease them before they become major problems.

You have already established sexual patterns in your relationship, problems can arise if, in your grief, those past patterns don't feel right. One of you may need the closeness and intimacy that sex can bring, the other may want to be left completely alone. Both are normal reactions.

Sometimes one partner may feel guilty for having pleasure at such a sad time while others fear another pregnancy and similar complications.

Let your partner know of your needs. Don't assume that he or she feels the same way you do, or assume that his or her need for sex ignores you baby's death.

Sexual problems are difficult to discuss with outsiders at any time, but when they arise after a tragic event such as the death of your baby, they not only make you feel isolated from outside help but from one another at a time when mutual support is essential. These difficulties can be further compounded if your baby has died as a result of a genetic abnormality and you may be afraid to resume sexual relations for fear of another pregnancy.

CONSIDERING ANOTHER PREGNANCY

It is not unusual to have mixed feelings about another pregnancy. The fear of a future pregnancy is a very natural reaction following the death of your baby. "If I lost one, I can lose another" or "I couldn't bear to go through all those months of worrying".

Soon after the death of a baby, many parents, especially the mother, desperately want another baby. This feeling is natural. However it is important to allow yourself some time to grieve and to recover
emotionally from the death of your baby. This desperate need often diminishes as the months go by - a new baby will not replace the baby who has died. You can't successfully say "hello" to your next baby until you have said "goodbye" to this baby...... and saying "goodbye" takes time.

If your baby died from a genetic disorder or a condition that may occur again, you will need extra advice and help. Folic Acid supplements are now recommended for all pregnancies and are available without prescription from your pharmacy. Following the birth of a baby with a neural tube defect (anencephaly, spina bifida, hydrocephalus, microcephaly) extra levels of folic acid are required, these should be prescribed by your doctor. Genetic counselling is available following a referral by a G.P. or Consultant to the National Centre For Medical Genetics, Our Lady’s Hospital for Sick Children, Crumlin, Dublin 12. The Rotunda Hospital, Dublin provides an amniocentesis service in conjunction with the Genetics Centre and will also see patients from around the country on referral by a doctor.

A subsequent pregnancy is always a stressful and worrying time for both parents as they are more aware of all the things that can go wrong. The father may be suffering his own anxieties, worrying about his partner and the stress she is under and he may also have doubts about the successful outcome of another pregnancy. Fear of losing another baby inhibits many couples from emotionally investing in the pregnancy. Even when the pregnancy progresses normally, it may be difficult to be positive. The prospect of another delivery is often very frightening, it may bring back painful memories. Some hospitals provide support or counselling for parents during a subsequent pregnancy.

The time to start a new pregnancy is a very personal decision. Pregnancy depletes the store of essential nutrients and it is advisable to allow some time to recover, both physically and emotionally, after your baby has died.
Before starting another pregnancy it is advisable to get into good physical condition. It is now recognised that the health of both parents is important when planning a pregnancy.

**Another pregnancy**

When you have decided to have another baby, be aware that your first visit back to the hospital may be distressing. It is advisable to bring your partner or a friend with you. You may not want to return to the same doctor or to the same hospital. There is no need to feel guilty about this. It may help to write down any questions you would like to ask your doctor, as it may be difficult to recall them at this time. Talk to hospital staff about your worries and doubts, as their reassurance and support will help.

When telling your family and friends of your new pregnancy you may be aware of a special joy - and relief - on their faces. They may think everything will be alright when you have another baby to think about, or that another baby will erase the loss. Although another pregnancy, another baby will reduce some of those empty feelings, it is by no means a solution, you will always have one less child.

**When there is not another pregnancy**

Following their baby's death some couples decide not to have another baby. For other parents another pregnancy may not be possible. In some cases medical conditions make it impossible to conceive. For others, medical or genetic problems mean that a future pregnancy would be high risk.

However, great difficulty can arise if one parent wants another baby and the other cannot consider another pregnancy. This will create a very stressful situation within the relationship and for some people counselling may be helpful at this time. The final realisation that there will be no more children can be very painful and is often a new bereavement in its own right.
Remember..........

* Grief is a normal reaction to death and takes time to resolve.
* The feelings that go with grief - anger, sadness, confusion, lack of interest, are normal.
* Don't avoid thinking about your baby.
* Communicating your feelings is very important - don't avoid talking about your baby.
* Be patient with your partner. Remember everyone experiences grief in their own way. Because they may not show grief in the same way as you, it does not mean they are not also feeling the loss deeply.
* Put off making major decisions such as changing jobs or moving house if possible.
* Do something with your feelings. Write about them. Make up an album in which to place memories of your baby.
* Remember to reassure your other children of your love and concern for them.

WHERE TO FIND HELP:

ISANDS. Irish Stillbirth and Neonatal Death Society
It is natural to want to talk about your baby. You probably think about him/her all the time and continuously relive the circumstances of his/her birth and death. Your grief is very intense - you experience so many different emotions at the same time that you may feel unable to cope. These feelings are normal and it helps to express them.

It can be particularly helpful to talk to someone else who has had a baby who has died. You can do so by contacting ISANDS., all our
befrienders are parents who themselves have had a baby who died. We may be able to put you in touch with other parents whose experience was similar to yours. You can talk on the telephone with an ISANDS befriender whenever you feel the need for support and someone to listen. You can contact us now or at any time in the future.

We also organise Support Meetings for parents, these are informal meetings where bereaved parents can talk to each other. Many parents find that they feel less isolated and alone after meeting other parents who are going through similar grief.

It can also be helpful to write about your baby. Many people find that they can express their feelings by writing a poem or letter to their baby or by keeping a journal of how they feel. You might like to submit a letter or poem for printing in the Parent’s Page of our Newsletter.

The telephone number and address of our main office and your nearest local contact are listed on the back of this Booklet.

OTHER PEOPLE TO TURN TO:

Midwives/Nurses If you have developed a relationship with a particular member of staff who cared for you or your baby, you may find it helpful to arrange to meet them again at a later date.

Hospital Chaplain As the chaplain may have been involved with you at the time of your baby’s birth/death he/she can be an important support to you.

Medical Staff You may have questions or concerns that you would like to discuss. It is always possible to arrange to see your Paediatrician, Obstetrician or Doctor at a later date.

Social worker If your hospital has a social worker, he/she can see you while you are in hospital and you, your partner and family
should not hesitate to contact him/her at any time in the future. Some hospitals provide group meetings for bereaved parents.

G.P. It is important to let your family doctor know about your baby’s death as he/she may not have been informed yet. In the months ahead your G.P. can offer medical advice and ongoing support. He/she should receive a report on your baby from the hospital and will be able to go over the details with you again if you wish.

**The Public Health Nurse** Soon after you are discharged from hospital the nurse will call to see you. If you do not have a visit and would like one, contact your local health centre.

**Local Clergy** Your local clergy may be unaware of your baby’s death and you may like to contact them. They can help you with bereavement support or you might like to arrange a service for your baby.

**Bereavement Groups** Many areas have Bereavement Support groups. Enquire at your local Library or Church.

**Counselling** A Counsellor can help you to deal with your grief in a safe and supportive environment. Referral for counselling is not necessary. You may contact the Irish Association for Counselling and Therapy and/or the Irish Association for Integrative and Humanistic Psychotherapy for a list of accredited counsellors.

**Self help groups:**
**ISANDS** - Irish Stillbirth and Neonatal Death Society - A support group for families bereaved by stillbirth or neonatal death.

**S.O.F.T.** - Support Organisation for Trisomy - A support group for families of babies and children with Potters Syndrome (Trisomy 13), Edward’s Syndrome (Trisomy 18), and related disorders.

**T.A.M.B.A.** - Twins and Multiple Birth Association - a support for families bereaved by the death of twins or other multiple births.
The Miscarriage Association - a support group for families who suffer a miscarriage.

Incu-Babes - a support group for families of babies in intensive care units.

I.S.I.D.A. - Irish Sudden Infant Death Association - A support group for families of babies who died from Sudden Infant Death Syndrome (Cot Death).

The addresses and telephone numbers of the above self help groups may be found in your local telephone directory or by contacting ISANDS.

ISANDS.
CARMICHAEL HOUSE
4 NORTH BRUNSWICK STREET
DUBLIN 7
Telephone 01- 8726996

Available in Leaflet form from ISANDS

When Your Baby Dies Before Birth.
Neonatal Death.
On The Death of a Twin.
Another Pregnancy.
Leaflet for Fathers.
Your Other Children.

Additional information leaflets available from ISANDS;
* For Parents Whose Babies Died A Long Time Ago.
* What Family And Friends Can Do.
* Prayer Service for Babies Funerals and Anniversaries.
* General Information Leaflet on ISANDS.
BOOK LIST

When a Baby Dies: The Experiences of Late Miscarriage, Stillbirth & Neonatal Death. — (Kohner, Nancy & Henley, Alix) Pandora 0-04-440934-6

Empty Arms : Coping with Miscarriage, Stillbirth and Infant Death — (Ilse, Sherokee & Applebaum, Arlene (Ed.)) Wintergreen 0-9609456-6-0

Holly : Story of Stillbirth. — (Hemmings, Louis) Samovar 1-874136-01-7

Empty Arms: Emotional Support for those who have suffered Miscarriage or Stillbirth. — (Vredevelt, Pam) Questar

Living After a Death : Guidebook for the Journey through Bereavement. — (Walsh, Mary Paula) Columba 1-85607-136-7

Grieving After The Death Of Your Baby: Written to help parents and families find ways of expressing their grief and remembering their baby. (Thomas, Jenni, Kohner, Nancy & The Child Bereavement Trust) Available through ISANDS, Head Office, Carmichael House.

For Children:
All Shining in the Spring. — (Parkinson, Siobhan)

Waterbugs and Dragonflies— (Stickney, Doris).Mowbray, London


Videos:
When Our Baby Died: For parents and their families, friends and all who cared for them. In the video, parents, grandparents and children talk about their feelings. They explain what the death of their baby meant to them and how it has changed their lives. They describe some to the things they have done to express their grief. (Thomas, Jenni & The Child Bereavement Trust).

ISANDS
IRISH STILLBIRTH AND NEONATAL DEATH SOCIETY

MEMBERSHIP FORM

PLEASE PRINT

NAME: .................................................................................................................................

ADDRESS: ..........................................................................................................................

County: ............................................................................................................................... Telephone Number: ........................................

Yearly Membership subscription £10.00
(£5 if unemployed)

Please enclose cheque/postal order made payable to I.S.A.N.D.S.
Post to: ISANDS, Carmichael House, 4 Nth Brunswick St., Dublin 7.

Optional Information
(for our records only)

Baby's Name: ............................................................................................................................

Date of Birth: ............................................................................................................................

Cause of Stillbirth or Neonatal Death (if known)

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ISANDS is a company limited by guarantee not having a share capital. Charity No.: CHY 11507
Produced by ISANDS
Irish Stillbirth & Neonatal Death Society
&
Funded by
Health Promotion Unit
Dept. of Health

Local Contact:

01 - 872 2236 Ann
01 - 493 1645 Margaret

ISANDS, Carmichael House, 4 Nth. Brunswick St., Dublin 7.
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