SOFT UK

Support Organisation for Trisomy 13/18 and related disorders

Charity number 1002918

www.soft.org.uk

Your Baby

SOFT provides support for families affected by Patau's syndrome (trisomy 13), Edwards' syndrome (trisomy 18), partial trisomy, mosaicism, rings, translocation, deletion and related abnormalities and rare conditions including holoprosencephaly.

Truth has no special time of its own. Its hour is now. Always. Albert Schweitzer

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This booklet is dedicated to the memory of Dale Knights,
Trustee of SOFT UK who died 8.1.03.

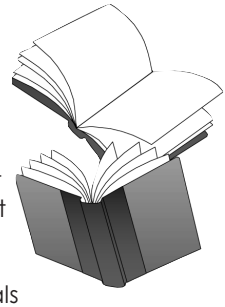
INTRODUCTION

SOFT UK, the Support Organisation for trisomy 13, 18 and related disorders, was founded in June 1990 by Jenny Robbins and Christine Rose. In 1988, Jenny gave birth to a daughter, Beth, who had trisomy 13 and lived for three months. In the same year Christine had a son, Jonathan, who suffered from a partial form of trisomy 18 and lived until he was 19 years old. There was very little information for parents when Beth and Jonathan were born, and SOFT now publishes a range of literature covering the various problems families face when affected by these conditions. Jenny and Christine have since had healthy children and continue to co-ordinate SOFT activities together with a team of trustees and volunteers around the country.

Jenny Robbins and family with Beth

Jonathan Rose and sisters

SOFT UK BOOKLETS



SOFT booklets are a valuable source of information about chromosomal abnormalities and related disorders. Recent developments in antenatal screening mean that many chromosomal problems are now diagnosed well before birth, and it is NHS policy to ensure that health professionals counsel women in order that they can make an informed decision whether or not to undergo screening.

Your Unborn Baby explores the issues confronting parents after a prenatal diagnosis of trisomy 13 (Patau's syndrome), or trisomy 18 (Edwards' syndrome), and includes sections about chromosome abnormalities, what is involved if a termination is chosen, how to plan when the pregnancy continues, and where to get genetic advice.

Your Baby deals with the birth of a child and the early months of life, or death if it occurs. Every family is unique. What may be right for one child or family is not necessarily right for another and parents can use the shared memories in these booklets as a basis for discussion between themselves and their medical advisers. SOFT does not recommend particular methods of treatment, and new treatment must never be started or existing treatment changed without consultation with your doctor and other medical professionals. SOFT does not represent any political or religious groups.

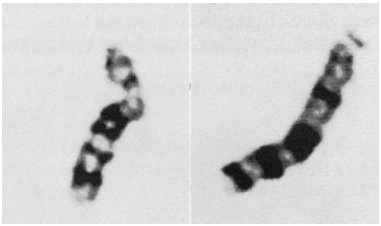
FOR PROFESSIONALS

'As always the need for communication is paramount among all the professionals involved. Any one of us may see only a few families of babies with trisomy and may not have the latest information to hand. The SOFT UK literature can also be of help to us and to colleagues in primary or community care and is available on request. Much of the information applies to other handicapping conditions too.'

Dr Una MacFadyen Paediatric Consultant & Medical Adviser to SOFT U.K

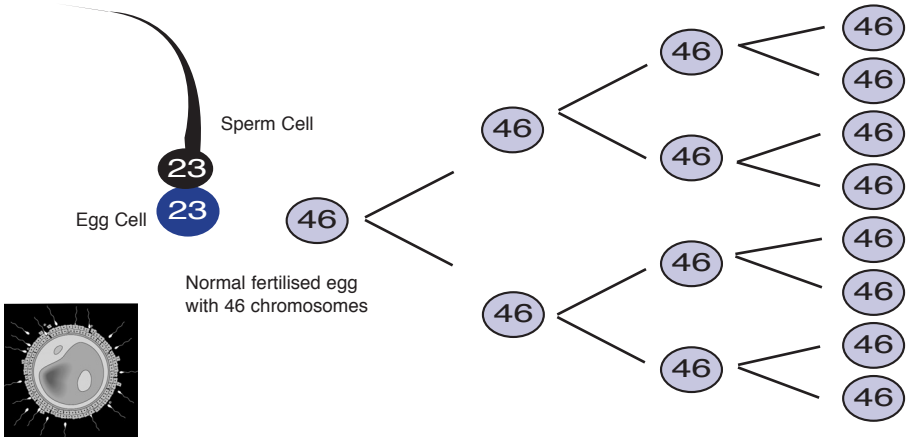
CHROMOSOME DEFECTS, WHAT ARE THEY?

There are 22 pairs of chromosomes, numbered 1-22 in order of size, and one pair of sex chromosomes (XX in females and XY in males) making a total of 46 chromosomes in each normal human cell. One X chromosome is inherited from the mother and the other sex chromosome inherited from the father, is either X (baby girl) or Y (baby boy) and determines the sex of the child. Each chromosome can be considered as consisting of a long tightly packed string of genes.



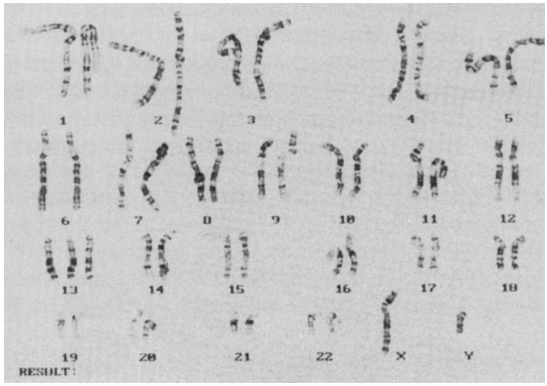
THE HUMAN EGG AND SPERM CELL

The human egg cell and the human sperm cell each contain only 23 chromosomes. When the egg is produced by the mother, the pairs of chromosomes in the egg cell split into two, and only one of each pair remains in the egg. The same happens with the sperm cell. When a healthy egg is fertilised by a healthy sperm, the fertilised egg has 46 chromosomes and is the unique blueprint for the individual baby that grows.



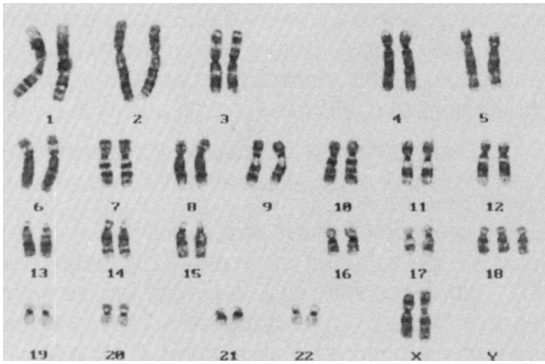
KARYOTYPES

A Karyotype, or picture of chromosomes, is prepared from a sample of blood, skin, bone marrow or connective tissue. The cultures are grown and the thread-like chromosomes in the cell are released on a slide and stained with dyes before being photographed and arranged in order of size to make study possible.



13 KARYOTYPE

Karyotype 1. Has three number 13 chromosomes in each cell, the full trisomy 13 or Patau's syndrome.



18 KARYOTYPE

Karyotype 2. Has three number 18 chromosomes, the full trisomy 18 or Edwards' syndrome.

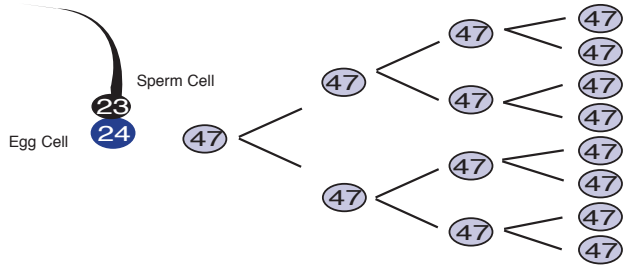
TRISOMY

The tri in the word trisomy means three. In each cell there is one set of three identical chromosomes among the normal pairs.

TRISOMY IN PREGNANCY

The extra chromosome may be in the egg cell produced by the mother or the sperm cell produced by the father and the additional genetic material affects every stage of the development of the baby, rather like too much information on computer software would prevent a computer from functioning properly. It has been estimated that as many as 95 out of every 100 embryos with trisomy 13 or 18 are lost in early pregnancy.

Families have often been affected by these conditions without realising it because up to half of all pregnancies are miscarried, maybe before a woman realises she is pregnant, and 1 in 5 confirmed pregnancies end naturally within 3 months. Many of these losses are caused by a chromosome abnormality, but a woman is unlikely to be offered chromosome tests to confirm the reason unless previous problems during pregnancy have indicated this might be a cause.



TRISOMY ORIGINATES IN THE EGG CELL OR SPERM CELL AND RESULTS IN 47 CHROMOSOMES INSTEAD OF 46.

WHY DOES IT HAPPEN?

Nobody knows. Every pregnant woman has a slight risk of having a baby with a chromosome defect which affects about one in every 200 births. The risk of having a baby with trisomy 13,18 or 21 (Down's Syndrome) increases with age, but most babies with trisomy are born to mothers in their twenties because more babies are born to women in this age group. Except in rare cases that are inherited, chromosome defects are usually one-off events which tend to occur more often when a mother is older. Only rarely is there a previous history of such a birth.

'In many instances we don't know the answers. Why it happens is a mystery. We know what happens but nobody knows why it happens.'

Dr. Ian Young: Professor of Paediatric Genetics former SOFT Medical Advisor

PATAU'S AND EDWARDS' SYNDROMES

Trisomy 13 was named Patau's Syndrome after the doctor who identified the chromosomes responsible in 1960, and trisomy 18 or Edwards' syndrome was named after Dr John Edwards for the same reason.

Trisomy 13 and 18 births occur about once in every 1,800 pregnancies and are the most common autosomal trisomies after trisomy 21, which is also known as Down syndrome. Trisomy 13 affects equal numbers of boys and girls whereas babies with trisomy 18 are three times more likely to be girls.

In the 12 months April 2008 to April 2009 there were 172 diagnoses of Patau's and 495 diagnoses of Edwards' syndrome. 91% of Patau's and 92% of Edwards syndrome diagnoses were made prenatally, and 65% of Patau's and 68% of Edwards' pregnancies were terminated. It is estimated that there were 18 live births with Patau's syndrome and 37 live births with Edwards' syndrome. *(National Down Syndrome Cytogenetic Register Annual Reports 2008/09 - data are provisional)*.

'Katie survived for 9 days. She was born with two large holes in her heart; so she did not stand much chance of any life. Naturally we were all devastated, but knowing that she had such a poor quality of life made the pain a little easier to bear.'

'Laura was rushed to SCBU and put on a ventilator. I was told she weighed 2lbs 10oz by the midwife and was sent a photo of her. She looked like a beautiful and perfect baby'.

'Due to my anxiety and the suspicion of a small for dates baby I was admitted at 39 weeks for observation. I was monitored for three days; the baby showed signs of fetal distress due to mild contractions. An emergency caesarean was performed and Joanne was born weighing 3lbs 12oz. The only obvious abnormality was the corneal eye opacities. She also appeared to be very underdeveloped for a full term baby. 3 weeks later blood tests showed that Joanne had trisomy 18'.

'Little Susan was delivered by caesarean section 5 weeks early and everyone expected her to survive only hours, possibly days. From the scan we also thought (quite wrongly) she was going to be horrendously disfigured. In hospital the goal posts kept moving. I felt in a bottomless pit, every time I began to pull myself up another piece of information on her condition would put me back down'.

'I was happy and laughing right to the end of my labour when I finally gave birth to our son. Then the world stopped. All I could see was our baby with a cleft lip. My husband says he will never forget my face. Each day another thing was found to be wrong with Ellis. Then at 5 days old his chromosome tests were complete. He had trisomy 13 and would not live long'.

'When Jacqueline was born I thought the world was over. But then it became a real joy, knowing that I had been given a chance to look after this very special person. You always think it will not happen to you; but when it does it is amazing. That's when you realise how wonderful it can be'.

'When we first realised Elliott had abnormal chromosomes, the extent of his problems were still unknown. All we knew was that we loved him desperately and would try to move heaven and earth to make his life as comfortable as possible'.

RELATED DISORDERS

Butterfly In The Wind

A child is a butterfly in the wind
Some can fly higher than others
But each one flies the best it can.
Why compare one against the other?
Each one is different
Each one is special
Each one is beautiful

The degree of the medical problems and disability can vary widely in children with a related disorder although they may have the same chromosome defect. This is because the genetic material that is extra or missing will be **different in every case,** and the professional opinion of a clinical geneticist should be sought.

PARTIAL TRISOMY

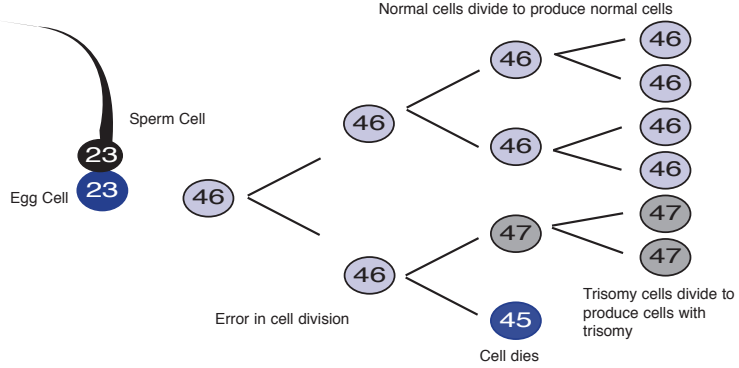
In partial trisomy there is a small extra piece of a chromosome attached to another chromosome. This may be called an unbalanced translocation.

'Hannah has partial trisomy 13 and we were given little hope of her survival in the early days, as the paediatrician assumed she had Patau's syndrome, and we learned the truth only after insisting we saw a genetic consultant. The paediatrician still gave little hope of improvement long term, not believing she would ever support herself. Hannah now walks happily to school.'

'Jonathan has a rare form of partial trisomy 18, and when he was diagnosed the consultant stressed how serious his particular condition was. Jonathan is now 19 years old. He has lived in a purpose-built residential home since 2000. The challenge now, is to move him to an adult centre being built 2007.'

MOSAICISM

Mosaicism means there is an error in the cell division after the fertilised egg splits into two cells.



There is an extra chromosome in some cells but not in others. The cells with 45 chromosomes die.

'We had a prenatal diagnosis of Mosaic 12 for Heather and the extreme rarity of the condition and the very poor prognosis were devastating. We refused the advice to terminate without further tests, opinions and research. Ultimately after five weeks we took the decision to continue the pregnancy. Heather is now 6 years old. She is beautiful to look at and has a bubbly, caring personality. She is doing very well at school and in her own words in her school report, "finds nothing hard." We have moved since Heather was born and here her history is not known nor is it apparent in any way. No day passes without us remembering our good fortune and the support we received from SOFT in allowing ourselves time to reach our decision.'

NB 2010 Heather has just sat her A levels and has been offered a place at medical school.

'Kyle was born in the July and we were still waiting for his chromosome results in December. By the time we were finally told he had mosaic 18 we had experienced the death of our dreams for the little boy we longed for. Kyle is now 10 years old and we no longer fear the present. He is a very special joy in our lives'.

'We were told Danielle had trisomy 13 mosaicism when she was two weeks old and that she could live for weeks. Dani is now 7 years old and is a loveable little girl with heart and lung problems. She took her first steps before she was three'.

When a child with the full trisomy 13 or 18 does much better than expected, the explanation may be that there is a proportion of normal cells which the geneticist was unable to identify on the very tiny samples obtained and the child has a low level of mosaicism.

RING CHROMOSOMES

In rare cases chromosomes can form rings due to loss of genetic material from both ends of the chromosome. Cell divisions during the development of the embryo, fetus, child, and adult, may involve further damage to the ring chromosome, and generally this cell division happens at a lower rate and body growth is slowed.

'Katy is nearly 9 years old and we were told she had ring 13 when she was 5 months old, and no clear picture of her future prospects. She needs no special nursing, just 24 hour attention on daily functions which are very slow.'

'Tyanne has ring 18. She was bottle fed, which was very slow. At 6 months old I was unhappy and asked for an assessment. The paediatrician was good and we soon had a diagnosis. We spoon feed her, avoiding lumps as she cannot chew. Tyanne crawled at 10 months and is trying to pull herself up. She is small, has constant ear infections, a squint and a dislocated hip which they are correcting'.

DELETIONS

A deletion means that there is part of a chromosome missing. The long arm of the chromosome is referred to as q and the short arm as p. A deletion of one of the long arms of chromosome 13 would be 13q-, and numbers can be used to specify exact areas of the chromosome.

'Our son Joe had a deletion on one of the long arms of chromosome 13 (13q-). The effect of the deletion is still becoming apparent, notably small stature, hearing and visual difficulties, and mental handicap. He is not a 'trisomy' boy and is a happy, lively and well child.'

'Jenny has a deletion of the short arm of chromosome 18 (18p-). She suffered badly from fits and GO Reflux. Since she has had the Nissan operation and a gastro tube, she keeps her food and her drugs down and the fitting is controlled completely. The operation has transformed her. She now plays with toys, laughs and is beginning to vocalise.'

HOLOPROSENCEPHALY (HPE)

Holoprosencephaly is when the front part of the brain fails to develop into clearly separate right and left halves. Generally this severely affects the function of the brain, although among children with this condition there is considerable variability in the degree of malformation and its effects. Babies diagnosed with this condition usually have a small head, excessive fluid in the brain, cleft lip, varying degrees of learning difficulties, epilepsy, hormonal problems, or problems with the heart, bones, bowel or bladder. Although a baby with holoprosencephaly may not have abnormal chromosomes, it is common in trisomy 13.

'Michael had holoprosencephaly and lived for 6 months. Throughout his life he was tube fed, and on medication to stop fits and GO reflux. He didn't sleep much at night and we had frequent trips to hospital for respite care and illness. At 5 months he was unable to swallow mucus and we had to use a portable suction pump. One of my proudest moments was when I dressed him in a little sailor suit and walked through the hospital to the car park. Lots of people gave me admiring glances as though to say "What a lovely boy.'

'James has holoprosencephaly. He takes his drinks from a bottle, but as he gulps he does get colic. He is constipated but will eat virtually anything, if mashed! He has regular physio for a slightly dislocated hip and to aid correct spine formation and posture. James is registered blind due to a damaged optic nerve. He still has the soft spot on top of his head. When it closes he may need a shunt inserted to drain fluid from the brain. He attends school and is now 4 years old.'

GENETIC INFORMATION

Genetics is the study of human cells and a Clinical Geneticist will interpret the results of chromosome tests taken from blood, skin, bone marrow, or connective tissue. Parents may not always be given the definite answers they seek, and in some cases the information will be a mixture of the certain, the probable, the possible, and an element of wait and see. Just as people have different characteristics (they may be tall, short, have brown eyes, blue eyes etc.) and suffer from a variety of different conditions (for example eczema or asthma) so babies will have individual differences although sharing the same syndrome.

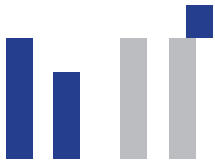
'No research has been undertaken to find out why different children live to different ages. They live to different ages because of different problems within their bodies.'

Ian Young Professor of Paediatric Genetics.

CAN PARTIAL TRISOMY BE INHERITED?

A baby can have partial trisomy when the parents have normal chromosomes, but in rare cases a parent may be a carrier if he or she has a balanced rearrangement of their chromosomes. A balanced rearrangement is when a piece of one chromosome is attached to another without there being any extra or missing genetic material.

Other family members may carry the balanced translocation and a clinical geneticist can explain how a future baby might be affected. Larger hospitals usually have a Genetics Department, and to obtain a referral you can ask your Obstetrician or G.P.



Rearranged chromosomes

When two pairs of chromosomes have a balanced rearrangement, the (carrier) parent is healthy and unaware of the different pattern in their chromosomes unless tests are performed.

When the parent cell divides to produce an egg or sperm the following can happen:

The baby inherits the normal chromosome from each pair of chromosomes and has normal chromosomes.

The baby inherits the chromosome with a piece missing and the chromosome with the extra piece attached (both the rearranged chromosomes) so overall there is no extra or missing genetic material. The baby is healthy but carries the balanced translocation which may affect future generations.

The baby inherits the chromosome with an extra piece (extra genetic material) and has a partial trisomy of that chromosome (see partial trisomy).

The baby inherits the chromosome with a piece missing, ie. there is genetic material missing and the baby has a deletion of that chromosome (see deletions).

'Andrew has partial trisomy 18 as a consequence of his dad having a pericentric inversion on chromosome 18. We were given a 5-10% recurrence risk for any future pregnancy and we had amniocentesis during my second pregnancy which showed normal chromosomes. Amy was born by elective caesarean section when Andrew was 18 months old and is just fine.'

'My two year old son has partial trisomy 18 and I have been told I carry the genetic trait that caused him to have this. At first I felt guilty but it helped to talk to others in the same situation and we have since had a healthy daughter.'

'After the birth of our daughter who had partial trisomy 13 we consulted a geneticist and the results of blood tests showed my husband has a balanced translocation. At first he felt it was his fault and it took us a long time to talk about it. His father has been tested and is also a carrier.'

LETTER FOR PROFESSIONALS

This letter is for colleagues who have to face the distress of telling parents their longed for baby has a serious condition such as trisomy 13 or 18. There is no easy, painless, or single right way to give this information but, with the help of parents who form SOFT UK, I have gathered some suggestions about what is most helpful and what is most hurtful to parents in their encounters with health professionals.

All parents appreciated factual information as early as possible. When the person who first tells them that a trisomy has been detected has only limited experience of the condition, they would rather this was admitted and access to more information offered. Please use words as near to plain English as possible 'Edwards' syndrome' means even less than 'trisomy, a condition with an extra chromosome' to most parents. Generalisations do not help. Any decisions that have to be made need to be based on maximum knowledge and genuinely informed choice.

There is usually time to share facts and debate the right decisions before planning intervention. Parents really need this time and resent feeling rushed into a decision before they are ready. When decisions have to be made quickly, as when an emergency C section for fetal distress is considered, do not assume parents will feel the long term prognosis justifies non-intervention. Some parents will want to do all they can to enhance whatever chance the baby has of even limited length and quality of life. This can include opting for a C section or, later, discussing the risks of heart surgery and considering breathing monitors and learning resuscitation.

Most parents appreciate being able to talk to someone else who knows what it is like to have a baby with this condition and early contact with SOFT, or other relevant support groups, should be offered. Every baby is different and using generalisations such as 'incompatible with life' means little when parents want to know how long the baby may live and what will happen if the baby survives more than a few hours or days. Around 10% of babies with trisomy 13/18 survive for several months and some live for several years. All babies have severe developmental delay and the family need to know these possibilities and how they will be supported over this time.

These issues are important both to the parents of a baby diagnosed as having trisomy after birth, but also to those whose diagnosis is made early in pregnancy when there

is a need to consider termination or to support the family through adjusting to preparing for a baby with abnormalities. As always the need for communication is paramount among all the professionals involved. Any one of us may see only a very few families of babies with trisomy and may not have the latest information to hand. The SOFT literature can be of help to us and to colleagues in primary or community care and is available on request. Much of the information applies to other handicapping conditions too.

Please do not feel patronised or that I am trying to tell you your job. Many parents report they have had positive support and a sharing of their worries with their health carers, but for those who have inadvertently been left feeling lost and suffering alone at this time of enormous stress, anything we can do to help seems well worth trying.

Yours sincerely UNA MACFADYEN
Consultant Pediatrician and medical adviser to SOFT UK

BIRTH OF A BABY

HOW SOON CAN A DIAGNOSIS BE MADE?

There are various physical signs that may alert the midwives and doctors. Babies with a chromosomal abnormality often have a low birth weight, low set ears, heart and eye defects and unusual palm and fingertip patterns.

'When my daughter with trisomy 18 was born I knew there was something wrong. Unlike my other two children she wouldn't go to the breast, she was sleepy and floppy with her two hands tightly clenched.'

The following problems may also be present in trisomy 13 or 18: abdominal defects (omphalocele); cleft lip and palate; back of head enlarged (occiput); clenched fists, undeveloped nails and overlapping index fingers; club/rocker bottomed feet; spina bifida; spine defect (meningomyelocele); defects of the scalp, diaphragm, lungs, kidneys and ureter; small mouth and jaw; joint contractions (arthrogryposis).

'I was surprised and horrified when baby Leah was born with trisomy 13. At first only her cleft soft palate and club foot were evident and I thought that was disastrous enough. Little did I realise the complexity of the syndrome.'

'When I came round after the section, the doctor told us they suspected a syndrome because Jonathan had low set ears, his heart seemed on the wrong side, there were respiratory problems, he'd been blue, he had a short sternum, foot defects and dislocated hips.'

'Sophie weighed 4lbs 12oz and had trisomy 13. She had extra fingers and a cleft palate.'

'Beth had eye defects, a heart murmur and low set ears. She had only one crease on the palm of her hand and clenched her fingers over her thumbs.'

'Our son had a scalp defect measuring one inch in diameter and it was repaired at 2 days old.'

WHEN A BABY IS STILLBORN OR DIES SHORTLY AFTER BIRTH

Babies with a severe chromosome abnormality may suffer from major medical problems and be stillborn or die shortly after birth. After delivery some babies can need resuscitation and oxygen before being able to breathe unaided and the nature of this should be discussed beforehand. Parents may decide strenuous resuscitation is not appropriate.

See section about bereavement

'Even though Amy had died before she was born, she is precious and still an important part of our family. The fact that I was given time to be with her and hold her has always been vital in enabling us to think of her as a real person'

'When my son was stillborn I was so upset I didn't want to see him, but the midwife handed him to me in a shawl. The things he had wrong didn't matter any more. The baby was our son and we cuddled him together for as long as we wanted and kissed him goodbye. Those moments are now treasured memories.'

WHEN A BABY LIVES

Parents are shocked and suffer a 'bereavement' when they first realise something is wrong with their baby. Without being unrealistic the facts should be shared with compassion and sensitivity and the family need to mourn the loss of the 'healthy child' of their hopes and dreams.

Everybody feels helpless when a life-threatening chromosome defect is confirmed and parents want to know how long their baby will live. About 10% of children with the full trisomy 13 and 18 live beyond the age of twelve months, but children are not statistics and in many circumstances accurate predictions of life expectancy are not possible.

'Paediatricians diagnosed Patau's syndrome when Freddy was born. They told us an extra chromosome 13 was not compatible with life and our son died shortly afterwards.'

'We were told beautifully and fully by a very sympathetic geneticist when our son was 2 weeks old. Our paediatrician saw him once a week until he died at home from kidney failure aged five and a half weeks.'

'When she was diagnosed they said that she would only live for 8 weeks. We were in such a rush to get her home, we didn't really know how hard it would be, but figured we could manage to make her short life the best in the world.'

'A consultant told us some hours after Sophie's birth she would not live long. I nursed her at home until her death at 11 months. Looking back I would have liked to know she could have lived as long as she did, rather than be told she would die soon.'

'Trisomy 18 was confirmed in the first week and we were told there was little help for her. When she was 15 days old we brought her home to feel the love of her family and she is now 5 years old.'

RELATED DISORDERS

The outlook for babies with other chromosomal abnormalities or related disorders such as partial trisomy or mosaicism may be much more hopeful and the effect may be mild, moderate or severe, depending on the precise nature of the chromosome disorder. A clinical geneticist and the baby's paediatrician can explain how the development of the baby may be affected.

'Frequency of occurrence, gaps in medical knowledge and lifespan of babies combine to invalidate previous statistics.'
Dr John Cary - SOFT USA

SPECIAL CARE IN HOSPITAL

Some babies require the facilities of the Special Care Baby Unit only until breathing and feeding are established. These babies are then transferred to a 'baby ward' and may be able to go home when hospital nursing is not required.

'The SCBU were marvellous letting me hold her and spend as much time with her as I wanted. Katie died when she was three days old'.

'We fought to save Hannah. The intensive care unit team did everything they could; but after the fourth bout of pneumonia we could not put her through any more pain. The spark that was Hannah had gone, so we took her home and, within the love of our family, she died peacefully.'

'Half way through my pregnancy we knew Suzannah had trisomy 13. She was born normally with lots of lovely red hair and weighed 6lbs 11oz. We cuddled her for a few hours before she was taken to the Special Care Baby Unit. She couldn't feed because of her cleft lip and palate and a drip was set up. The difficult question of surgery arose because Suzannah had a bowel obstruction and surgery would be required to correct it. When we considered her other medical problems we felt that this high risk surgery would not be appropriate for Suzannah. We were then able to choose to care for her at home. We had Suzannah for 16 days and we made that time extra special.'

Where there are major life threatening problems and the future of the baby seems hopeless, it may not be right to provide the highest level of life saving skills, but the decision not to give intensive care to prolong the life of a very sick baby does not mean that loving care is withdrawn. The child can be kept comfortable and peaceful with much of the nursing care being provided by the parent or parents and supported by the medical staff.

'The doctors recommended doing no surgery or heroics and we agreed with them at the time.'

'No one really told us what to expect but, with hindsight, now I can see that, with the physical conditions Louisa had, she would not have lived long. I know that I didn't want her to suffer. That was my main concern.'

TAKING BABY HOME

Parents may have the option of taking a baby home when hospital care is not required and it is not sufficient for families to be told to 'ring the hospital if problems arise'. Specialised support should be arranged and a structured care plan to prepare a family for problems that may arise, such as feeding, constipation and apnoea. The care plan must be flexible to the changing needs of the baby or the family. Parents do not want to take their baby home to die. They want to take their son or daughter home to live, until such time as death occurs.

Families taking a baby home should be informed about Special Care Baby Unit staff home visits, community paediatric nurses, physiotherapy, respite and shared care, and state allowances.

'Always feel that you can ask for information or advice and as many questions as you need, as often as you want. Ask the people you trust and who can give you the information you need.'
Dr Una MacFadyen : Consultant Pediatrician.

'Annabel came home during the day and went into hospital every night. We were supported by our doctor and HV as she needed to be tube fed. We knew Annabel was going to die but never regretted having her home where she died of heart failure when she was five weeks old.'

'Sophie stayed in hospital for 19 days. Two days before Christmas we collected her for the day and then decided on Christmas Eve to keep her home. We were so glad we looked after her at home until she died at 11 months.'

'We never regretted bringing Leah home. Despite the problems, we were blessed to be able to care for her as long as we did. She died peacefully in her sleep at 4 months; nothing could have prevented it.'

'Suzannah came home and after a difficult first night when she had several apnoea attacks which required resuscitation, things settled down and we had some quality time at home. We took lots of photographs, especially when we went visiting friends with Suzannah. On the 7th January, Suzannah weakened and died peacefully in our arms. In many ways it was a relief for her and we took great comfort from knowing that Suzannah has gone to heaven.'
Suzannah T13

RESPITE CARE

The different types of respite care provided in an area should be discussed with the family although not envisaged at this stage. Should the needs of the baby become intensive, the parents may welcome shared care and the opportunity to rest and spend time with each other. Many children's Hospices provide welcome respite.

'Emma comes home during the week and returns to hospital at the weekend.'

'Parents should be offered respite care and support from the start. They may not be ready to accept it, but it should be there as a possibility. It took us years to stop feeling guilty about using short term care, but others enjoy looking after Alastair.'

'The good thing to come out of our son's stay in hospital was the discussion on respite care with the consultant. John will now stay one weekend a month on the children's ward until he has a place on the rota of the excellent respite care centre nearby.'

COPING WITH FEEDING DIFFICULTIES

Many parts of the body do not develop properly when there is a chromosome abnormality and babies suffer from 'failure to thrive' and feeding difficulties causing slow growth and low weight gains.

BREAST FEEDING

Feeding problems can cause slow growth and low weight gain because babies lack the co-ordination to suck and swallow properly. Breast milk protects a baby against certain infections and mothers who want to breast feed can express their breast milk for bottle or tube feeding. The National Childbirth Trust and many hospitals have electric breast machines for use at home, available for hire.

'I tried to breast feed and was told it was my fault I was not succeeding. I suffered terrible guilt because it was something I wanted to do for Hannah.'

'I tried and tried to breast feed but it was too difficult, so I got hold of a National Childbirth Trust electric breastpump and fed expressed breastmilk in a bottle. Joe gained weight very slowly.'

'I expressed my breast milk using an NCT electric pump that I had at home and fed our daughter Heather very successfully for the eight months she lived. I felt it was worth all the effort as her weight gain was very good. At 7 months she weighed 121bs, at birth she had been just over 31bs.'

BOTTLE FEEDING

There are many powdered and liquid baby milks available and the midwife will advise on what to use and how much to give.

Babies may need frequent and smaller feeds. Enlarging the hole of an ordinary teat does not solve the feeding problems and panic and choking soon result. Babies can swallow air when using ordinary feeders and this causes wind, vomiting and colic.

'Feeding was a 24hr job. Katie would suck 2oz milk in half an hour and then vomit. After sleeping for an hour she would wake hungry and so on.'

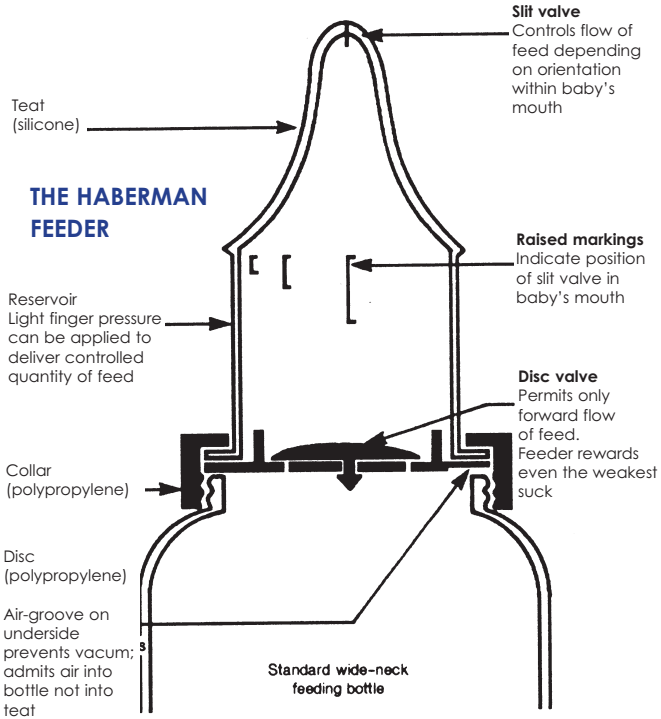
'David and I fed Jonathan in shifts during the night. When he woke he was given as much milk as possible. This way we managed to sleep for about 4 or 5 hours each without worrying about him. We soon learned when to sleep and when it was our turn to be awake!'

'Melissa was fed by breast, tube and bottle for the first week. Then just bottle fed, when we fought to get every possible drop inside her.'

BOTTLE FEEDING - THE HABERMAN FEEDER

The Haberman Feeder was invented by a mother who experienced the misery of feeding problems after her daughter was born with a rare syndrome and was designed to help babies who have a condition that makes feeding difficult.

The Haberman Feeder concentrates the baby's sucking effort directly onto the milk in the teat so that even the weakest suck gets results and gives the baby complete control. Air swallowing is reduced, and babies with feeding difficulties and/or a cleft palate can benefit significantly. The parent can help the baby by gently squeezing and releasing the teat to control the amount of milk that flows into the baby's mouth. (Contact SOFT for a leaflet about the Haberman Feeder).



'Because my daughter had a cleft palate, I had to feed every hour and she gained weight very slowly. After eight weeks she started to lose weight and by three months had dropped to 5lbs 12oz. After using the Haberman Feeder she put on 1lb in two weeks and sucked 5oz in an hour. Her weight increased steadily from then on.'

CLEFT PALATE

Babies with a cleft palate are unable to make a seal between the mouth and the nipple/bottle teat and cannot suck effectively. A plate can be fitted in the roof of the mouth. (Also see Haberman Feeder).

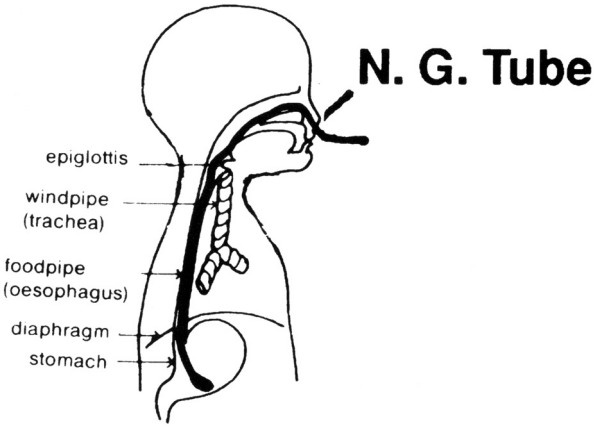
'Danny had a cleft lip and palate and was NG fed until his lip was repaired at 5 months. Some friends even learned how to feed him for me. Before tube feeding we encouraged him to take as much milk as he could from a bottle with enlarged hole in the teat. After his lip repair Danny drank entirely from the bottle.'

'Ellis' heart was checked and rechecked by our specialist who gave the okay for his cleft lip operation. He looked so small but he was marvellous - he had a proper little button nose and a proper little mouth - how I cried! There was my proper little boy!'

TUBE FEEDING

Babies unable to feed orally or demanding one or two hourly feeds may need tube feeding even temporarily to gain weight and prevent the parents becoming too exhausted to cope. The three types of tube feeding are:

OG * tube in the mouth and down the oesophagus.
NG * tube in the nose and down the oesophagus.
Gastrostomy * tube inserted in a small opening through the skin directly into the stomach.



THE POSITION OF AN N.G. TUBE IN THE STOMACH

'A lot of Guy's progress was because I was taught in hospital how to tube feed so he had milk even when he couldn't suck.'

'Katy took her bottle within a week of her colostomy and continued to do so fully for l2 weeks when she went on part tube/part oral feeding. Now she is 100% naso-gastric fed. I was not upset by this as we had been warned it could happen and she conserves her little energy for surviving.'

Although nursing experience is helpful, parents without any medical knowledge can learn to tube feed at home and they quickly become the experts on tube feeding their baby. Continuous overnight feeding by mechanical pump or naso-duodenal (i.e. to beyond the stomach) tube may be tried where ordinary methods of feeding have failed. A period of time is required for evaluation before a gastrostomy is considered or where surgery is not advisable.

TUBE FEEDING - A PERSONAL ACCOUNT

The following was written by a mother in her early twenties who had no previous medical experience and whose daughter had trisomy 13 and needed to be tube fed:

'My daughter Ashlee was tube fed. My first thought was of horror, "I can't do that", but realising this was the only way I could take her home and that nervousness and hesitancy would only prolong her stay in hospital, I made myself think there was nothing to it. After midwives helped me to tube feed her and explained what to do I sailed through her other feeds until I got her home. Then came the difficulties and I discovered how to manage by experience.'

'Before each feed I washed my hands and prepared everything I needed. I turned my baby on her side to prevent her choking if she was sick and propped her up slightly with a pillow. Putting the tube in the side of the mouth reduced retching and to make sure the tube was in her stomach I always did a litmus test. If she became distressed when the tube went in I stroked her face to reassure her before starting the feed. An unsettled baby causes much frustration. If she didn't want her feed I removed the tube and tried again later.'

'Tilting the stopper and pushing it gently into the syringe ensured the milk didn't gush into her stomach which would have startled her into bringing it up again. If she strained during a feed the same thing happened and I had to be quick and put the stopper back in the syringe to hold the milk in place before it drenched both of us.'

'I never removed the tube while milk was being administered, but nipped it close to the mouth to suspend the milk and repeated this procedure when she had finished feeding, always remembering the baby must not sit up when the tube is in. Eventually I was so experienced I could cuddle her as she was tube fed. The Special Care Unit gave us an emergency advice line to phone if we ever needed help or advice and also provided tubes and mucus extractors. As my daughter grew, her feeds increased and I needed to use larger syringes'.

PROBLEMS ASSOCIATED WITH TUBE FEEDING

A mucus extractor or chest physiotherapy before a feed can help a congested baby. Some medicines irritate an empty stomach and others do not work so well when given with food .

Parents should ask the paediatrician or nursing staff for advice when problems arise.

COLIC

Colic is painful for a baby and distressing for the family. Smaller and more frequent feeds may help and the Haberman Feeder can reduce the amount of air swallowed during a feed (See Haberman Feeder, page18). The baby should be given a thorough medical examination to eliminate the possibility of other medical conditions and, in cases of severe colic, anti-gas medication may be prescribed.

'Jonathan had chronic colic and at 8 weeks old he was prescribed a medicine not normally given to babies under 6 months. Merbentyl relaxed his stomach and mildly sedated him. I had to hold him over my shoulder for at least 20 minutes after each dose to prevent any possibility of choking. We used the doses at night to get some sleep. The colic stopped at 10 months old.'

CONSTIPATION

Babies with trisomy 13 and 18 may be prone to constipation and discomfort can be relieved by diet, fluids or medication depending on the cause and severity. Midwives may suggest adding a little (brown) sugar to the feed as a temporary measure for the very young baby, but suppositories may be needed for chronic constipation. Always seek the advice of the baby's doctor or health visitor.

'Our son has trisomy18 and suffers from chronic constipation. Sometimes the motion would be rock hard and not emerge for 4 or 5 days. Although suppositories and laxatives would work in emergencies our pediatrician preferred a gentler method. He now has paediatric Dioctyl every day. This softens the motion and he manages a bowel movement, on his potty, at least every other day.'

GASTRO-OESOPHAGEAL REFLUX - VOMITING OF FEEDS

Reflux vomiting may be caused by a defect in the working of the stomach that allows fluids to run back up into the oesophagus of a baby and can cause a burning feeling as in severe heartburn. When the baby has a chromosome disorder such as trisomy 13 or 18, chronic GO reflux can result in failure to thrive, pneumonia and other complications.

Refluxing may be helped by:

* Placing the baby on a level surface with the head raised slightly at an angle of about 30%.
* Giving smaller and more frequent feeds.
* Thickening agents such as Nestargel and Carobel.

'Nicola was vomiting badly at least twice a week and, although she has medicine for her sickness, we still want to control it completely. The SOFT information on refluxing has been very helpful and we are going to discuss it with our paediatrician.'

'Feeding was a 24 hour job. Beth would suck 20mls of milk, then fall asleep and wake hungry a couple of hours later. She would vomit several of her feeds, daily, however carefully I fed and winded her. I only managed because I had a very supportive husband who took over when I was too exhausted to wake up at night.'

APNOEA

APNOEA SPELLS

Apnoea is breath holding and happens more frequently in early infancy, especially when a baby has trisomy 13. The baby stops breathing without warning and becomes limp and blue. Breathing usually starts again after a few moments which will seem like a lifetime. Parents may consider the use of breathing monitors and learning simple resuscitation.

Apnoea has been described as 'the brain forgetting to tell the baby to breathe' and slight stimulation or even resusitation may be needed. A paediatrician will advise whether to have an apnoea monitor at home and what to do in an emergency.

'At the age of 7 weeks, Amy had a fortnight when she was extremely poorly and stopped breathing each time she awoke. These periods could be 2 or 3 minutes; one lasted about 8 minutes. It was indicated that she could not live more than a few hours but she fought on, gradually gaining strength.'

'When Beth had her first apnoea spell I panicked. She screamed, then stopped breathing and turned blue. I picked her up and patted her back and she suddenly started breathing again. At the time I didn't know the cause and was very frightened, but each time we rocked her gently when it happened and patted her cheek until 'she came back'. When she was 3 months she started having spells whenever I fed her and we could see she was getting much worse. Within a few hours she died in my arms.'

'We were scared to death each time Kelsey stopped breathing during apnoea spells but never regretted bringing her home and when she was older they stopped'.

'Ellis had two violent apnoea attacks within half an hour that morning, then another two during the day - but we and the staff managed to bring him round without oxygen, as we had decided. It was a very difficult decision to come to but I believe it was the only one we could make. He died so peacefully, as we cuddled him.'

SEIZURES

Seizures may describe frequent jitteriness lasting seconds or mild fits which cause the limbs to twitch. These may do little more than startle the baby, occasionally causing crying and tend to happen more often when the child is going into or coming out of sleep. They are called myoclonic jerks and are caused by an excess of electrical activity in the brain.

SOFT UK

This is a pull out supplement of photographs sent in by parents showing babies and children affected by trisomy 13 (Patau's syndrome), trisomy 18 (Edwards' syndrome), and related disorders.

Sadly, many of those pictured who had the full trisomy 13 or 18 have died.

Parents who have recently lost a baby or child may not wish to view the photographs at this time, and can remove the supplement if they wish.

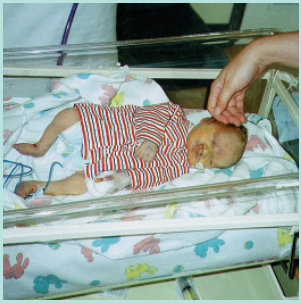
The **www.soft.org.uk** website does not have photographs on the Remembrance Stars and Contact Us pages. All parents who have suffered a loss after a diagnosis of trisomy 13 or 18 may request a remembrance star.

The home page has a link to the SOFT UK newsletter.

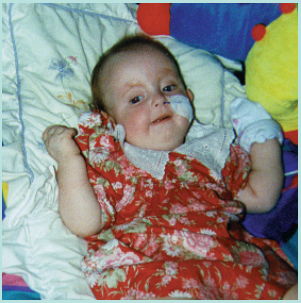
The trisomy 13/18 page has data showing the number of pregnancies in England and Wales in 2008/9 affected by trisomy 13 and 18, and stories about children with the related disorder of mosaicism. The SOFT UK Children's page has photographs and stories about older SOFT children.

SOFT UK

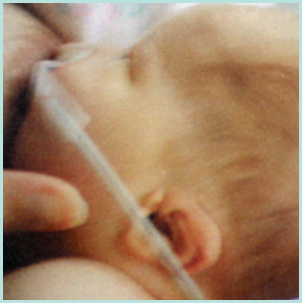
Photographs of babies and children with



Patrick t13



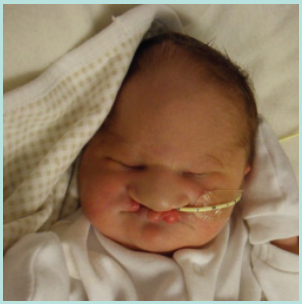
Aimee t18



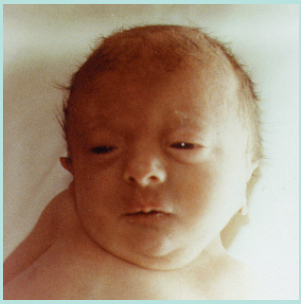
Lucy Alexandra t13

Amy t13

Kieran t18

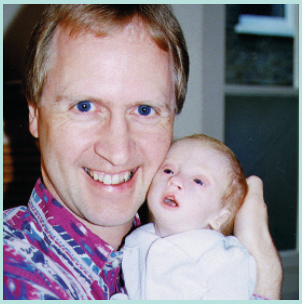


Hope Louise t13

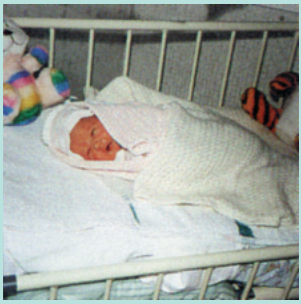


Russell t18

Beth t13

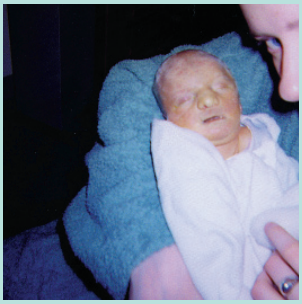


Christopher t18



Holly t13

Emma t18



Liam t13

trisomy 13 (Patau's syndrome) and trisomy 18 (Edwards' syndrome)

Hazel t13

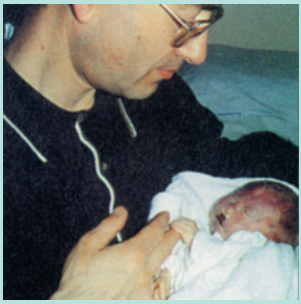
Suzannah t13

Chantelle t18

Celia t18

Jack David t18

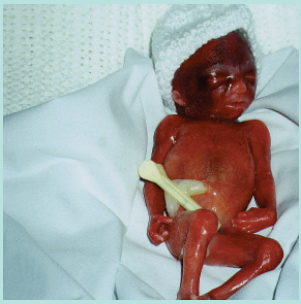
Heather t18



David t13

Hannah t18

Jack t13



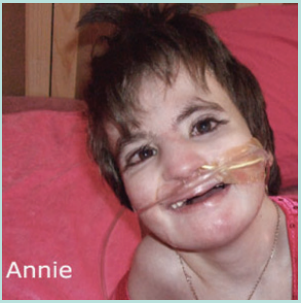
Naomi t18

Joshua t13

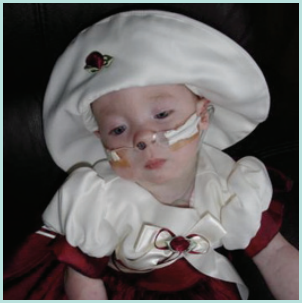
Sarah Elizabeth t13

Saskia and Katie's story www.soft.org.uk SOFT Children's page


Saskia t18



Annie t18


Emma t18


Chantal t18

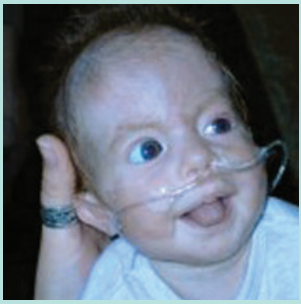

Oliver t13

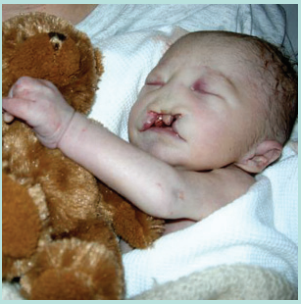

Charlotte t18

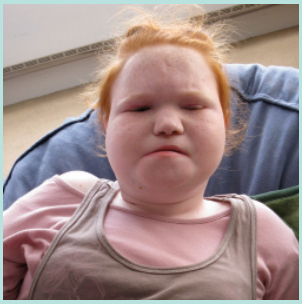

Louise Emily t18


Connor t13

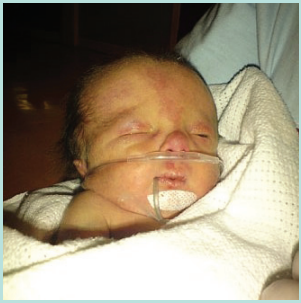

Mhairi t18


Evie t18

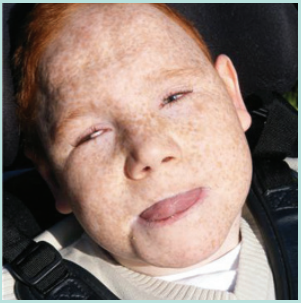

Joseph t13


Katie t13

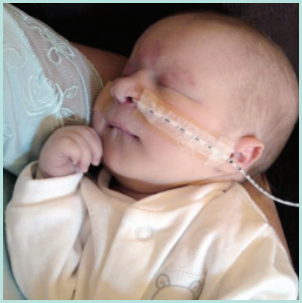
John - A life worth living www.soft.org.uk SOFT Children's page



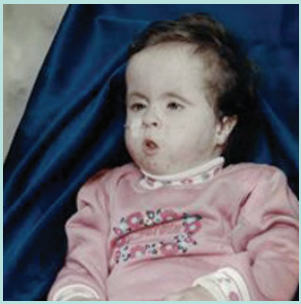
Lucas Andrew t18



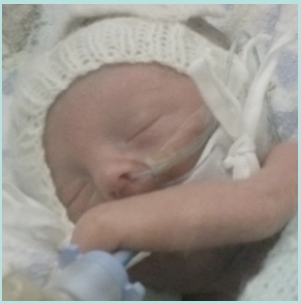
John t13



Hannah Sophia t13

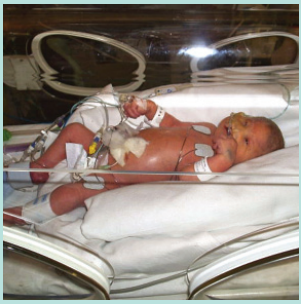


Rachael t18

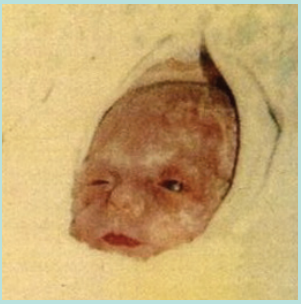


Liam t18

Simon t18

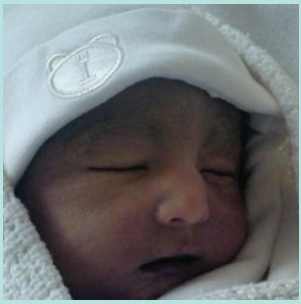


Mackinnley t13

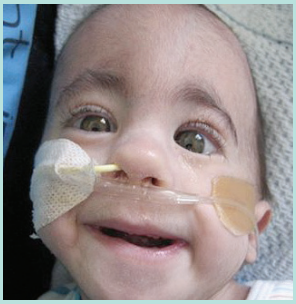


James t18

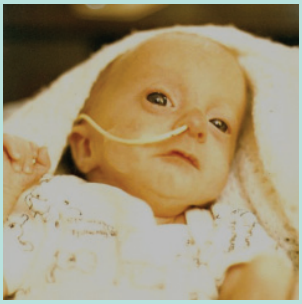
Kate-Lynne t18



Priya t18



Noah t18

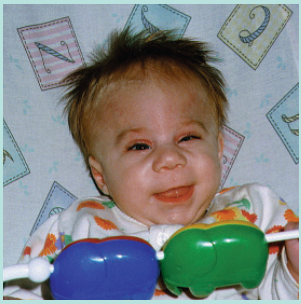


Sophie t18

SOFT UK supports children with a related disorder.

Related disorders include partial trisomy, mosaicism, rings, translocation, deletion and holoprosencephaly.

The degree of the medical problems and disability can vary widely in children with a related disorder because the genetic material that is extra or missing will be different in every case. Some children may be profoundly handicapped, but many are much lesser affected, and several children with mosaicism or partial trisomy have entered mainstream education. Heather (trisomy 12 mosaic) has just sat her A levels and has been offered a place to study medicine at university.



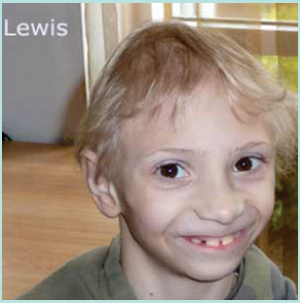
Charlotte partial t13

Luke t13 mosaic

Ellie t18 mosaic

There is a link to the newsletter on www.soft.org.uk with articles written by parents whose child has a trisomy 13 or trisomy 18 related disorder. Lily and Lewis' story are on the Trisomy 13/18 page.

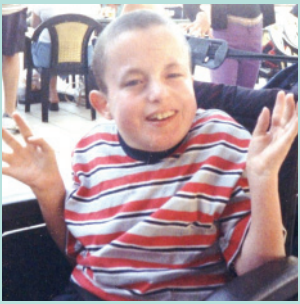
with related disorders



Lewis t18 mosaic


Lily t18 mosaic

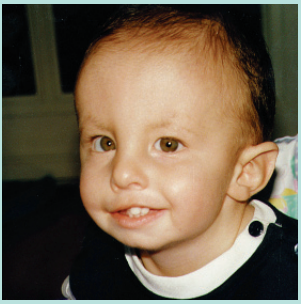

Mia t18 mosaic


Jonathan partial t18

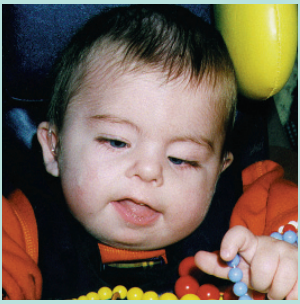

Sophie dup 7q

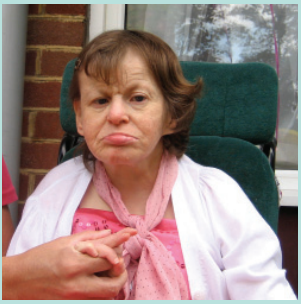

Heather t12 mosaic


Michael holoprosencephaly


Louis partial t18


Demi t18 mosaic


Andrew partial t18


Carol partial t13


James holoprosencephaly

During severe seizures the body of the baby will be rigid and the limbs extend. Treatment consists of anti-convulsant medication and it can be difficult finding the correct dosage. Too much and the child becomes lethargic and unresponsive, too little and there may be an increase in the number and severity of the seizures. Seizures can be accompanied by apnoea and you will be taught the best way to look after your baby during a convulsion or an attack of apnoea.

'Michael was born with holoprosencephaly and suffered from severe fits in his first few days. The drug Diazepam was used and later Phenarbarbitone; the dose was altered as and when necessary. These drugs were successful. We cared for him from 3 days old until he died and he never had any more fits.'

'Our son suffered from severe epileptic fits and initially they gave us great cause for concern because he would stop breathing and require resuscitation. His seizures are now under control and he is very lively, possibly due to a reduction in his anti-epilepsy drugs.'

'We were not told of the high incidence of seizures in children with Patau's syndrome. After one seizure John gave a larger than normal jump and within a few seconds his lips and nose turned blue. The rigidity receded but he did not start to breath so I gave him mouth to mouth resuscitation. After a few moments of this and massage, John gave a gasp and started breathing. At this stage he was still very blue and so we took him to the hospital where the paediatrician told us that his myoclonic jerks had progressed to epileptic seizures accompanied by apnoea spells. This was a traumatic time for us and others, like grandparents, who became nervous of handling John. After his third blue-light rush to hospital the paediatrician prepared us for the worst and said he didn't know if they would be able to control the attacks. We had to rethink our approach and our confidence was boosted when the paediatrician prescribed a rectal Diazepam to be given if John did not seem to be recovering from the first seizure. Our confidence grew when we used it for the first time and proved that it worked. Through time John responded better to his daily medication.'

KIDNEY AND URINE INFECTIONS

Kidney defects make babies prone to urinary infections and these should be suspected if the baby develops a fever or other unexplained symptoms. Recurrent urine and kidney infections may need long term antibiotic therapy although they can eventually lead to renal failure.

'One of the explanations given for John's increased tendency to urine infections is that, due to his small genitalia and therefore short urethra, it is much easier for a bug to enter the urinary tract. For this reason his nappies are changed regularly and a long term maintenance dose of antibiotic, together with Vitamin C, is now given.'

MASSAGE AND PHYSIOTHERAPY

Physiotherapy and gentle massage can begin as soon as baby is well enough in hospital or comes home. Babies with trisomy 13 and 18 clench their fists in a characteristic way and a physiotherapist can demonstrate the correct way to give the baby gentle massage and stretching exercises.

'At birth Dani's hands were clenched tightly and it was several months before we could open them. Gradually, with massaging and using little dumbell shaped rattles for her to grip, they became more supple. She now has full use of all her fingers although her grip is weak.'

'One of the first things the physiotherapist showed us was how to open our son's tiny clenched fingers. At the time our son objected but we now watch him play with his toys and are glad we spent the time doing it over and over again.'

Chest physiotherapy assists in the prevention of chest infections and a good seating position from a few weeks old will improve head control and aid mucus drainage. Parents can learn how to use a suction machine if needed.

'Before feeding Jonathan, I put him on his tummy over my knees with his head down. Using cupped hands I thump his back to produce a hollow sound, then repeat on his sides, and VERY gently on his chest cavity. After five minutes I sit him up and hope he coughs. Clear mucus means all is well, but I run to the doctor for antibiotics if it is green! We also find it calms him if he is crying or in a temper.'

'We have been doing exercises with John from an early age. Initially chest therapy, slapping his back and chest SOFTLY with cupped hands and gradually moving on to gentle stretching exercises. This sounds like a rigorous routine for a baby of a few months, however we managed to build it around playtimes and wakeful times and we noticed an improvement in his sleeping pattern when we started exercising him regularly.'

MASSAGE

Some hospitals encourage massage with unscented massage oil to which a few drops of an essential oil such as orange blossom or lemon has been added, but it is essential to consult the paediatrician or physiotherapist before starting any treatment.

'When our son was a baby we massaged his limbs and now he really stretches out and kicks in the bath. He receives hydrotherapy, which he loves.'

PLAY THERAPY AND TOYS

Physiotherapists can show parents how to stimulate their babies. To aid eye development and co-ordination silver paper or shiny bells can be moved slowly across in front of baby for the infant to 'track'. Mobiles are beautiful to watch and music or bells are interesting to listen to. Although a baby with trisomy may not reach out to take a toy immediately, by holding it in front of baby, rattling it, turning it for the eyes to follow, placing it in baby's hands, they will begin to experience 'play'. The usual time for a Child Development Centre to offer a regular 'play, stimulation and physiotherapy' session is when baby is about 6 months old, but much can be done before that at home by parents and visiting therapists. Hydrotherapy is another excellent means of stimulation and fun and therapy for stiff muscles and limbs.

'Beth had a felt ball with bells in it which we used to put in her hands and shake gently'

HEAT SENSITIVITY

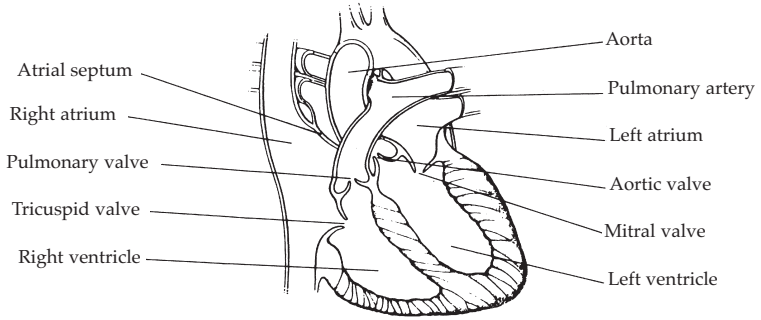
Babies with trisomy 18 may be sensitive to changes of temperature and can become distressed in hot weather.

'One moment our son is hot, then blue with cold. I have to watch him closely. It's as though his body thermostat is not working properly.'

'During the hot summer Jonathan became floppy and refused to drink. He was hospitalised, rehydrated and recovered. We never take him out in direct sunlight. Luckily we have one room that is always cool and he lives in it during a hot spell. We have noticed that his tolerance to light and heat has improved as he's got older.'

HEART DEFECTS

Heart defects affect about 80% of babies with trisomy 13, 90% of babies with trisomy 18 and may be mild or life threatening.



The Normal Heart

The heart is divided into 4 chambers. The upper chambers are called the atria (auricles) and the lower chambers are called the ventricles. Blood is pumped through these chambers, aided by 4 heart valves which open and close.

COMMON HEART DEFECTS

Ventricular Septal Defect - A hole between the lower chambers of the heart. The heart has to work harder and may become enlarged. A small opening does not strain the heart and the only abnormal finding is a loud murmur. A large opening can cause serious complications. The loudness of the murmur does not tell how large the defect is. The baby may need treatment to clear congestion from the lungs and make breathing easier.
Atrial Septal Defect - A hole between the two upper chambers of the heart making it difficult for sufficient oxygenated blood to be pumped to the body's tissues. A heart murmur is heard.

Dextrocardia - The location of the heart in the right side of the chest.
Tetralogy of Fallot - A large hole between the two ventricles and a narrowing at or just beneath the pulmonary valve. This results in blueness (cyanosis) which may appear shortly after birth.
Patent Ductus Arteriosus - Every baby is born with an open passage way between the aorta and the pulmonary artery (ductus arteriosus). This normally closes within a few hours of birth and failure to close is quite common in premature babies. When a baby has a chromosomal abnormality this process may take several weeks and if this fails to happen some of the blood that should have gone through the aorta and on to nourish the body, is returned to the lungs.

'A heart murmur was the first problem, also pulmonary hypertension and irreversible lung disease. The cardiologist diagnosed two large holes in the heart and misplaced arteries, but we were advised surgery was not an option as she would not survive the anaesthetic. Recently a heart catheter confirmed the diagnosis and she came through a three hour anaesthetic without problems, so we hope the situation will improve.'(trisomy 13 mosaic).

'Our baby, Annabel, had a large hole in the heart and she died from cardiac failure when she was five weeks old.'

'Rebecca needed oxygen as the hole in her heart allowed blood from different chambers to mix.'

'Emma has three holes in her heart but in her case we have been told they are not life threatening.'

'Kaylie gained from 5lb 2 oz to 5lb l5 oz in four weeks but then started to lose weight and when she was two months old the doctor admitted her to hospital with congestive heart failure.'

'Gradually Amy grew stronger and eventually we began to take her home for periods. Towards the end of her life, Amy began to show signs of heart failure and gradually tired of life. When she died it was very peaceful. For this we were both grateful.'

TESTS

There are tests to determine the extent of a heart defect and these will include a physical examination and possibly blood and urine tests. After reviewing the examinations and tests, the heart specialist (cardiologist) will make recommendations about possible treatment and may want to see the child at regular intervals.

Chest X-ray ~ Provides information about the size and shape of the heart and the lungs.

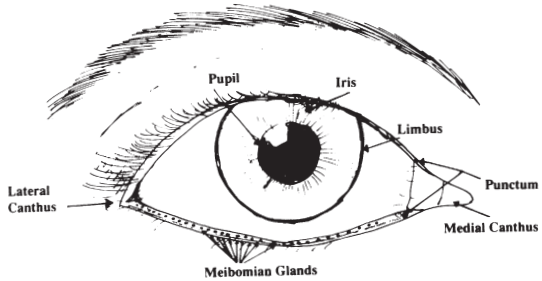
Electrocardiogram ~ Electrical impulses generated by the heart beat are recorded on a graph.

Echocardiogram ~ High frequency sound waves create an image of the heart.

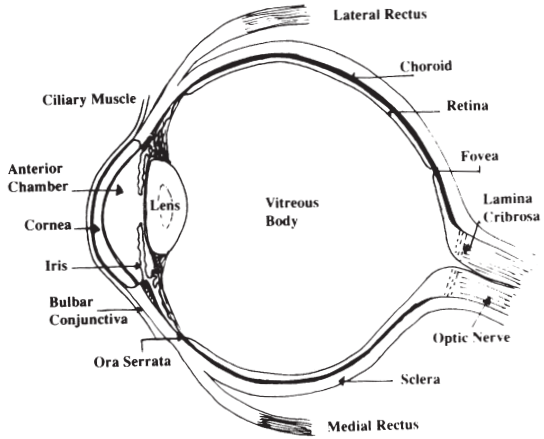
EYE PROBLEMS

Chromosome defects can result in the lids not developing. A baby will be unable to see when the eyelids completely cover the eyes, or if the lids are partially separated and vision will be restricted to looking in one direction only.

Surface anatomy of the eye



The eye cut in horizontal section



The eyeballs may be absent or miniature (micro-ophthalmus). Such small eyes often have short or long sight. The cornea is the window of the eye and an abnormal shape creates a gross distortion of vision.
Absence or poor development of the eye muscles can result in double vision and a squint (strabismus) where the eyes do not move together as a pair and occasionally the eye will be unable to move in a particular direction.

'Josh had an operation on his eyes and then what a different baby! It was very hard work with Josh as he used to cry constantly, but after the operation he began to smile and laugh, it was lovely.'

'Nicola had two operations for her squint and one was successful. Her eyes are almost straight and this makes such a difference. She is now a nosey baby and touches everything and is more mobile.'

PREVENTING EYE INFECTIONS

The function of the eyelids are to protect the eyes and blinking removes dust and bacteria that settle on the surface of the eye. Poor eyelid action leads to eye irritation.

When the lids are partly open there is a space where bacteria can collect and this and inefficient blinking may explain why babies can have chronic eye infections with persistent sticky eyes requiring antibiotic therapy. Careful bathing of the eyelids using sterile saline moistened buds to clean the lid edges is a good idea.

'Our son had persistent sticky eyes. Even in his sleep his eyes would be partially open. We bathed them regularly and used an antibiotic cream from our GP whose expertise in eye problems was invaluable to us.'

'Only one of Beth's eyes had developed and was very small. Her other eyelid never opened and drops for the daytime and ointment at night were prescribed to prevent eye infections'

'Joanne was born with corneal eye opacities which appeared as a white membrane that covered part of her eyes.'

LIGHT SENSITIVITY

The iris is the coloured part of the eye and can be absent (aniridia), or mis-shapen (coloboma) . These defects reduce the sharpness of the image formed by the eye and are not easy to correct. They may allow excess light to enter the eye causing children to have an aversion to bright light.

Children can react badly to light levels even when the eyelids are closed, as light penetrates the eyelid and enters the eye if the pupil is missing or enlarged. Glasses with a combination of protective ultraviolet absorbing, (and possibly infra-red absorbing), lenses with a tint to reduce glare can help.

Any degree of cataract reduces vision and scatters the light entering the eye thus causing glare and sensitivity to bright light. Some relief can be obtained by using protective lenses and a peaked hat or cap to shade the eyes can also help. The jelly-like vitreous material between the lens and the retina may not be clear, and can cause similar problems to cataract.

Specialist advice is always worth seeking.

'Melissa's eyesight is good but a major disability is her intolerance to light which places limits on her everyday life.'

'Jonathan has special glasses made by Mr. Garwood (SOFT Eye Specialist). We have been successful using them in the garden, in the shade, where he will open his eyes and look through them. He is never placed in direct sunlight, or taken outside on a very hot day, it is too dangerous.'

BEREAVEMENT

SOFT UK would like to thank SOFT Bereavement Adviser Erica Brown, Vice President of Acorns Children's Hospices in the West Midlands, for her valuable contributions to the BEREAVEMENT and HOW BROTHERS AND SISTERS ARE AFFECTED sections of this booklet

The world may never notice if a snowdrop doesn't bloom,
Or even pause to wonder if the petals fall too soon.
But every life that ever forms, or ever comes to be,
Will touch the world in some small way, for all eternity.
The little one we longed for, was swiftly here and gone.
But the love that was then planted, is a light that still shines on.
And though our arms are empty, our hearts know what to do.
For every single heart beat says that we love you.

Author Unknown

No two people react in exactly the same way to the death of a loved one, or to the diagnosis that their baby is going to be anything but perfect. Parents want their child to be healthy and the knowledge that a baby has a serious chromosome defect is devastating.

There are various stages of grief but we don't always follow a set pattern and not everybody needs expert counselling. However, everybody does need to share the sorrow of losing a loved one with someone. At whatever time your baby dies no-one can really prepare you for the great sense of loss that follows.

'There is a period of grief you go through and the need to mourn the 'normal' baby for which you have been planning and hoping.'

'I feel a bit sad that we have never been offered any formal genetic counselling, and we never had any follow up after Anna died, either from the obstetric or paediatric field.'

'When Susan died, my overwhelming feelings were those of relief that her life hadn't been prolonged. I thought that because she was severely handicapped that this would make my grieving easier. However I found myself desperately wanting her back, not with trisomy 18, but as a strong healthy little girl.'

IN SHOCK

The initial shock brings a numbness that could be described as being on 'auto pilot'. We can function but are shielded from the full impact of what has happened. A person may be heard to be saying over and over again 'It can't be true'. C. S. Lewis wrote, 'A sort of invisible blanket between myself and the world'. This not accepting reality may lead to guilt as we recognise what has happened.

'I think any mother of an 'abnormal' child feels some guilt as if she made her child that way - she can feel as if she is not worthy to be a proper mother. To exclude her from the world of children reinforces that feeling of inadequacy.'

ANGER AND GUILT

As we question, there may be anger and guilt focused against other people; for example, doctors and loved ones also resentment against those who don't appreciate their own healthy babies. Such bitterness is quite normal but can become destructive if you are unable to share it. Parents turn to each other for support, but it is unlikely two people will experience exactly the same emotions at the same time and this can put a strain upon a relationship.

'I still find people's attitudes very hard, even my sister in law was surprised I was still depressed. Everybody expects me to be back to normal but how can you when you feel like shouting out, "Do you know my baby died months ago and it still hurts so much it may as well be last week."

'It took me a long time to deal with the loss of a twin. I felt resentful that I had wanted only one child, been given two and then had one taken away.'

IF ONLY

There may be a short period fantasizing when you keep thinking, 'If only.....'Then the loss becomes very real and the bereaved parent releases the sadness and may spend a lot of time weeping. This is when one feels most lonely, but it is when the healing process begins and is very important. Try to share this stage with someone you trust. Your partner may or may not be able to cope, and it seems it will never end and you may feel resentful towards members of your family who can share a joke together. They may welcome the chance to tell you their true feelings so do try to talk to them and to your children about how you are missing your baby. You will soon be ready to pass on to the next stage which is considered the most difficult because it needs a certain amount of effort to achieve. It is 'letting go'.

LETTING GO

We cannot cling forever to the baby we loved and who has died. There is no benefit to either ourselves or the deceased. Avoid making impractical promises like vowing to visit the grave every day. Siblings will grow to resent

this and it will achieve nothing. Letting go may awaken guilt, but you cannot rebuild your life until you are free from the burden of grief. As you let go memories become less painful and easier to cherish.

'I think that after a few months we began to see the light at the end of the tunnel. There are obviously still tears, but it is only now that we begin to realise how few people can actually identify with what we are going through.'

LEARNING TO LIVE AGAIN

This is the final stage and since grieving uses a lot of energy you need to 'get fit'. Do some of the activities you used to enjoy but had to give up. Make new friends and spend time on hobbies and interests.

MEMORIES WHEN A BABY DIES DURING PREGNANCY OR SHORTLY AFTER BIRTH

When a baby dies during pregnancy or is still born, parents may decide to have a funeral as an acknowledgement of the baby's life. Should you choose not to have a private service, the hospital will ensure your baby is laid to rest with dignity. You may be asked for permission for a post-mortem, and it is up to you to agree or refuse.

Losing your baby during pregnancy or shortly after birth does not have to mean you have no memories. There are many things you can do to make these memories, such as keeping a diary or even an online blog of your baby, or start a scrapbook with the scans, cards or photographs you have.

You may want to plant a special tree or flower for your child, or have their name written beautifully in the snow or sand captured in a photograph forever, or maybe you would like to name a star after your baby, there are so many alternatives.

Taking a clipping of your baby's hair that you can keep close can help you feel as if part of them is still with you, footprints and handprints can be made, or casts taken before or after your baby has died. These can then be made into jewellery or plated, and ashes can become diamonds, a permanent and beautiful reminder of your little one. Memory boxes and chests are widely available, and you can store mementos of your child to keep as precious memories.

It is important to do what you feel is right and keep whatever you want to. There is no 'proper' way to grieve and everyone is different.

'When I first found out about Liam at 15 weeks I decided to start a blog for him, I wanted to keep his memory alive forever and this seemed the best way to do it. I still write there 4 months after his passing, I find it helps me still and gives me somewhere to let myself go emotionally. His little feet were so beautiful and it became an obsession to have as many copies in as many different forms possible. We kept

everything, even the sheet he slept on. Initially I couldn't even look at them but now I am so glad I have them all.'

'Each year we mark her birthday and by talking about her in our daily lives we are keeping her memory alive. She is too important to be forgotten.'

FUNERAL ARRANGEMENTS

The last thing any parent wants to do is organise their child's funeral, but it does help to be a little prepared, if not on paper then in your own head. Some people find it helps to have arranged and paid for the funeral in full before needing it, others see this as too upsetting, as if they are sealing their child's fate. You need to do what you both feel comfortable with. It can help to ask a family friend to lend a hand with this, as a means of support.

The first step is to find a suitable funeral director, and recommendation is a good way to go about this. The way they deal with clients is much more important than the size and familiar name of a company. Ring to make an appointment as it means they can set aside enough time to talk things through. The last thing you want to feel is rushed, and if you have your own ideas about what you would like, then ask. Special arrangements may be made for the release of balloons or doves for example, but these will add to the cost of your child's funeral.

Think carefully about the music you want, you do not have to choose hymns or music immediately, in fact you do not have to have a religious service or hymns if that is your wish. You may have a particular chaplain or religious leader in mind to conduct a service, or you can use your local hospital chaplain, it is entirely up to you.

Smaller caskets can often be swamped by lots of flowers. You may want to limit the number of people allowed to send flowers and ask for donations to a charity instead. Make sure the funeral director is aware of any clothing you want to dress your child in as they will be able to do this for you.

Above all make sure you and your partner are in agreement about the funeral arrangements, consider each others wants and needs, no matter how personal they may seem to you they will have a special meaning to them.

'The last two days have been spent arranging Liam's funeral. Just when you want to curl up and die in corner you find yourself with what seems an endless list of things to do. We decided to buy a little pyjama set, complete with shawl, and I like to think of him as sleeping and his funeral as us saying goodnight, so pyjamas seemed very appropriate. We had chosen Sally, the hospital Chaplain to perform the ceremony, as she had met Liam a couple of times in his short life and prayed for him with us while he was here.'

A FATHERS GRIEF

It must be very difficult
To be a man in grief,
Since "men don't cry"
and "men are strong"
No tears can bring relief.
It must be very difficult
To stand up to the test,
And field the calls and visitors
So she can get some rest.
They always ask if she's all right
And what she's going through.
But seldom take his hand and ask,
"My friend, but how are you?"
He hears her crying in the night
And thinks his heart will break.
He dries her tears and comforts her,
But "stays strong" for her sake.
It must be very difficult
To start each day anew.
And try to be so very brave
He lost his baby too.

COUNSELLING SERVICES

Some hospitals and health authorities have access to bereavement counselling services for parents. For example, in Leicester the LAURA Centre offers help to parents with experience of loss of a child and in Gloucestershire Winston's Wish provides counselling and activities for bereaved children.

PERSONAL EXPERIENCES OF BEREAVEMENT

'There is a period of grief you go through and the need to mourn the 'normal' baby for which you have been planning and hoping for nine months. I had this grief at my daughter's birth and shed many tears. But I hadn't really recognised my feelings and it wasn't until I attended a talk by a psychologist and he put my feelings into words, that I was able to cry and it was easier to come to terms with our unexpected child.'

'I am 23 years old and never thought I would feel and know what I do. Dealing with the death of our child was always, to me, something that happened when you were 80.'

'Freddie died shortly after birth and we had no other children to cushion the blow. To lose a first child is, it seems, the end.'

'After Michael died I worried that I had not loved him enough and blamed myself for rejecting him when he was first born and I was told he had T. 13. Now I know parents can feel this way, but I wish my family would talk about him. They seem to have forgotten he ever existed.'

'My husband and I still share our grief but he keeps a lot of his emotions in and is terribly upset when we talk about Leah. A Compassionate Friends group which meets locally has helped me greatly to look back and write down everything I remembered from the day she was born to her funeral. When that was accomplished I felt tremendous satisfaction.'

'After Amy died we attended several bereavement sessions with two other couples who had lost infants through SIDS (Sudden Infant Death Syndrome) and spoke at a bereavement seminar. This and books helped us considerably.'

'I have found out that because Louisa lived for only a few hours, not days or weeks, I felt very much as though it wasn't a real event. People didn't consider that she had been a person and consequently I was made to feel that it wasn't like a normal bereavement.'

'Time with Hannah was so precious. We filled it with love and laughter so now we have many special memories of our dear little daughter.'

'When Susan died, my overwhelming feelings were those of relief that her life hadn't been prolonged. I thought that because she was severely handicapped that this would make grieving easier. However, I found myself desperately wanting her back, not as she was with trisomy 18, but as a strong, healthy little girl.'

'I think that after a few months we began to see the light at the end of the tunnel. There are obviously still tears, but it is only now we begin to realise how few people can actually identify with what we are still going through.'

'A patient at work asked me if I had any children. I told her all about my son being stillborn with trisomy 13. Afterwards I couldn't stop shaking. I miss being pregnant and I miss my baby boy.'

'I thought that I was coping up until a few weeks ago when I began to look through Cheryl's photos and from then I haven't been able to sleep. I think it is because it is getting closer to the time when she was born and sadly died.'

'I feel a bit sad that we have never been offered any formal genetic counselling and we never had any follow-up after Anna died, either from the paediatric or obstetric field.'

'At 2. 00am the next day the ventilator was switched off. We were taken to a private room and Laura was brought to us. She died in my arms at 3.13am. I sat and held her and cried and cried. I have photos of Laura and a lock of her hair; also her hand and foot print. Even now I look at them and cry.'

'I read a poem at the funeral which meant a great deal. We wanted to produce the service sheet as a lasting reminder of the day and it has proved useful to send to people rather than trying to recount the events on the telephone .... never easy.'

BROTHERS AND SISTERS

Do not stand at my grave and weep
I am not there, I do not sleep
I am the thousand winds that blow
I am the diamond glints on snow
I am the sun on ripened grain
I am the gentle Autumn rain
I am the early morning light
I am a star that shines at night
Do not stand at my grave and cry
I am not there. I did not die.

Every year thousands of children face bereavement through the death of a grandparent, parent, sibling or friend. When someone dies, adults are understandably so engrossed in their own grief that children's grief may be unnoticed. However, the way in which children are helped when sad things happen may have a profound effect on how they are able to adapt to loss and change throughout their lives.

For a child or young person, bereavement can be an acutely sad and difficult time, to the point of being overwhelming. Children differ in exactly how and when they respond, and what they need of others as they live through the experience.

FIVE SIMPLE RULES

- Share your grief with your other children
- Encourage them to share their grief with you
- Express your love with kisses and cuddles
- Make quality time to talk and listen
- Answer questions honestly

WHAT TO SAY

The kindest course is to tell a child what is happening or has happened in words they understand. In the absence of a truthful explanation, children's fertile imaginations will conjure up the worst possible scenario sometimes imagining that they are responsible. Use simple phrases, answer questions honestly and say if you don't know the answers. Children will ask what they need to know.

'After our baby died our young son thought you have a baby for a while, the baby lives for a short time, and then the baby dies. We explained that only very poorly babies that can't get better are the ones that die. The healthy ones don't die.'
'Mum was going to have a baby and the whole family was excited, especially me.

All my friends had baby brothers or sisters and I couldn't wait to play with our baby. My little sister arrived and we called her Beth. But mummy and daddy kept crying because Beth was very poorly.'

'My small son wet his bed and became miserable at home so I arranged visits to a counsellor which helped us a great deal. He is much happier now.'

'Our 3 year old expressed strong feelings about the death of his baby sister. He was angry and sad and resented her because she wasn't there for him any more.'

'Rhiannon is 3 years old and misses Jessica too and often asks if we can have another baby that is well and will be able to stay.'

YOUNG CHILDREN

Children's grief reactions are usually intense but short-lived. Young children are receptive to the grief of a parent and can become clingy, and they may sometimes refuse to go to bed alone and want to keep adults in sight. Avoid changes in the daily routine such as meal and bed times. Seeing a parent in distress is very frightening and parents should be prepared for emotional and physical responses such as tearfulness, bedwetting, and tantrums.

Younger children can feel guilt and imagine they contributed to the death in some way, even by wishing the baby would go away when they experienced pangs of insecurity. They must be reassured that the baby was different and weak, and the death was nobody's fault. Children are at a 'magical' stage of thinking, believing that the world revolves around them and they may therefore feel responsible if a baby dies.

Death can be related to events in the natural world such as animals and flowers dying, and use the word 'dead' to describe what has happened to the baby. Words like 'loss' and 'taken from us' should be avoided since young children often understand language literally and may think that death is not permanent.

Young children are not able to sustain grieving behaviour for long periods. It is thought this is likely because they are so overwhelmed by emotions that they 'withdraw' from the grief and get on with familiar routines. Their expression of sadness tends to range from bitter outbursts of crying to quiet withdrawal.

There are picture books for very young children to help them understand, and they can be encouraged to express their feelings by drawing pictures and engaging in play.

'We told our children their baby sister had gone to heaven, and her body was like an empty chrysalis after a beautiful butterfly had flown away.'

'Today my friend came over with a baby who is a few weeks old. My daughter Ella aged three went quiet, and when I went to make the tea she followed me and asked me if our baby Hope, who had died, had come back. She kept staring at the baby and I think she realised she didn't look the same, and once I told her it wasn't Hope she was a lot happier but very wary of the baby.'

'Well, happier times have come with the birth of Gemma. She is very, very special to us. We shall of course never forget Lee and when Gemma is older she shall learn all about him.'

CHILDREN AT SCHOOL

School may become the one place in their lives they feel is unaffected by the death and they might appear to be 'coping' remarkably well. Occasionally children may refuse to go to school, feeling that if they are at home they can make sure that all is well there.

Children may worry about breaking down in front of school friends. They may have off days when concentration is difficult, or get into arguments and fights. Teachers need to know what has happened and what information the child would like the class to know. The school should provide a quiet 'safe' space where children can spend time during the school day if they wish to rest, and someone the child can go and confide in.

'After my baby sister died it was horrible going to school and I wanted to stay at home. One teacher was very nice and I used to go to her whenever I was upset and she would give me a drink and some biscuits'.

OLDER CHILDREN

Older children will worry about the reality of death, their own and a parent. Many become over-protective of a parent and try to assume the family tasks and responsibilities, or they can be sullen and refuse to talk about what has happened. They may try to protect the adults around them by hiding their grief or giving other reasons for being sad. Some children develop vague headaches and stomach pains. Where families are members of faith communities, children's understanding of what happens after death will reflect the teachings and beliefs of the community and what they have been taught. Children are interested in death rituals and funerals and may be happier to talk to someone outside the immediate family such as a close relative or teacher. They can express their feelings by keeping a daily diary, and new interests such as sport or music are a positive step.

'They told me Beth was very ill and one day I came home from school and found out she had died. That night I prayed that when I woke up my baby sister would be in her crib, but I knew it would never come true. I wish I had spent more time with Beth and I tried to help Mummy as much as I could.'

WAYS OF SUPPORTING CHILDREN

- Provide continuity of care and routines
- Encourage creative play and activities such as painting
- Talk to the child about what has happened
- Answer questions honestly and in age-appropriate language
- Reassure the child that they were not responsible for what has happened
- Encourage fun and enjoyment as well as opportunities to express fears and concerns

VIEWING THE BODY

Funeral Directors and hospitals have a Chapel of Rest and many families take their other children to see the body of the dead baby. Parents may be anxious about the effect this might have on brothers and sisters, but children have vivid imaginations and it is kinder for them to see, and perhaps hold the dead baby to reassure themselves the body of the child looks peaceful and is no longer alive. It may be difficult for the adults to accept this, but for the children death is a natural part of life, and they may have had experience of it with wild animals, pets and older relatives. Siblings treasure a personal keepsake or photograph.

A FUNERAL

Warn children this is a sad occasion and the way we say goodbye when someone dies, and involve them in the planning of the funeral, perhaps to place flowers on the coffin, say a prayer or reading, or choose a favourite song or hymn.

'As we had prepared our girls for Dara's death our older child was reluctant to attend the ceremony or funeral and particularly the cemetery. But the paediatrician insisted they go through the entire experience from holding Dara after her death to the funeral, as children need a beginning, middle and end. They have no unhappy memories and have a definite relationship with Dara to this day. We found the attitude very helpful.'

'At the funeral I didn't cry. I think I had run out of tears. Everybody was very sad and we put a bunch of wild flowers on her coffin.'

SHARING GRIEF

Parents preoccupied with their own grief may not realise just how unhappy their other children are. Families share happiness and they should be able to share sadness and tears and understand that grieving can be a lengthy process. Don't be afraid to let your children see you cry, and tell them what has made you sad or even angry, and explain that this anger is not directed at them, and that it is tiredness that may be making you irritable and bad tempered.

Give extra cuddles to the quiet child who is suppressing their emotions in order to protect the parent from further distress. Older children tend to hide their feelings anyway and wonder if their behaviour contributed to the death. There are books written about death aimed at all age groups, and it can help to read them together and discuss the way the issues are dealt with. A video, 'When a Child Grieves' can be obtained from the Child Bereavement Trust.

'I want to say I miss you
But I know it makes them cry,
I want to hug and kiss you
And never say goodbye,
They talked in gentle whispers
And said that you had died,
So I sit here quietly playing
And keep you deep inside'

A NEW BABY

Parents worry about the health of future children, and another pregnancy is an anxious as well as happy time. There is no right time to get pregnant and for some people healing and the return of confidence comes much sooner than for others. Parents must decide according to their own individual circumstances.

Some couples 'try' to have another baby without delay and older women may decide time is a luxury they do not have. Other couples need to wait until they are ready and, for some parents, there will be no other baby and the baby with trisomy will be their only experience of parenthood.

'I had a further miscarriage two months ago, and I do doubt my ability to have babies as I seem to be surrounded by women producing healthy babies. You get quite jealous that they breeze through 9 months and you wonder when you will lose your baby and worry the whole time.'

'After Joshua died my life felt very empty and I began to consider another baby. We went to see a geneticist to have our own chromosomes tested and to discuss what the chances of another baby with chromosome abnormalities were.'

'*Although another baby will never and should not replace Kate we both feel we wanted her so much that for the sake of her memory and for her sister and for ourselves we will try again, but always in my mind is the worry that I don't know if I could cope with the loss of another baby if things go wrong. We have been told we will be sent for tests in London. I hope we have the courage to try again.'*

'The first thing we needed to know, was I medically fit to bear another child? I was 41 when Beth was born by elective Caesarean. The next question was whether we were emotionally ready to make a decision regarding another child. I did not want to 'try' for a baby, but neither did I want to prevent one. Were our children ready for another brother or sister? They loved Beth but faced losing her at any time.
Beth died when she was 3 months old and I discovered I was pregnant the day before the funeral. It is difficult to grieve for one baby and take joy in another and I plodded through my pregnancy on a day to day basis, refusing to plan ahead until after the baby was born. We decided to call our new baby Daniela, and later pregnancy was traumatic as I did not dare to take Daniela's apparent good health and safe birth for granted.

Beth was our daughter and we will always love her and imagine her growing up year by year, but after her death there was a vacuum. We had such a lot of love to give, and no baby to cuddle and give it to. Daniela filled that vacuum and replaced some of our pain with happiness and laughter. We told ourselves that Beth would not have wanted us to be miserable for ever and we were sure she would have adored her sister.'

A SOFT booklet "Your Unborn Baby" is available for families who wish to consider the issues of prenatal diagnosis and pregnancy testing in more detail.

RENEWED SADNESS

A new pregnancy brings renewed pressures and sadness for the baby that died. Ante-natal screening must be considered, but whatever the advice you do not have to undergo invasive testing unless you wish to do so.

'During my next pregnancy I had every test that was on offer. Each brought temporary reassurance but I would then worry that the next one would show that something was wrong. It wasn't until my baby was born and was so obviously healthy that I allowed myself to relax a little.'

'When my son was born we were thrilled that he was healthy, but as he grew and developed normally we realised how disadvantaged our daughter had been with all her problems.'

'I was lucky and my second child is healthy. I have a very different attitude to his and others life though. Just as parents of babies with serious problems know they may only have them for a short while, I feel that even for a "normal" person, each day is a gift and an experience to be thankful for.'

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ABOUT SOFT UK Registered Charity 1002918

SOFT is the Support Organisation for trisomy 13 (Patau's syndrome), trisomy 18 (Edwards' syndrome), and related disorders such as translocations and mosaicism. SOFT provides help and information for families after a diagnosis of one of these conditions. Families are put in touch with befrienders who are willing to listen and share their experiences. Each year Conference Days are organised and members can meet together and talk to other families and to medical professionals.

SOFT supports a network of area co-ordinators, and publishes a range of literature dealing with the various problems families face when affected by one of these conditions.

INFORMATION FOR PARENTS

SOFT UK distributes Your Unborn Baby and Your Baby booklets, and newsletters free of charge to family members. The newsletters and booklets produced by SOFT UK meet a desperate need for practical and positive information presented in a sensitive way and they are on the www.soft.org.uk website, but if you request a paper copy, professionals and students are asked for a donation of £5 per information pack to cover the cost of printing and postage.

SOFT booklets can be used as a basis for discussion between a carer and their medical advisers. We do not recommend particular methods of treatment, and we advise parents that new treatments must never be introduced or existing treatments changed without consultation with their doctor or other medical professionals.

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News, photographs, data, on-line booklets and remembrance stars

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FUNDRAISING AND DONATIONS

To obtain a fundraising pack or SOFT fundraising guidelines you can ring the help line on **01213 513122** or forward your details using the enquiry box on the Contact Us page of **www.soft.org.uk**.

Without generous donations and imaginative fundraising SOFT UK would not be able to publish YOUR UNBORN BABY and YOUR BABY booklets, produce newsletters, fund SOFT Days or regularly update the website and SOFT Remembrance Page.

To make online donations please use our secure Virgin Money Giving account by clicking the button on the fundraising page of **www.soft.org.uk** or send a cheque payable to SOFT UK c/o 48 Froggatts Ride, Walmley, Sutton Coldfield, West Midlands B76 2TQ

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OTHER SOURCES OF SUPPORT FOR PARENTS

ARC Antenatal Results and Choices 0207 631 0285
(ARC publish 'Another Pregnancy' for families considering another pregnancy)

Contact a Family 0808 808 3555

Down's Syndrome Association 0845 230 0372

Child Bereavement Trust - Child Deaths Helpline 0800 282 986

Compassionate Friends 0845 123 2304

Relate 0300 100 1234

Samaritans 08457 909 090

SANDS helpline 020 7436 5881

Spina Bifida and Hydrocephalus 08454 507 755

TAMBA (Twins and Multiple Births Association) 0800 138 0509

Unique 01883 330766

G.I.G Genetic Interest Group 020 7359 1447

Disability Alliance 020 7247 8776

BENEFITS FOR BABIES/CHILDREN WITH TRISOMY 13, TRISOMY 18 OR A RELATED DISORDER

Parents can apply for DLA as soon as there is a diagnosis of trisomy 13, trisomy 18 or a related disorder. Form DS1500 needs to be obtained from your Doctor and may be submitted to your local Disability Benefits Centre, as soon after birth of your baby, as possible

DISABILITY LIVING ALLOWANCE FOR CHILDREN.

Disability living allowance (DLA) provides help towards the extra costs of bringing up a disabled child. It is paid on top of almost any other income you may have and gives you access to other kinds of help. There are two parts to DLA:

• **a care component** - for children needing a lot of extra personal care, supervision or watching over because of their disability. This is paid at 3 different rates. It can be paid from the age of 3 months, or from birth for a terminally ill baby;

• **a mobility component** - a higher rate for children aged 3 or over who cannot walk or have severe walking difficulties and a lower rate for children aged 5 or over who can walk but who need extra guidance or supervision on unfamiliar routes outdoors. The higher rate may also be paid to children getting the highest rate care component who are severely mentally impaired; with extremely disruptive behaviour; deaf-blind children.
(taken from DISABILITY RIGHTS HANDBOOK 32nd Edition April 2007 - April 2008 page 188). Disability Alliance © 2007. www.disabilityalliance.org

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