

# Continuing Pregnancy with a Diagnosis Of Down's Syndrome

## A Guide for Parents

A DOWN'S SYNDROME ASSOCIATION PUBLICATION





## ■ INTRODUCTION

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**If you are reading this booklet, you (and your partner, if you have one) are expecting a baby. Congratulations!**

Receiving the news that your baby has Down's syndrome can be a shocking experience. This booklet aims to dispel some of your fears, reassure you that many other parents have felt the same way that you do, and introduce you to a little information about Down's syndrome itself. In our experience, parents who find out about their child's condition before s/he is born are better informed and often over the shock of the diagnosis by the time of the birth. This makes them better equipped to be able to bond with their baby as they would any other child.

This booklet is based on parents' responses to a questionnaire on the Down's Syndrome Association website. The questionnaire was reproduced with the kind permission of the Down Syndrome Association of Orange County.

We begin with an introduction to the condition. There follows a long section of quotes from other parents who have been in your position. Some of them may be helpful, some upsetting; you may find it useful to dip in and out of the quotes and not try to take in too much at once. The final section of the booklet gives advice on telling your family and friends about the diagnosis, and signposts you to further information and organisations that are all here to help you.

## ■ WHAT IS DOWN'S SYNDROME?

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In 1866 an English doctor, John Langdon Down, described a group of people who shared a consistent pattern of characteristics. The syndrome was named after him and is now called Down's syndrome or Down syndrome.

Down's syndrome is a genetic condition that results in some level of learning disability and a range of physical characteristics. The learning disability significantly affects a child's ability to learn compared with other children of their age - it does not mean a child cannot learn at all. Down's syndrome is one of the most common causes of learning disability.

About one baby in every thousand is born with Down's syndrome.

## ■ WHAT CAUSES THE SYNDROME?

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The human body is made up of cells. Each cell is like a factory, that makes everything needed for growth and to maintain the body. Every cell contains a nucleus in which genes are stored. The genes control the work of the cell, as though they contain a set of instructions. Genes are grouped in rod-like structures called chromosomes. Usually, the nucleus of each cell contains 23 pairs of chromosomes. 23 are inherited from the mother and 23 from the father. This makes 46 chromosomes in all.

In people with Down's syndrome, all or some of the cells in their bodies contain 47 chromosomes, as there is an extra copy of chromosome 21. This additional genetic material results in the range of physical features and developmental characteristics associated with Down's syndrome.

### *There are three types of Down's syndrome:*

**Trisomy 21** - in which all the cells in the body have an extra chromosome 21. About 94% of people with Down's syndrome have this type.

**Translocation** - in which extra chromosome 21 material is attached to another chromosome. Around 4% of people with Down's syndrome have this type.

**Mosaic** - in which only some of the cells have extra chromosome 21 material. About 2% of people with Down's syndrome have this type.

The type of genetic variation that children experience does not significantly alter the effect of Down's syndrome.

## ■ ANYONE CAN HAVE A BABY WITH DOWN'S SYNDROME

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Down's syndrome affects people of all races, religions and economic backgrounds and in all countries around the world. It can happen to anyone.

Although the chance of having a baby with Down's syndrome increases with the mother's age, babies with the syndrome are born to mothers of all ages. Over half of all children with Down's syndrome are born to mothers under the age of 35 years.



As yet, no one knows what causes the presence of the extra chromosome 21. It can come from the mother or the father. There is no way of predicting whether a person is more or less likely to make an egg or sperm with an extra chromosome. What we do know is that nobody is to blame. As far as we know, nothing done before or during pregnancy causes the syndrome.

**This is one mother's interpretation of the experience of having a child with Down's syndrome:**

## ■ WELCOME TO HOLLAND

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*"When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.*

*After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."*

*"Holland?!?" you say. "What do you mean, Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."*

*But there's been a change in the flight plan. They've landed in Holland and there you must stay.*

*The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.*

*It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around... and you begin to notice that Holland has windmills... and Holland has tulips. Holland even has Rembrandts.*

*But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."*

*But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things... about Holland."*

By Emily Perl Kingsley

Here are some of the responses to our questionnaire from parents who found out their unborn baby had Down's syndrome:



### How did you find out that you were carrying a child with Down's syndrome during your pregnancy? What do you remember about the experience?

- Had the triple test, where the result was a 1 in 14 chance of having a baby with Down's syndrome. Followed this with an amniocentesis, which confirmed the diagnosis. I remember feeling totally shocked at the result, thinking there must be a mistake and not believing it could be happening. Also remember having spent about a whole week in a complete blur, not thinking about anything else but the result.
- At my first scan, the nurse asked me if I had thought about having tests done to check if my baby was ok. I said no because I was in my early 30's and did not agree with testing anyway. Then I asked why and she replied that the Nuchal Fold was larger than it should be which may indicate Down's syndrome. It was a real shock and the nurse was quite blunt. She then told me I should speak to some doctors about my 'options'. I had to wait quite a while, very upset among many happily pregnant women to see the specialists.
- We found out she had a heart defect at her 19 week scan. From there we were referred to Leeds General Infirmary for a more detailed diagnosis. It was there that the issue of Down's syndrome was raised. It was then another week before my wife could get an amnio. However we did get the results back the following day after a FISH (rapid) test. I remember that after we found out from the cardiologist that the risk was there we quite quickly decided that if there were no other complications then we would go ahead with the pregnancy.
- Although I had half expected it, I still couldn't believe that this was happening to me. The midwife was excellent, telling me to take some time to take the news in and phone her back as soon as I had any questions. I phoned her back about an hour later and asked her to talk me through the options, which she did, going through the next steps if I continued with the pregnancy first. She continually stressed that I would be well supported whichever path I chose. She took time to



talk through all the extra tests and care I would receive if I continued with the pregnancy. That first day, my partner and I cried a lot. There was a sense of "why us?" but for me this was quickly replaced with "well, why not me?". I devoured every bit of information I could lay my hands on, as I had to deal with the cold, hard facts and all the possibilities without having the baby to hold in my arms. My partner and I split shortly after we received this news

(unrelated circumstances) and I felt terribly isolated as I discovered that most women choose to terminate in my circumstances. The following four months were very difficult and gave me plenty of time to worry about everything!

- I had an amnio. I was terrified to have it done beforehand and did not want to do it. My husband talked me into it because he felt we HAD to know (I was carrying twins). Oddly enough, he asked the genetic counsellor what would happen if one twin had Down's syndrome and not the other. It was a possibility that had never occurred to me ... I had only ever thought that both or neither could have Down's syndrome. I received the information by phone (the doctor who had the information hadn't been able to contact my gynaecologist, who should have given me the information, and was too busy to wait. Three years later, I can still remember where I was and what kind of a day it was. The shock was huge. My husband was outside in the garden and I went out and wept in his arms. Worse, he had to leave me an hour later and I was alone with my thoughts all afternoon. My gynaecologist called later in the afternoon to find out how I was (presumably the other doctor had managed to contact her - why oh why did he not refrain from telling me over the phone?) It was one of the hardest days of my life...
- Problems detected at routine 20-week scan, followed by amnio. Very difficult time, whirlwind of appointments. Felt rushed and pressured into making a quick decision.
- Had a dating scan which revealed a Nuchal Fold of 5mm. Then had a CVS which confirmed after a three day wait that my baby had Down's syndrome. Felt sad, angry, grief, yet also relieved that we knew what we were dealing with and could move forward.

- Amniocentesis. Heartbreaking! But treated very well by the medical community. When advised to have amnio, the radiographer told us to look at it as not finding out to terminate, but to do everything we could before birth to educate ourselves, adjust, and commence any in-utero tests we could to ensure the arrival of a healthy baby.



## **Thinking back, when you first heard the news of your child's diagnosis, what do you wish you had known then that you know now? Is there anything you wished you had done differently to prepare?**

- Nothing different. The reason we wanted to find out pre-natally was to better prepare ourselves for what we would have to face. Hence, after the initial shock, we started doing our research -through the DSA website, we contacted local parents and groups, etc and by the time our daughter was born, we felt we had prepared enough for the time being.
- I can only describe how much joy my son has given me. Although the first year was a challenge and there were low points. My son is a happy, funny little boy who always makes people smile. Looking back I shouldn't have worried that I could not cope or think I would not be a good parent to a child with Down's syndrome. I shouldn't have worried so much! My own selfishness was the only barrier to loving my child.
- Nothing! I think very little would have changed our minds. She was our child and that was that. We did research quite heavily about Down's syndrome but there is such a huge variation between one child and the next that there is still an element of stepping into the unknown - rather like any other baby!
- I don't know of anything that would help prepare parents for the news. However, I do wish the doctors would focus more on the positives rather than discussing all the possible medical and developmental problems.
- I wish I'd known then that my baby would still be beautiful and would develop and do all the things typically developing babies do, albeit at a slower pace, and that he would teach

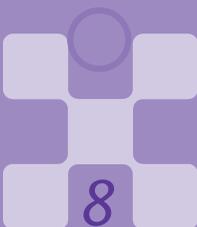


me a lot of things. I wish I'd made contact with the DS-UK email group before his birth, as that would've been a great comfort, and it probably would've helped to read some of the materials produced by DSA, as I have found that to be very positive and well written.

- I wish I had known more about Down's syndrome before I got the amnio. Down's syndrome is made out to be an AWFUL thing, much worse than it really is and the general level of ignorance that is common just fuels that.
- I wish I had known how much support would be available once our baby was born. We spent a lot of time worrying about possible problems such as health and behaviour - which have not materialised, thankfully.
- I was just offered a termination by the consultant. I would have liked a more balanced view. He just said that she would be in pain, and if it was up to him he would have a termination. Everyone would be behind me. I'm just glad I didn't take his advice and I wish he could see my daughter now. She has just had her 9th birthday and she is the light of our lives!!

### **What advice would you give to expectant parents who have just learned that their baby has Down's syndrome in order to help them in preparing for their child - emotionally - logistically - medically?**

- Get some reading done as to what Down's syndrome is, what to expect, etc - but you need to be careful not to get overloaded with too much information, especially as every child with Down's syndrome is unique and different. It definitely helps to talk to parents who've already had babies with Down's syndrome, as they can give the best practical advice.
- Just love them the same as any other child.
- Read up a little on Down's syndrome but do not think that your child will have everything wrong with them or that they will not be able to achieve anything. Do not be overwhelmed by all the information. Be prepared to love your child no matter what and they will achieve at least happiness!





- First and foremost - Research. And not just books and the Internet. Talk to people, meet with groups - there is a lot of support out there and a lot of people who can help. We made a point of telling everyone that we were expecting a child with Down's syndrome within the hour of us finding out. Saying it helped concrete it with ourselves and, bar only one person, we got a lot of positive response from our friends and family.
- Take time to enjoy the pregnancy, once the initial shock has passed. Continue to prepare for the baby the same as you would have without the diagnosis. I found meeting other young children with Down's syndrome very comforting. Remember that your baby really will inherit the physical features of its parents. Join the DS-UK email group if you are seeking support and/or reassurance. Read materials produced by the DSA for a very positive view. When telling friends and family, try to be positive about it - they really do take your lead. I found that many people took the news completely in their stride when I told them in a positive way. The only unfortunate responses I had were from an older generation, but fortunately things have moved on hugely in the past twenty years.
- Tell your friends and family immediately - you might need a support group ... Know that YOU can make a big difference in his life. Make sure that he grows up in a world that is as normal as that of any other child.
- First and foremost your baby is a child. That baby has great potential and sure it will be a challenge but the joy of each accomplishment cannot be put into words!
- In our opinion, it made no difference that Bradley has Down's syndrome. However we are glad that we had the diagnosis before he was born so it would not be a shock for us and our family once the twins were born.
- Don't read about health problems unless you know they apply to your baby. Remember at first it will be just like any other baby. He/she won't look like a monster, you will love your child. See if you can be put in touch with another family who had a pre-natal diagnosis.



- That they are babies first!! They are not very different at all than other newborns. Just love them, that's all they want and need...
- Take it one day at a time, don't worry about the future, everything will work out fine! Don't overload yourself with information (which is what I did!). Especially, when researching Down's syndrome be aware of the publication

date of the information you are reading as things have changed dramatically in the last 5/10 years. Also, realise every child is different (just like the population of children without Down's syndrome) and that every child is unique. One family's experiences may be different to yours. At the end of the day your child will be loved, accepted, and will be an asset to any community.

### **What did you find to be supportive? Or, what would have been supportive?**

- Although I was afraid to tell my family at first, they were very supportive. Since then I have found that the most supportive thing is attending a group for parents of children with Down's syndrome. It has been good to talk to others about their experiences!
- Knowing there are people out there who are ready and waiting to help if needed.
- The midwives were incredibly supportive. They arranged my antenatal visits for outside normal clinic times so that they could give me plenty of time to discuss my concerns. Specific chat forums, noticeboards, email groups can all be very supportive. Seeking out other parents in similar situations was helpful. Being put in touch with my health visitor before the baby's birth would've been some help.
- It would have helped if, at the maternity unit, someone had at least mentioned the fact that my daughter had Down's syndrome. I needed to talk about it. The personnel all treated her as if she was exactly like her sister and I NEEDED to know what the differences would be but due to the silence, I never dared ask.



- A parent support group that I joined when Jodie was a year old was invaluable. I wish I had joined sooner but I was a bit in denial. I thought that I would just treat Jodie the same as my other children and that would be fine but you do need help and the sooner the better really. Plus I met lots of other people in similar circumstances and we were all able to help each other. Also professionals were on hand to give advice.
- I got in touch with the DSA when I found out and they put me in touch with my local group which was a great support to know that I was not alone.
- Would have been supportive to have met with families who had been through a positive diagnosis of Down's syndrome in pregnancy and who now have a healthy, beautiful child. If they can cope, we can cope!

### **Any additional words of advice or encouragement to expectant parents of a baby with Down's syndrome?**

- You'll get over the shock in good time, after which you'll think of your little one as just any other baby, with a few extra needs. It helps to be positive about it, and every little thing they do will bring you such joy that no one can describe it.
- It's your baby! That is the most important thing to remember. They will require everything any other baby needs and just a little more. But they will enrich your life. Our daughter is now a major driving force in our family and we are now closer and more positive than ever. She is a bundle of fun and carries a lot of the family trait for inquisitiveness! She is a constant surprise and joy - and your son or daughter will be as well!
- You are not alone. You've chosen a path that will bring you great joy. We are fortunate that so much has been done by previous parents to ensure inclusion and good health care for our children. It may take a bit longer to get to know your baby, but rest assured s/he will be beautiful and will bring you more happiness than you can imagine right now.
- Give your child every chance to develop and meet his challenges and you will never be disappointed.



- I would say look at what your child can achieve not what he can't. Stay positive. Your child will be capable of great things with lots of encouragement from family and friends. It does take courage but I've found that if you have a positive attitude people will follow your lead.
- Having a baby with Down's syndrome is no different from having a baby without Down's syndrome. The smile on his face makes every problem go away.
- You will have several difficult months before your child is born, when all you have is a medical condition - not a child. When your child is born, you will have a baby to love and care for, and get to know, as well as the medical details that precede the birth. It is easier to love a child than a medical condition!
- Just keep an open mind...babies with Down's syndrome are as normal as normal can be.
- Enjoy your pregnancy, enjoy your baby and gets lots of information so that you are ready for all outcomes. Its not easy and you will have bad days as well as good ones but try to think positive.
- It is not a terminal diagnosis, just a different one from what you were expecting. Take time to adjust (and cry), but then begin to enjoy the new challenges you'll face in bringing up this unique person.
- I never had doubts about loving or accepting Thomas, only fears about the difference Down's syndrome would make to my son's life. If I knew back then what I know now, I would have saved myself a lot of stress and worry!! Our son is loved by our family, friends and community. He has a twin brother (who does not have Down's syndrome) and an older sister who both just adore him.

## ■ NEXT STEPS

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You will probably never forget the moment you found out that your baby has Down's syndrome. Families say the moment remains very clear in their memories. People react in many different ways. You may feel overwhelming sadness, you may feel too numb to react at all. Do not assume that your partner, if you have one, is experiencing this the same way as you. It is ok to react in whichever way you do. Your partner's way of coping is ok too. You are not alone, other people have felt this way before you. In time most people adjust to the news. Their baby becomes a well-loved member of their families, just part of their everyday lives.

Evidence from research shows that many families who receive a pre-natal diagnosis find that they are able to use the time between diagnosis and the birth of their child to adjust to their new situation. By the time of the birth of their child, many families will find that they have adjusted to the fact that their child has Down's syndrome and they are simply looking forward to the birth of their new baby. This experience is different from families who receive a post-natal diagnosis and who have to adjust to a new baby who has Down's syndrome.

As with any pregnancy, it is important that you look after your physical and mental well-being. Because of your situation you may find that the routine antenatal care, which is an important part of your pregnancy, is inappropriate or insufficient for your needs. Not all health professionals you come into contact with will be well informed about people with Down's syndrome. You may want to discuss with the health professionals involved who will be your lead carer - the one you can turn to for support for yourself.

Attending antenatal classes with other parents-to-be who do not have a baby with Down's syndrome might be difficult for you. Some parents choose not to attend such classes and therefore need other ways to prepare for the birth of their baby; do discuss your needs with your midwife or lead carer. If you do not feel like attending check-up at your local hospital, you can arrange for the check-ups to be carried out by your family GP.



Talking with other parents who have a child with the same condition can be a source of help and comfort at this time. They can answer many of the questions surrounding the reality of living with a baby or child with a particular condition. The DSA can put you in touch with your local parent support group. Some parents worry that their baby with Down's syndrome will need special equipment and toys; this is not the case!

When you are ready to find out more about people with Down's syndrome, you can contact the DSA for further literature. The DSA has produced early years support materials for parents of young children with Down's syndrome. There is a list of further reading and useful websites at the end of this booklet.

## ■ SOME THOUGHTS ABOUT TELLING OTHERS

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### *Your Children*

Don't be afraid to involve your children as soon as possible. It's ok to show them that you hurt - they realise that already.

Tell your children in an honest and open way. They may not understand or remember all the information, so follow their lead, keep listening and answer their questions. If you treat the Down's syndrome as just one aspect of your baby's life, your children will too.

### *Other People*

Telling family and friends can be very hard. Only you know when and how it is best to tell other people.

Sometimes you need to tell close friends or family so you have someone to cry with.

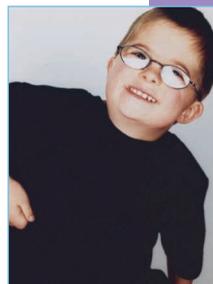
Sometimes it is easier to tell the most gossipy of your friends and ask them to pass the information around so that people know before they talk to you.

Sometimes it is best to wait until you have come to terms with the news yourself and are able to cope with the other person's reaction.

Give your family and friends DSA literature.

You may find you are very sensitive to people you meet when you are out and about.

Sometimes family, friends and people you meet say insensitive and hurtful things. Try to ignore these comments. They are usually based on ignorance and misunderstandings. Our experience is that most parents receive positive reactions!



People will follow your lead. If you are open, honest and positive about Down's syndrome, they will be too! Your baby will be like a baby! Your baby will eat, sleep and cry and need nappy changes, your baby will grow up and go to school.

## ■ USEFUL CONTACTS AND ORGANISATIONS

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The following organisations provide information, advice or support. Some of them may have information or services that will help you or your child. Others may not be particularly relevant for your family. Website and email groups are listed separately in the web-based resources section.

In addition to these organisations, many local and regional groups offer support and advice to individuals with Down's syndrome and their families. Contact the Down's Syndrome Association to find out if there is a group near you.

## ■ DOWN'S SYNDROME ORGANISATIONS

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### *The Down's Syndrome Association*

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome. We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website. Printed copies are available for a small fee. Single copies of most leaflets and information sheets are available free of charge to members.



## **The Down's Syndrome Association**

The Langdon Down Centre  
2a Langdon Park  
Teddington  
Middlesex TW11 9PS

Helpline: 0333 121 2300 or 020 8614 5100

Fax: 020 8614 5127

*Email:* [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk)

*Website:* [www.downs-syndrome.org.uk](http://www.downs-syndrome.org.uk)

## ***Down's Syndrome Scotland***

158/160 Balgreen Road  
Edinburgh  
EH11 3AU

*Tel:* 0131 313 4225

*Fax:* 0131 313 4285

*Email:* [info@dsscotland.org.uk](mailto:info@dsscotland.org.uk)

*Website:* [www.dsscotland.org.uk](http://www.dsscotland.org.uk)

## ***Down Syndrome Ireland***

30 Mary St.  
Dublin 1

*Tel:* 01 873 0999

*Fax:* 01 873 1064

*Email:* [info@downsyndrome.ie](mailto:info@downsyndrome.ie)

*Website:* [www.downsyndrome.ie](http://www.downsyndrome.ie)

## ***Down's Heart Group***

The Down's Heart Group offers support and information to families who have a member with Down's syndrome and heart problems.

PO Box 4260  
Dunstable  
Beds LU6 2EA

*Tel:* 0845 1668061

*Fax:* 0845 1668061

*Email:* [info@dhg.org.uk](mailto:info@dhg.org.uk)

*Website:* [www.dhg.org.uk](http://www.dhg.org.uk)

## ***Mosaic Down Syndrome UK***

Mosaic Down Syndrome UK has a website set up as a support tool for parents of children with Mosaic Down's syndrome.

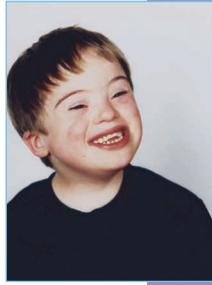
*Email:* [judy.green@blueyonder.co.uk](mailto:judy.green@blueyonder.co.uk) or

[bill.green@blueyonder.co.uk](mailto:bill.green@blueyonder.co.uk)

*Website:* [www.mosaicdownsyndrome.org](http://www.mosaicdownsyndrome.org)

## ■ WEB-BASED RESOURCES

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The following list provides some starting points if you want to look for information about Down's syndrome on the Internet.

While the following website addresses are recommended, we are not responsible for the material on these sites or for any linked sources of information.

### **Canadian Down Syndrome Society**

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

### **Down Syndrome Health Issues - USA**

[www.ds-health.com](http://www.ds-health.com)

### **Down Syndrome Information Network - UK**

[www.down-syndrome.info](http://www.down-syndrome.info)

### **Down Syndrome New South Wales - Australia**

[www.dsansw.org.au](http://www.dsansw.org.au)

### **Down Syndrome Research Foundation - Canada**

[www.dsrp.org](http://www.dsrp.org)

### **National Down Syndrome Society - USA**

[www.ndss.org](http://www.ndss.org)

### **Riverbend Down Syndrome Parent Support Group - USA**

[www.altonweb.com/cs/downsyndrome/index.htm](http://www.altonweb.com/cs/downsyndrome/index.htm)

### **UK Resources for Down syndrome**

[www.43green.freeserve.co.uk/uk\\_downs\\_syndrome/ukdsinfo.html](http://www.43green.freeserve.co.uk/uk_downs_syndrome/ukdsinfo.html)

### **Down's Syndrome Association Of Orange County - USA**

[www.dsaoc.org//programs/tunnelEnglish.pdf](http://www.dsaoc.org//programs/tunnelEnglish.pdf)

The website address above is for a publication called 'Light At The End Of The Tunnel - Reflections From Parents Whose Child With Down Syndrome Was Diagnosed Before Birth'.



## ■ EMAIL DISCUSSION LISTS

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### *DS-UK discussion list*

Based in the UK. Provides informal support, discussion and information for parents and professionals caring for individuals with Down syndrome.

To subscribe to the DS-UK discussion list go to:

<http://listserv.down-syndrome.net/archives/ds-uk.html>

Or send an e-mail to: [listserv@listserv.down-syndrome.net](mailto:listserv@listserv.down-syndrome.net) with the phrase 'subscribe DS-UK' in the body of the message.

### *Down-syn listserv/newsgroup*

The oldest and most international e-mail discussion list on Down syndrome - based in the USA.

To subscribe to the Down-syn list, go to:

<http://listserv.nodak.edu/scripts/wa>

If you don't want to subscribe, you can access the list archives at:

<http://listserv.nodak.edu/archives/down-syn.html>

### *Down Syndrome Information Network discussion lists*

The Down Syndrome Information Network offers a variety of e-mail discussion lists for parents, professionals, researchers, and individuals with Down syndrome. For more information go to:

[www.down-syndrome.info/discuss](http://www.down-syndrome.info/discuss)

### *Downs-Heart mailing list*

The Down's Heart Group in the UK operates the Downs-Heart mailing list. For details go to:

[www.yahogroups.com/subscribe/Downs-Heart/](http://www.yahogroups.com/subscribe/Downs-Heart/)

## ■ ADDITIONAL READING

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### **Need To Know - Down's syndrome**

*Kristina Routh*

Heinemann Library 2005 ISBN: 0-431-18850-5

### **Understanding Down syndrome - A Parent's Guide**

*Cliff Cunningham*

Souvenir Press 2005 ISBN: 0-285-63697-9

### **The Down syndrome Handbook - A Practical Guide For Parents And Carers**

*Richard Newton*

Vermilion, 2004 ISBN: 0-09-188430-6

### **Living with Down syndrome**

*Sue Buckley*

The Down Syndrome Educational Trust 2000

ISBN: 1-903806-01-1

### **Down syndrome - The Facts**

*Mark Selikowitz*

Oxford University Press 1997 ISBN: 0-19-262662-0

### **Babies with Down syndrome - A New Parent's Guide**

*Karen Stray-Gunderson (editor)*

Woodbine House 1995 ISBN: 0-933149-64-6

### **A Minor Adjustment**

*Andy Merriman*

Pan Books 1999 ISBN: 0-330-36748-X



The photographs in this booklet were taken by Richard Bailey, photographer and father of Billie-Jo, who has Down's syndrome. They were part of an exhibition called '365 - Shifting Perspectives', where he photographed a different child with Down's syndrome for every day of the year, to illustrate the individuality of those children.

***If you would like further information on the Down's Syndrome Association, or are interested in joining as a member, please give us a call on the number below.***

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If you can, **please make a donation** of any amount so we can continue to supply information free to those who need it. Thank you.

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