

SOFT UK

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Trisomy 13/18 For Siblings

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This booklet was written as a discussion aid for parents and siblings after the diagnosis, birth, or loss of a baby affected by trisomy 13 (Patau's syndrome), or trisomy 18 (Edwards' syndrome). The bereavement may have occurred during pregnancy.

There are three sections aimed at different age groups. Parents can select the appropriate level and use the text and pictures to answer their child's questions.

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Our Special Baby

for pre school siblings



Mummy was having a baby.
We were very happy, but one
day the doctor had sad news.

Our baby was not growing like
other babies. Our baby will never
walk and talk, or play like other
children.








We don't know how long our
baby will be with us.





We can remember our baby in many different ways.



We think about our baby when we see stars at night,  or rainbows in the sky,  or butterflies.   

We can keep a memory box, plant a tree, and release balloons.



Every year we will remember our baby on the day of their birthday.





Our Special Baby

for primary school siblings

Mum was going to have a baby, a new brother or sister, and we were excited.



One day the doctor had some news. Our baby was not growing like other babies.

Our baby would never talk and walk, or or go to school and play like other children. We did not know how long our baby would be with us.



It was nobody's fault. The doctors and nurses did not know why our baby was so ill.

It was a very sad time for everyone and we cried.



There are lots of ways we can say goodbye and show how special our baby was to us all.



Families may choose to hold a service, play music and sing songs.

We can say prayers, write poems and give flowers.



Or light candles and plant a tree in a special place.

We can name a SOFT star and release balloons.



Every year we will think about our baby on the day that would have been their birthday.



Our Special Baby

for older siblings

Our body is made from cells and they keep dividing as a person grows. Every cell has two pairs of chromosomes numbered 1 to 22 and each pair is different.



Can you spot the difference? Look at the length.

Girls also have a pair of XX chromosomes and boys have a pair of XY chromosomes.

Trisomy means three chromosomes, not the usual pair.



Trisomy 13 can be called Patau's syndrome and there are three number 13 chromosomes in every cell.



Trisomy 18 can be called Edwards' syndrome and there are three number 18 chromosomes in every cell.



A baby with trisomy 13 or 18 will not develop and grow in the same way as a baby with normal chromosomes.

Every baby is unique. Babies with trisomy are individuals too, and they will all be different. Trisomy 13 and trisomy 18 are very rare and nobody knows why these things happen.

A mother may be told during pregnancy that her baby has one of these conditions, and the baby may die before birth.



Parents are sometimes told their baby has trisomy 13 or trisomy 18 after the baby is born, and it is a very sad time for all the family.



A few babies with trisomy 13/18 live after they are born, and they may be able to go home. They will grow and develop more slowly than a healthy baby.



Some of these babies will have a heart problem and need help with breathing and feeding. Some babies will have a gap in their top lip.



It is rare for babies with the full Edwards' or Patau's syndromes to grow up.

But a few do.

These children have many medical problems and can need a lot of special care.





When a baby or child dies it is a very sad time and it may be difficult to talk to people about it. Find a friend, or relative, or teacher you are comfortable with, and try and share how you feel.



After a baby dies, some families may light candles, read a poem, say a prayer, release balloons, plant a tree, or name a remembrance star.



A faith leader can hold a service for a family to say 'goodbye' to the baby they love. You may be able to help plan the service and take part. You might like to draw a picture, write a letter, or think of a poem?





We will always love our baby. Memories are very special, and as time passes it may become easier to talk about your brother or sister.

Some mothers have another baby who is healthy, but the family never forget the baby that changed their lives.



After such a sad loss, another baby is like a rainbow after a storm, and some families call their new baby,

a rainbow baby





This page is for you to write your baby brother or sister's name and the date of your baby's birthday. If you have a memory card, picture, photograph or poem, you can place them on this page.



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was compiled by Jenny Robbins
in memory of SOFT UK babies.



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