“A different child”

Having a child with Down's syndrome

“Et anderledes barn”

Om at få et barn med Downs syndrom

Landsforeningen Downs Syndrom

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Our heartfelt congratulations

The child you now have is probably not what you expected, but it is your child. This booklet is the work of a number of parents of children with Down's syndrome. We have all tried to face the challenge of the new little life in our hands and have felt uncertainty, sorrow and anger: a world turned upside down. We can't diminish the feelings you and your closest relatives will have, but we hope that this booklet can help you prepare for the little newcomer's future.

In the course of time all our children become a natural part of our families. The sorrow and disappointment we experience to begin with are slowly but surely replaced by a feeling of pleasure and pride in our children. Their spontaneous enthusiasm and implicit trust are very life-affirming. Many enjoyable moments await you.

We have collected some useful information about Down's syndrome which we hope will answer some of the questions that many grapple with in the early days: Why have I got a child with Down's syndrome? How will the child's life turn out? It has helped us greatly to have contact with other parents of children with Down's syndrome. So we have included a page in this booklet which has been written by the local parents group in your region. It includes a description of what the group does and how to get in contact with them. You can also share this booklet with your family and friends – it can help them to better understand your own situation.

And do remember that you can always visit the National Down's Syndrome Association website to find further information about Down's syndrome. The Internet address is: www.downssyndrom.dk

Once again, congratulations on your new child. And to the little one, a big welcome to the world.

Kitt Boel
President
National Down's Syndrome Association

Hjerteligt tillykke med dit barn

Du har fået et barn, som nok ikke er, hvad du forventede, men det er dit barn.

Denne pjece er samlet af en lang række forældre til børn med Downs syndrom. Vi har alle prøvet at stå med et lille nyt liv i hænderne og har mærket usikkerhed, sorg og vrede: Vores verden blev vendt på hovedet.

Vi kan ikke tage dine følelser fra dig og dine nærmeste, men vi håber, at denne pjece kan være en hjælp til det nye liv, som venter.

Vores børn er alle med tiden blevet en naturlig del af vores familier. Den sorg og skuffelse, vi oplevede i den første tid, er langsomt og sikkert blevet afløst af glæden og stoltheden over vores børn. Deres spontane begejstring og tillid er meget livsbekræftende for deres omgivelser. Der venter dig mange glæder.

Vi har samlet nogle nyttige informationer om Downs syndrom, som kan besvare nogle af de spørgsmål, som mange tumler med den første tid: Hvorfor har jeg fået et barn med Downs syndrom? Hvordan vil barnets liv forme sig?

Det har hjulpet mange at få kontakt med andre forældre til børn med Downs syndrom. Derfor er der en side i pjecen her, der er skrevet af den lokale forældregruppe i dit amt. Her kan du se, hvordan du kan få kontakt med dem, og hvad de laver.

Du kan også give denne pjece til familie og venner – det kan hjælpe dem til at forstå den situation, du er i.

Du kan altid klikke dig ind på Landsforeningen Downs Syndroms hjemmeside, for at finde yderligere oplysninger om Downs syndrom. Adressen er: www.downssyndrom.dk

Endnu en gang tillykke med barnet og velkommen til verden til den lille ny.

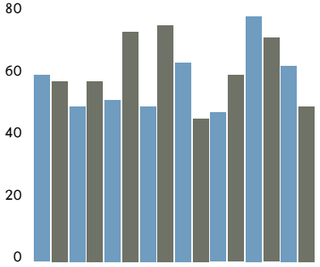
Med venlig hilsen
Kitt Boel
Formand for Landsforeningen Downs Syndrom

Down's syndrome

By Peter Bækgaard
Consultant Paediatrician, Glostrup County Hospital

What is Down's syndrome?
Down's syndrome gets its name from the English doctor John Langdon Down, who first described the condition in 1866. It is the most frequently occurring chromosomal disorder in children; on average out of every 900 births one child is born with Down's syndrome. In Denmark about 70 children are born with Down's syndrome annually – of which a few more are boys than girls. The frequency of children born with Down's syndrome increases markedly with the woman's age. For women in their twenties, one child out of 1600 is born with Down's syndrome, whereas for women in their forties the frequency is one in every 100 births.

However, even though the frequency increases with age, it is almost only women under 35 who give birth to children with Down's syndrome. This is because Denmark, in common with several other countries, first offers amniocentesis or placental biopsy – the tests used to discover Down's syndrome – to pregnant women over 35. It is important to note that Down's syndrome occurs with approximately the same frequency in all ethnic groups. This means that lifestyle and external influences do not play any role in causing the chromosomal disorder in the individual parent couples.



Number of children born with Down's syndrome 1985-2000
Source: Cytogenetic Central Register, Århus.
**) excludes Fyn County*

There are three kinds of chromosome disorders
Down's syndrome is more technically called trisomy 21 (from the Greek and Latin tri-, meaning three), because the child always has an extra chromosome located on chromosome pair no. 21. As a result, the child has 47 chromosomes instead of the normal complement of 46. This extra chromosome most commonly originates from the mother's egg cell which has not separated off half of its chromosome pair no. 21 before fertilisation. When the sperm cell's single chromosome no. 21 is added, the new embryo is then equipped with three no. 21 chromosomes. Formed in this way, it is called free trisomy.

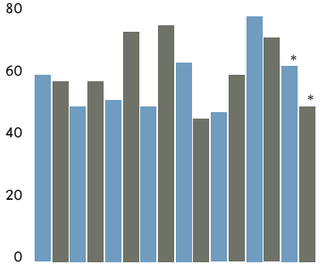
Another variant is known to occur rarely. In this case the extra chromosomal material corresponding to chromosome no. 21 behaves in another way, called translocation. This form of Down's syndrome is – in contrast to free trisomy 21 – an hereditary form. Finally there is a third form known as mosaic mongolism, in which both normal cells with 46 chromosomes and cells with 47 chromosomes appear in the same child. The symptoms in these children are often somewhat milder.

Downs syndrom

Af Peter Bækgaard, overlæge
Børneafdelingen, Glostrup Amtssygehus

Hvad er Downs syndrom?
Navnet Downs syndrom stammer fra den engelske læge John Langdon Down, som i 1866 beskrev tilstanden. Det er den hyppigste kromosomforstyrrelse, som man kender hos børn. I gennemsnit bliver der født én med Downs syndrom for hver 900 børn, der fødes. I Danmark fødes der omkring 70 børn med Downs syndrom om året – lidt flere drenge end piger. Hyppigheden af børn født med Downs syndrom stiger stærkt med kvindens alder. For kvinder i 20-års alderen gælder, at for hver 1600 børn der fødes, har én af dem Downs syndrom, for kvinder i 40-års alderen gælder, at for hver 100 børn har én af dem Downs syndrom.

Selv om hyppigheden således stiger med alderen, er det næsten kun kvinder under 35 år, som føder børn med Downs syndrom. Dette skyldes, at vi her i landet – som i flere andre lande – først tilbyder fostervandsprøve eller moderkagebiopsi til gravide over 35 år, så her er der chance for at opdage Downs syndrom. Det er vigtigt i denne sammenhæng at nævne, at Downs syndrom forekommer nogenlunde lige ofte i alle etniske befolkningsgrupper, hvilket også betyder, at levevis og ydre påvirkninger ikke spiller nogen rolle for årsagen til kromosomforstyrrelsen hos de enkelte forældrepar.



Antal fødte børn med Downs syndrom i perioden 1985-2000
Kilde: Cytogenetisk Centralregister, Århus.
**) excl. Fyns Amt*

Der findes tre slags kromosomforstyrrelser
Downs syndrom kaldes også trisomi 21, fordi det næsten altid drejer sig om, at barnet har fået et ekstra kromosom på kromosompar nr. 21. Derfor har barnet 47 kromosomer i stedet for de 46, som er det normale antal.

Det ekstra lille kromosom stammer oftest fra moderens ægcelle, som ikke har fået fraspaltet den ene halvdel af sit kromosompar i tide. Sammen med sædcellens enlige kromosom nr. 21 udstyres det nye foster derfor med tre kromosomer nr. 21 – såkaldt fri trisomi.

Den anden variant forekommer kun meget sjældent. Her optræder det ekstra kromosommateriale svarende til kromosom nr. 21 på en anden måde, kaldet translokation. Denne form for Downs syndrom er – i modsætning til fri trisomi 21 – en arvelige form.

Endelig taler man også om mosaikmongoler, hvilket vil sige, at der hos barnet optræder både normale celler med 46 kromosomer og celler med 47 kromosomer. Symptomerne hos disse børn er ofte lidt mildere.

Når man på fødegangen eller barselgangen har fået mistanke om, at barnet kan

When it is suspected on the maternity ward or post-natal ward that a child could have Down's syndrome, a blood test can be taken following parental consent. The results of the chromosome test are known after 24-48 hours, and it is only this test which can reveal whether the child has a chromosome disorder and if so, which of the three types it is.

Characteristic features of infants with Down's syndrome

Down's syndrome is a stable condition which gives the child a characteristic look and common features. But just like other children, children with Down's syndrome naturally also acquire looks and features from their parents and family line.

Common features include the small nose and characteristic eye shape with a special fold of the skin at the inner edge of the eye (epicanthus). It is this feature, a notable characteristic of the people of Mongolia, which led to the terms mongolism or mongol being formerly used to describe children with Down's syndrome. The newborn child will probably already show evidence of some slackness in the muscles, which are more soft and moveable than usual. The child may also have a rather quiet disposition. Most suck well at the breast or bottle but some may need supplements, possibly via a tube into the stomach. Infants with Down's syndrome have a greater tendency to bring something up from the stomach, but this disappears after babyhood.

Almost everyone who works in the healthcare sector is familiar with Down's syndrome. Naturally the extent of knowledge can vary, but it is certain that everyone will know that special caring needs are involved.

It is important to emphasise that Down's syndrome itself is not a disease which can be cured, but examinations for possible complications may be carried out, as well as advice given regarding stimulation, physiotherapy etc.

Complications

The most important priority for the newborn infant is to have the **heart** examined, and the doctor will do this at an early stage. By listening to the heart and comparing it with the infant's colour and breathing, a good assessment of the child's condition can be made. About 4 out of 10 children with Down's syndrome have a deformity in heart which must be examined carefully. It is therefore the rule that all children with Down's syndrome are examined at an early stage using ultrasound (echo cardiography), because it can be difficult to reveal the necessary details with a stethoscope. Fortunately, only a few children need more thorough treatment in the form of medication or possibly a heart operation. Two paediatric surgery centres in Denmark carry out the preliminary examination and possible operation, namely "Rigshospitalet" in Copenhagen and Skejby Hospital in Århus.

A special **gastrointestinal examination** may also be necessary, because children with Down's syndrome can have some inborn strictures. Another minor problem is

have Downs syndrom, tilbyder man efter aftale med forældrene en blodprøve på barnet. Der er svar på prøven i løbet af 1-2 døgn, og det er kun en kromosomundersøgelse, som kan afsløre, hvilken af de tre typer der er tale om.

Karakteristiske fællestræk hos spædbørn

Diagnosen Downs syndrom betyder, at det drejer sig om en stabil tilstand, som giver barnet et karakteristisk udseende og fælles træk. Men ligesom andre børn ligner børn med Downs syndrom naturligvis også deres forældre og har familiens træk.

Nogle af de fælles træk er den lille næse og de lidt skrå øjenspalter med en særlig hudfold (mongolfold eller epicanthus), og det er her udtrykket mongolisme eller mongolbørn, som børn med Downs syndrom tidligere blev kaldt, stammer fra. Det nyfødte barn vil nok allerede i dagene efter fødslen være lidt mere muskelslapt samt blødt og bevægeligt end forventeligt; måske også lidt mere stilfærdig i sin væremåde. De fleste sutter godt ved brystet eller af flaske, men nogle må have tilskud, evt. med sonde. Børn med Downs syndrom gylper ofte mere end andre, men det hører op efter spædbarnsalderen.

Stort set alle personer, der arbejder i sundhedssektoren kender til Downs syndrom. Naturligvis ikke lige grundigt alle sammen, men det er helt sikkert, at alle ved og kan fortælle, at det drejer sig om børn med særlige behov for omsorg og pleje.

Det er vigtigt at understrege, at Downs syndrom som sådan ikke er en egentlig sygdom, som kan helbredes, men man er i stand til at rådgive vedrørende stimulation, fysioterapi og andet samt undersøge for komplikationer.

Følgesygdomme

Det allervigtigste for den nyfødte er at få undersøgt **hjertet**, og det gør lægen en af de første dage. Ved at lytte på hjertet og sammenholde det med kulør og vejtrækning får man en god vurdering af forholdene. Godt 40% af alle børn med Downs syndrom har en større eller mindre misdannelse i hjertet, som skal undersøges nøje. Derfor er det en hovedregel, at alle børn med Downs syndrom på et relativt tidligt tidspunkt skal undersøges med ultralyd (ekkokardiografi), fordi det kan være svært at afsløre hjertedetaljerne i stetoskopet. Heldigvis er det kun enkelte børn, som har behov for mere indgående behandling i form af medicin eller måske hjerteoperation. To børnekirurgiske centre her i Danmark foretager forundersøgelse og eventuelt operation, nemlig Rigshospitalet i København og Skejby Hospital i Århus.

the tendency to constipation, which in the vast majority of cases can be handled with a change of diet or suitable medication.

During the first weeks, an **eye examination** is usually carried out. A small percentage (1-2%) of children develops lens opacity which reduces vision; this needs to be assessed and monitored by an eye specialist. Later on, there will be a further need for examination by an eye specialist since in many cases there are errors of refraction (hence a need for glasses) and a tendency for children with Down's syndrome to squint.

During the first six months, the child's **hearing** must be tested, since ear infections are a problem in around half of all children with Down's syndrome (the other 50% have no more infections than ordinary children). Ear problems are usually associated with viral diseases like the common cold, influenza etc, but sometimes bacterially-caused complications like inflammation of the middle ear, bronchitis and pneumonia can occur.

Paediatric examinations

It is important that the child is offered the common paediatric examinations and vaccinations provided by the GP. In addition the Danish National Health Service recommends that the child is also vaccinated against hepatitis (hepatitis B). There can be many other subjects to discuss, and the GP may make a hospital referral, if a paediatrician has not already offered follow-up for the child and family at a paediatric outpatient clinic. Here, more regular checks can be offered according to guidelines described in "Checklist for children with Down's syndrome". (Checklists are reprinted in "På vej – En vejviser til børn med Downs syndrom i førskolealderen", see the reading list).

Development and the future

Children with Down's syndrome have delayed development in both coarse and fine muscular abilities, as well as in language and learning. Most learn to walk on their own when they are around two years old, and this is also the time when they usually speak their first words. But there are big variations in development. Most learn to read satisfactorily, but numbers and arithmetic can cause problems. When the children become adults, the vast majority will be able to live for example in shared accommodation, but they will always need help. It is difficult to predict exactly how your child will develop. But it is known that children with Down's syndrome who are helped and stimulated can progress far in their development. Work is still being carried out on developing new knowledge and methods for helping children with Down's syndrome.

Måske kan det blive nødvendigt med særlige **mave-tarmundersøgelser**, fordi børn med Downs syndrom kan have nogle medfødte forsnævringer. Et mindre problem er i reglen tendensen til tarmforstoppelse, som i de allerfleste tilfælde klares med kostændring eller medicintilskud.

Inden for de første uger, er det klogt at få foretaget en **øjenundersøgelse**, fordi et par procent af børnene udvikler en linseuklarhed, som giver synsnedsættelse og som skal vurderes og følges af øjenlægerne. Senere er der også behov for øjenlægekontrol, da der er stor hyppighed af brydningsfejl (brillebehov) og tendens til at skele hos børn med Downs syndrom.

I løbet af det første 1/2 leveår skal man tage stilling til, om **hørelsen** er helt i orden.

Tendensen til infektioner er et problem hos over halvdelen af børn med Downs syndrom. Oftest drejer det sig om virussygdomme som almindelig forkølelse, influenza og lignende, men også bakterielle komplikationer, såsom mellemørebetændelse, bronchitis og lungebetændelse. Den anden halvdel af børn med Downs syndrom har faktisk ikke væsentlig flere infektioner end almindelige børn.

Børneundersøgelser

Det er vigtigt, at børnene tilbydes de almindelige børneundersøgelser og vaccinationer hos den praktiserende læge. Derudover anbefaler Sundhedsstyrelsen, at der også vaccineres mod leverbetændelse (hepatitis B). Der kan være mange emner at diskutere, men måske vælger lægen at henvise til en af amtets børneafdelinger, hvis ikke allerede børnelægerne har tilbudt barn og familie en opfølgning på børneambulatoriet. Her kan man tilbyde en mere regelmæssig kontrol efter retningslinier beskrevet i "Checkliste for børn med Downs syndrom". (Checklister er optrykt i "På vej – En vejviser til børn med Downs syndrom i førskolealderen", se litteraturliste).

Fremtid og udvikling

Børn med Downs syndrom er forsinkede i deres udvikling, hvilket gælder både fin- og grovmotoriske færdigheder samt sprog og indlæring. De fleste lærer at gå alene omkring to-års alderen, hvor de første småord også kommer til. Men ellers er der stor variation i det enkelte barns udvikling. Hovedparten lærer også at læse lidt, men tal og regning kan volde problemer. Når børnene bliver voksne, vil de allerfleste kunne bo i f.eks. et bofællesskab, men de altid vil have brug for hjælp.

Det er svært at forudsige, hvordan netop dit barn vil udvikle sig. Men man ved i dag, at børn med Downs syndrom, der hjælpes og stimuleres, kan nå langt i deres udvikling. Der arbejdes stadig på at udvikle ny viden og metoder til at hjælpe børn med Downs syndrom.

Welcome to Holland

By Emily Perl Kingsley

I am often asked what it is like to have and bring up a disabled child.
This is my reply:

To be expecting a child is like planning a dream trip to Italy. You buy lots of guidebooks and make fantastic plans. The Colosseum, Michelangelo's David, the gondolas in Venice. You learn useful terms in Italian. Everything is very exciting.

After months of excited expectation the day finally arrives. You pack your suitcases and leave. Several hours later the plane lands. The cabin steward says: "Welcome to Holland".

"HOLLAND?!?" you exclaim.

"What do you mean, Holland? I booked a flight to Italy! I should be in Italy! All my life I have dreamed of going to Italy".

But the travel plan has been changed. You have landed in Holland and there you must stay.

It is not an awful, nasty, dirty place, plagued with hunger and disease. It is just a different place. So you have to go out and buy new guidebooks. You have to start learning a new language. And you will meet new types of people, who you would otherwise not have met.

The pace of life is different too, slower than in Italy; and not so magnificent. But after a while, when you have got your breath back, you look around... and begin to discover that there are windmills. And tulips. Holland even has Rembrandt.

But everyone you know is busy travelling to and from Italy. And they tell you what a wonderful time they had there. And for the rest of your days you will say: "Yes, that was where I should have gone; that was what I planned".

The pain never passes away, not ever... because the loss of the big dream is a loss of great, great importance. But if you use your life to mourn over the fact that you never got to Italy, you will never be free to value and enjoy what is very special, and really wonderful... about Holland.

Velkommen til Holland

Af Emily Perl Kingsley

Jeg bliver ofte spurgt om, hvordan det er at leve med og opdrage et barn med handicap.
Det er sådan her:

At vente et barn er som at planlægge en drømmerejse til Italien.
Du køber en masse rejsehåndbøger og lægger eventyrlige planer. Colosseum, Michelangelos David, gondolerne i Venedig. Du lærer dig nyttige vendinger på italiensk. Alt er meget spændende.

Efter måneders spændt forventning kommer endelig dagen. Du pakker dine kufferter og tager af sted. Flere timer senere lander maskinen. Stewardessen kommer ind og siger: "Velkommen til Holland".

"HOLLAND?!?" råber du.

"Hvad mener du med Holland? Jeg har bestilt en rejse til Italien! Jeg skulle være i Italien! Hele mit liv har jeg drømt om at komme til Italien".

Men der er lavet om på fartplanen. Maskinen er landet i Holland og der må du blive.

Det er vigtigt, at de ikke har ført dig til et rædsomt, fælt, snusket sted, fuld af pest, sult og sygdom. Det er bare et sted, som er anderledes. Så du må ud og købe nye rejsehåndbøger. Og du må til at lære et helt nyt sprog. Og du møder en helt ny type mennesker, du ellers ikke ville have mødt.

Det er som sagt et sted, der bare er anderledes. Tempoet er langsommere end i Italien; der er ikke så pragtfuldt. Men når du har været der et stykke tid og har fået vejret, ser du dig omkring... og opdager efterhånden, at der er vindmøller i Holland... og Holland har tulipaner. Holland har endda Rembrandt.

Men alle, du kender, har travlt med at rejse til og fra Italien... Og de praler af, hvor vidunderligt de havde det der. Og resten af dine dage vil du sige: "Ja, det var der, jeg skulle have været; det var det, jeg havde planlagt".

Og smerten ved det vil aldrig, aldrig, aldrig nogensinde fortage sig..., for tabet af den store drøm er et tab af stor, stor betydning.

Men, hvis du bruger dit liv til at sørge over den kendsgerning, at du ikke kom til Italien, bliver du aldrig fri til at værdsætte og nyde det helt specielle, det virkeligt vidunderlige... ved Holland.

Parental thoughts

Over time I have realised that she couldn't end up other places than with us. We have her because we are the best for taking care of her.

God, now I will never have any grandchildren.

What do I say to the neighbours when we come home with her? Will they come and see her and be disgusted?

When I look at her, will I ever be able to see our own features in her?

Whatever he wants to do, we will support it.

She will always be super-smartly dressed.

Now I have an ugly child that everyone will stare at – with pudding basin hair, corduroy trousers and thick lens glasses.

Just think how people in the street will stare at me when I am out with him.

How will it affect the relationship between me and my husband?

It was a turning point for me to meet other parents of children with Down's syndrome. It was nice to meet people in the same situation and share the suppressed thoughts. To discover that others have just the same thoughts. It was exciting to see other children with Down's syndrome and see how much they really can do. I look forward to it each time we meet.

They say children with Down's syndrome are always happy. What a load of nonsense. Children with Down's syndrome are like everyone else, sometime happy and sometimes not. They can also be really stubborn and temperamental.

I think it was so extremely unjust that I had a child with Down's syndrome. The only thing I wanted to do was scream. At the same time I hoped she would die. It was frightening.

What an unnatural mother. Fortunately I discovered that it was a completely normal reaction.

Do I now have a child who will live at home for ever?

Do I dare to hope that he dies during the operation?

The psychologist discovered that we were both hoping Christian had died – and we found out that it is completely normal in this situation. The psychologist expressed what we felt: "You have lost the child you expected to get, and you have gained another who you must learn to accept". In the first few days we tried to get an overview of the catastrophe. What about when he becomes an adult? What is he going to do? Where is he going to live?

Forældretanker

Med tiden har jeg indset, at hun ikke kunne ende andre steder end hos os. Vi har fået hende, fordi vi er de bedste til at tage sig af hende.

Gud, nu får jeg aldrig nogle børnebørn.

Hvad skal jeg sige til naboerne, når vi kommer hjem med hende? Vil de komme og se hende og væmmes?

Når jeg kigger på hende, vil jeg så nogensinde kunne se vores træk i hende?

Om det så er ridning, han har brug for, så vil vi bakke op om det.

Hun skal bare altid være supersmart i tøjet.

Nu får jeg et grimt barn, som alle vil glo på – med kasserollehår, fløjlsbukser og hinkestene.

Tænk, hvor folk vil glo efter mig, når jeg går med ham på gaden.

Hvordan vil det påvirke forholdet mellem mig og min mand?

Det var et vendepunkt for mig at møde andre forældre til mongolbørn. Det var rart at møde nogle i samme situation og alle de forbudte tanker fik frit løb. For at opdage at de andre såmænd havde de samme tanker. Og det var spændende at se de andre mongolbørn og se, hvor meget de i grunden kan. Jeg glæder mig til hver gang, vi skal mødes.

Det
er da godt, at mongoler er så glade. Sikke en omgang vås. Mongoler er som alle andre glade indimellem. Men de kan altså også være stædige og temperamentsfulde.

Jeg
synes bare, det var så hamrende uretfærdigt, at jeg fik et mongolbarn. Det eneste, jeg havde lyst til, var at skrige. Samtidig ønskede jeg, at hun måtte dø. Det var skræmmende. Hvilken ravnemor. Heldigvis opdagede jeg, at det var en helt normal reaktion.

Skal jeg nu have et hjemmeboende barn altid?

Tør jeg håbe, han dør under operationen?

Psykologen opdagede, at vi begge havde haft et håb om, at Christian døde – og vi fandt ud af, at det er helt normalt i denne situation. Psykologen udtrykte det, vi følte således. "I har mistet det barn, I ventede at få og I har fået et andet barn, som I først skal tage til jer nu".

I de første dage forsøgte vi at få overblik over katastrofen. Hvad når han bliver voksen? Hvad skal han lave? Hvor kan han bo?

How we are today

Nanna three years and 9 months

Nanna is a happy and active girl with a strong will and an affectionate nature. She communicates both with signs and short sentences. She is doing fine in her kindergarten, where there are some extra resources. She is fond of singing, dancing and music, and sings along with enthusiasm to the last word of the lyrics. She loves doing "gymnastics" and is learning to jump. Swimming is also fun! A lot of time is used on "reading" books and cooking on her toy stove, and Nanna loves her countless cuddly toys. "Bamse og Kylling" (Bear and Chicken) is her absolute favourite television programme. Nanna is unfortunately an only child, but is gradually beginning to form relations with other children with and without Down's syndrome. She is a little live wire who we wouldn't be without!

Mother 38 and father 40 at birth.

Marcus two years

Marcus was born in March 2000 at Roskilde County Hospital. At birth he weighed 3.17 kilos and was 50 cm long. We have been amazingly lucky that Marcus has so far not had any complications. Marcus is our first born so the attention around him was quite intense to begin with, which he enjoyed and still enjoys to the full. He is an amazingly happy little charmer who just slogs on and runs everybody off their feet. He is not so wild about crawling as yet, but pushes himself around at full speed – so why be troubled about learning to crawl? He gets up with the help of anything to hand and loves walking when you hold him by his hands.

Mother 23 and father 26 at birth.

Sådan har vi det i dag

Nanna tre år og 9 mdr.

Nanna er en glad og aktiv pige med en stærk vilje og et kærligt væsen. Hun kommunikerer både med tegn og kan sige små korte sætninger. Hun trives godt i sin børnehave, som er en almindelig institution med en basisgruppe, hvor der er lidt ekstra resurser. Hun er glad for sang, dans og musik og forsøger gerne med begejstring at synge med på sidste ord i hver sætning. Hun elsker at lave "gymnastik" og er ved at øve sig i at hoppe. Svømning er også sjovt! Der bruges megen tid på "læsning" i bøger og madlavning ved legekomfuret, og Nannas utallige sovedyr bliver passet og puttet. "Bamse og Kylling" er absolut favoritfjernsyn.

Nanna er desværre enebarn, men begynder så småt at skabe relationer til andre børn med og uden Downs syndrom. Hun er et lille livstykke, vi ikke ville være foruden!

Mor 38 og far 40 år ved fødslen.

Marcus 2 år

Marcus er født i marts 2000 på Roskilde Amts Sygehus. Ved fødslen vejede han 3170 g og var 50 cm lang. Vi har været så utrolig heldige, at Marcus indtil nu ikke har haft nogle følgesygdomme. Marcus er den første fødte, så opmærksomheden om ham har været ret stor fra starten, hvilket han har nydt og stadig nyder i fulde drag. Han er en helt utrolig glad, lille charmetrold, der bare okser derudaf og tager alle med storm. Han er endnu ikke vild for at kravle, men møver sig i fuld fart rundt – så hvorfor besvære sig med at lære at kravle. Han rejser sig op af alt, hvad han kan komme i nærheden af og elsker at gå, når man holder ham i hænderne.

Mor 23 og far 26 år ved fødslen.

Saga 2 years

Saga is an active girl with mosaic Down's syndrome. She is trusting and always happy, except when her parents scold her or do something she does not want. Then she gets stubborn, like all two-year-old children. She is the biggest charmer that ever was, and well aware of the fact. Her development is more or less "normal"; the biggest delay is her language. We started using Sign-For-Speech early on, and she used her first sign – music – just before her first birthday. Today Saga uses about 40 signs and has begun putting two signs together. She has a verbal language of four words and a lot of sounds. Her favourite occupation is playing with dolls and teddy bears, playing at cooking, dressing up, "reading" books, dancing, listening to music, singing, playing on the slide, crawling up on high chairs and kitchen benches and running as fast as she can. She has just become a big sister and that happened beyond all expectations. There has been no jealousy so far – we wonder how long it will last!

Mother 29 and father 31at the birth.

Sign-For-Speech is a form of communication where normal speaking language is supplemented with signs which are often borrowed from deaf sign language. It is only the meaning carrying words in a sentence which are supported by signs.

Sign-For-Speech promotes the development of the child's language. Many parents start to learn Sign-For-Speech when the child is around one year. You can read more about Sign-For-Speech in "På vej" (see the reading list).

Max 10 months

Max is a boy with a lovely temperament, which currently expresses itself when he is laid down. By preference he wants to sit up (he has just learned to sit without support), or walk with his mother or father in a baby sling and experience the big wide world. Max has always been amazingly present and loves to be entertained with songs and play. He had an operation for a heart condition when he was three and a half months old and may possibly need another operation later on. In spite of his heart condition he has always had the will and the strength to learn and explore, and that is a big part of Max's personality. He is still being breast-fed, but from the age four months he has been spoon fed and drinks from a cup with great pleasure.

Mother 32 and father 34 at the birth.

Saga 2 år

Saga er en aktiv pige, som har mosaik Downs syndrom. Hun er tillidsfuld og er altid glad, undtagen når hendes forældre skælder hende ud, eller gør noget, hun ikke vil have. Så gør hun modstand som alle andre toårige. Hun er den største charmetrold, der findes og er udmærket godt klar over det selv. Hun følger stadig mere eller mindre den "normale" udvikling, hendes største forsinkelse er sproget. Vi begyndte at bruge Tegn-Til-Tale tidligt, og hun brugte sit første tegn – musik, lige inden hendes et-års fødselsdag.

I dag bruger Saga ca. 40 tegn og er så småt begyndt at sætte to tegn sammen. Hun har et verbalt sprog på fire ord og en masse lyde. Hendes yndlings beskæftigelse er at lege med dukker og bamser, lege køkken, klæde sig ud, "læse" bøger, danse, høre musik, synge, rutsche, kravle op på høje stole og køkkenbænke og løbe så hurtigt hun kan. Hun er lige blevet storesøster, og det er gået over alle forventninger. Der er ingen jalousi indtil videre – hvor længe mon det holder!

Mor 29 og far 31 år ved fødslen.

Tegn-Til-Tale er en kommunikationsform, hvor det almindelige talesprog suppleres med tegn, som ofte er lånt fra døves tegnsprog. Det er kun de betydningsbærende ord i en sætning, som understøttes af tegn.

Tegn-Til-Tale fremmer udviklingen af barnets sprog. Mange forældre begynder at lære Tegn-Til-Tale, når barnet er ca. et år. Du kan læse mere om Tegn-Til-Tale i "På vej" (se litteraturlisten).

Max 10 mdr.

Max er en dreng med et dejligt temperament, som lige for øjeblikket kommer til udtryk, når han bliver lagt ned. Han vil allerhelst sidde op (han har netop lært at sidde uden støtte), eller gå med mor og far rundt i bæresele og opleve den store verden.

Max har altid været utrolig nærværende og elsker, når der synges og spilles for ham.

Han blev opereret for en hjertefejl, da han var tre en halv måned gammel og skal muligvis opereres igen senere. På trods af sin hjertefejl har han altid haft viljen og styrken til at lære og udforske, og det er en stor del af Max' personlighed.

Max bliver stadig ammet, men har fra han var fire mdr. fået skemad og drukket af kop med stor fornøjelse.

Mor 32 og far 34 år ved fødslen.

Esther Mathilde 19 months

Esther Mathilde is our first child and is idolized by the entire family – especially by her father, maternal grandfather and paternal grandfather. She is a real little charmer who knows how to get her own way. Esther is in day nursery together with her friend Anna and develops a lot by reflecting herself in the other children. She has some relatively soft joints which impede her coarse muscular activity, but her curiosity and stubbornness constantly spur her on to new adventures. She has recently started the transition from crawling on her stomach to crawling on her knees. She would very much like to stand up, especially to be able to explore what is lying on the table. Hamburgers with soft onions, soft ice cream, tomatoes and milk pudding are amongst her favourites. Broccoli and potatoes are not. Esther has been spared illnesses, except for one case of ear inflammation in connection with teething. In the photo Esther is on the beach with her grandparents who love looking after her.

Mother 32 and father 30 at the birth.

Lina 7 years

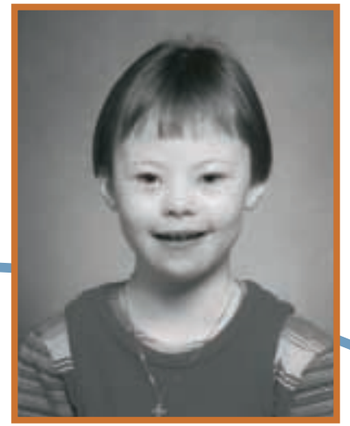
We are a family of four going on five (Lina will soon get another little brother) and have lived for the last 11 years in Levring. Lina was born with a minor heart condition which was operated on when she was 10 months old. It all went well. She started in "normal" day care when she was two years old, and then progressed to a special kindergarten when she was three. Lina could walk by herself at that age. She still needs a nappy, but has started learning to use the toilet. She gets a bit of help with eating, dressing and undressing. When she was five she started in a special school and has since achieved considerable linguistic development combined with Sign-For-Speech. Lina is an amazingly affectionate and positive girl; she is also a bit stubborn and has a desire to go walkabout, so you always need to keep an extra eye on her.

Mother 26 and father 31at the birth.

Esther Mathilde 19 mdr.

Esther Mathilde er det første barn, og hun bliver forgudet af hele familien – særligt af sin far, morfar og farfar. Hun er en rigtig lille charmør, der forstår at få tingene, som hun gerne vil have dem. Esther går i vuggestue sammen med sin veninde Anna og udvikler sig meget af at spejle sig i de andre børn i institutionen. Hun har nogle forholdsvis bløde led, der hæmmer hendes grovmotorik, men hendes nysgerrighed og stædighed driver hende hele tiden på nye eventyr. Hun er for nylig begyndt at skifte fra at krybe af sted på maven til at komme op på knæ og kravle. Derudover vil hun meget gerne op at stå, ikke mindst for at få lov at pille ved det, der ligger på bordet. Hakkedrenge med bløde løg, softice, tomater og koldskål er blandt favoritterne. Broccoli og kartofler er ikke. Esther har været forskånet for sygdomme, bortset fra en enkelt mellemørebetændelse i forbindelse, med, at hun fik tænder. På billedet er Esther på stranden med mormor og morfar, som hun elsker at blive passet af.

Mor 32 og far 30 år ved fødslen.



Lina 7 år

Vi er en familie på snart fem personer (Lina får snart en lillebror mere) og bosat de sidste 11 år i Levring. Lina blev født med en lille hjertefejl, som hun blev opereret for, da hun var 10 mdr. Og det gik helt fint.

Hun kom i "normal" dagpleje, da hun var to år og startede i en specialbørnehave, da hun blev tre år.

Lina kunne gå selv som tre-årig. Hun tisser stadig i bleen, men er begyndt at være renlig. Hun får lidt hjælp til spisning og hjælp til af- og påklædning.

Som fem-årig startede hun i en specialskole og har siden haft en stor sproglig udvikling kombineret med Tegn-Til-Tale.

Lina er en utrolig kærlig og positiv pige, og så er hun lidt stædig og har en trang til at gå på opdagelse, så man skal altid lige have et ekstra øje på hende.

Mor 26 og far 31 år ved fødslen.

Vincent 6 weeks

Vincent is the first born of twins, and is thus big brother to Nikita. They were born prematurely, and having Down's syndrome he was much smaller than his sister. He was born in week 32 and weighed 1.3 kilos. Today, six weeks later, he weighs 2.7 kilos. He can breast-feed a little but because that tires him, he gets expressed breast milk in a feeding bottle. Vincent was born without any heart condition. He really enjoys life; he eats, sleeps and wants lots of contact when he is awake.

Mother 32 and father 26 at the birth.

Freja 2 years

Freja was born at Næstved Hospital in a very normal birth after a full and normal pregnancy. About 10 minutes after the birth the midwife said that she suspected Freja had Down's Syndrome. She had all the signs: the single deep crease across the palm, sandal foot (unusually wide space between the large and second toe - Ed), low set ears, characteristic slant to the eyes, extra neck fold etc. – in short everything. But fortunately without any signs of complications. Freja is our ray of sunshine! We love her to bits and would not swap her for anything. The fact that WE got a child with Down's syndrome, we took as a challenge – there had to be a meaning to it!
Freja has developed at terrific speed.
At 10 months old she started in a special kindergarten (she is collected and brought home by bus every day), that she was very fond of attending.
She could sit unassisted at nine months, "bear walk" on all fours at one year, and walk upright by herself at 20 months. She is one lady who is full of go. Freja is an amazingly happy girl – whether it's five in the morning or it eight in the evening. She is very energetic and incredibly persistent, when there is something she would like. Besides that she is very affectionate and benefits from having both a big brother and a big sister who are both very fond of playing with her. We use Sign-For-Speech, and the first words are gradually on their way.

Mother 36 and father 33 at the birth.

Vincent 6 uger

Vincent er den første af et tvillingepar, dvs. storebror til Nikita. De er født for tidligt, og som mongol var han meget mindre end søsteren. Han er født i 32. uge og vejede 1265 gram.
I dag, seks uger efter, vejer han 2700 gram. Han kan die lidt, men fordi han bliver meget anstrengt, får han modermælk (som jeg malker ud) i sutteflaske.
Vincent er født uden hjertefejl. Han er en rigtig livsnyder, han spiser, sover og har et stort behov for kontakt, når han er vågen.

Mor 32 og far 26 år ved fødslen.

Freja 2 år

Freja blev født på Næstved Sygehus ved en ganske normal fødsel og efter en helt normal graviditet. Ca. 10 min. efter fødslen sagde vores jordemoder, at hun havde en mistanke om, at Freja var født med Downs Syndrom. Hun havde alle symptomer: Firefingerfure, sandalfod, lavtsiddende ører, skæve øjne, ekstra nakkefold m.v. – kort sagt alt, dog uden tegn på nogle følgesygdomme. Heldigvis.
Freja er vores lille/store solstråle! Vi elsker hende alle overalt på jorden og ville ikke bytte hende væk for en million. Det, at VI fik et barn med Downs, tog vi som en udfordring – der måtte jo være en mening med det!
Freja har udviklet sig i rivende hast. Hun kom 10 mdr. gammel i specialbørnehave (hun bliver hentet og bragt i bus hver dag), hvor hun er meget glad for at være.

Hun kunne sidde selv, da hun var otte/ni mdr. Da hun var et år kunne hun gå "bjørnegang/abegang" (strakte ben + hænder) og 20 mdr. gammel kunne hun gå selv. Så, ja det er en dame med fart på.
Freja er en utrolig glad pige – uanset om klokken er fem om morgenen, eller den er otte om aftenen. Hun er meget energisk og utrolig påholdende, når der er noget, hun gerne vil.
Desuden er hun meget kærlig og nyder godt af at have både en storebror og en storesøster, som meget gerne vil lege med hende.
Vi bruger Tegn-Til-Tale, og de første ord er så småt på vej.

Mor 36 og far 33 år ved fødslen.

Anders 1 year and 7 months

Anders was born in August 2000 by caesarean section and has had a difficult start in life. It turned out that he had two holes in his heart and one hour after learning this, we were told that he possibly had Down's syndrome. It was very tough. Anders has had long stays in the hospital with heart operations and getting a pacemaker before he was three months. The worst experience for him was in May 2001 when we were on our way home from summer holiday. Suddenly he stopped breathing up in the airplane. He received first aid from the cabin crew until we landed in Turkey. We will always be grateful to the cabin crew's heroic efforts. Now Anders is a very fit and able boy of eighteen months. He can say many words like "mother", "stop", "hi", "no", "sleep" as well as Arabic words (Anders' parents are from Jordan – Ed). He can stand up by himself and walk if you hold his hand. We are very fond of Anders. Just as we were sad when we were told that he had Down's syndrome and a heart condition, we are equally glad to have him now, and would not swap him for ten "normal" children.

Mother 31 and father 39 at the birth.

Marie 12 years

Marie is a girl with a lust for life and the courage of her convictions. She is in her fifth year at school and is very fond of the challenges it gives her. It is a pleasure to follow her development both physically and intellectually. A development which is not quite like other children's but still has a flow. The school is very important to Marie. It gives her day a pattern, and it is here that she meets her friends. Marie is a big arranger of social events and if it was up to her, we would have something arranged every day. She handles the telephone calls by herself and makes agreements which are then checked with the grown-ups. In our family we are in a way three adults, because Marie's big sister is 17 years old. It has given Marie great advantages all through her life. She has always been included with her big sister's friends and she has learnt a lot from that.

Mother 32 and father 32 years at the birth.

Anders 1 år og 7 mdr.

Anders er født i august 2000 ved kejsersnit. Han har haft en svær start på livet. Det viste sig, at han havde to huller i hjertet, og en time efter fik vi at vide, at han måske var mongol (Downs syndrom). Det var meget hårdt. Anders har haft lange ophold på sygehuset med hjerteoperationer og indlæggelse af pacemaker, før han fyldte tre mdr.

Den værste oplevelse for ham var i maj 2001, da vi var på vej hjem fra sommerferie. Pludselig holdt han op med at trække vejret oppe i flyet. Han fik førstehjælp af en stewardesse, indtil vi landede i Tyrkiet. Vi vil altid være taknemmelige for stewardessens store indsats.

Nu er Anders en meget frisk dreng. Han er halvandet år gammel og meget dygtig. Han har mange ord som "mor", "stop", "hej", "nej", "sove" samt arabiske ord. Han kan stå selv og gå, hvis man holder ham i hånden.

Vi er meget glade for Anders. Lige så kede af det vi var, da vi fik at vide, han var mongol med hjertefejl, lige så glade er vi for ham nu, og vi vil ikke bytte ham med ti andre "normale børn".

Anders forældre er fra Jordan.

Mor 31 og far 39 år ved fødslen.

Marie 12 år

Marie er en pige med masser af lyst til livet og sine meningers mod. Hun går i skole på femte år, og er meget glad for de udfordringer, det giver hende. Det er en fornøjelse at følge hendes udvikling både fysisk og intellektuelt. Den udvikling, der ikke er helt som andre børns, men alligevel har et flow.

Skolen er meget vigtig for Marie. Den giver hendes dag et mønster og samtidig er det her hun møder kammerater. Marie er "stor-arrangør" af sociale arrangementer og stod det til hende, skulle vi have aftaler hver dag. Hun klarer selv telefonopringninger og diverse aftaler, som så bliver checket med de voksne.

I vores familie er vi sådan set tre voksne, fordi Maries storesøster er 17 år. Det har hele Maries liv givet hende store fordele. Hun har altid haft en plads i rækken hos storesøsterens veninder og venner, og det har hun lært meget af.

Mor 32 og far 32 år ved fødslen.

Christian 10 years

Shortly after an otherwise normal birth we were told that Christian had Down's syndrome. In addition he had a minor heart condition which resolved by itself when he was around one year old. When we got Christian, we had already had a two year old boy with Down's syndrome. So we knew what it was about, and that it was not the worst thing that could happen. Christian could sit unassisted when he was eight months old, crawled at 10 months and walked when he was 17 months. He learned to use the toilet by the age of four, and has been in day-care and an ordinary kindergarten with an assistant nursery teacher. Today he attends a special school. He plays football in a newly founded football club for individuals who are development compromised. Christian loves to cycle and play computer games. He also has a good friend with whom he plays a lot and they alternate with sleeping at each other's homes. Christian is a well-functioning boy and so life-affirming that we have not regretted declining the amniocentesis in connection with our age.

Mother 38 and father 39 years at the birth.

Jonas 12 years

Jonas attends Storå School in Holstebro. He has a little brother of ten and a little sister of seven. His language is still rather incomprehensible but it gets better all the time. Now he can write his name and knows the numbers up to 10. He also eats with a knife and fork, takes showers, cycles without a support wheel and uses a scooter. Actually he is self-reliant with just about everything. Jonas has a great sense of humour and loves making fun. He loves orderliness and enjoys tidying up, especially for others. He is a busy user of PlayStation, computer and video films.

Mother 28 and father 28 years at the birth.

Christian 10 år

Kort tid efter en ellers normal fødsel fik vi at vide, at Christian havde Downs syndrom. Han havde desuden en lille hjertefejl, som voksede sammen omkring et-års alderen.
Da vi fik Christian, havde vi allerede igennem to år haft en dreng med Downs syndrom i aflastning. Så vi vidste godt, hvad det drejede sig om, og at det ikke var det værste, der kunne ske.
Christian sad selv ca. syv-otte mdr. gammel, kravlede da han var 10 mdr. og gik, da han var 16-17 mdr. Han var renlig ved fire-års alderen, og han har været i dagpleje og gået i almindelig børnehave med støttepædagog. I dag går han i specialskole. Han spiller fodbold i en nystartet fodboldklub for udviklingshæmmede. Christian elsker at cykle og spille på computer. Han har også en god ven, som han leger meget med og de skiftes til at sove hos hinanden.
Christian er en velfungerende dreng, han er så livsbekræftende, at vi ikke har fortrudt, at vi fravalgte fostervandsprøve, selvom vi havde alderen.

Mor 38 og far 39 år ved fødslen.

Jonas 12 år

Jonas går på Storå-skolen i Holstebro. Han har en lillebror på 10 og en lillesøster på syv år. Hans sprog er endnu lidt uforståeligt, men det bliver bedre og bedre. Nu kan han skrive sit navn, og han kender tallene op til 10. Han spiser også med kniv og gaffel og går selv i bad, cykler uden støttehjul og løber på løbehjul, ja faktisk er han næsten selvhjulpen med alt.
Jonas har en fantastisk humor og elsker at lave sjov. Han har ordenssans og holder sjovt nok meget af at rydde op (især for andre). Han er flittig bruger af PlayStation, computer og videofilm.

Mor 28 og far 28 år ved fødslen.

Heaven's very special child

A meeting was held quite far from Earth!
It's time again for another birth.
Said the Angels to the LORD above,
This Special Child will need much love.

His progress may be very slow,
Accomplishments he may not show.
And he'll require extra care
From the folks he meets down there.

He may not run or laugh or play,
His thoughts may seem quite far away,
In many ways he won't adapt,
And he'll be known as handicapped.

So let's be careful where he's sent,
We want his life to be content.
Please LORD, find the parents who
Will do a special job for you.

They will not realize right away
The leading role they're asked to play,
But with this child sent from above
Comes stronger faith and richer love.

And soon they'll know the privilege given
In caring for their gift from Heaven.
Their precious charge, so meek and mild,
Is HEAVEN'S VERY SPECIAL CHILD.

by Edna Massionilla
December 1981
The Optomist-newsletter for PROUD Parents
Regional Outreach for Understanding Down's Inc.

At bære

Af ukendt engelsk forfatter

Jeg har hørt, at der findes en gammel legende,
om hvad der oppe i himlen hændte.
Den siger, at engang den kære Gud,
sagde til englene, vil I gå bud?
Der et barn som skal fødes på jord,
vil I prøve at finde en far og mor,
som vil elske og pleje dets krop og dets sjæl,
det er netop en opgave helt speciel.
Barnet er svagt, det har handicap med,
så det kræver meget tålmodighed.
I ved, at jeg elsker alt svagt og småt,
og jeg ønsker, at barnet skal få det godt,
så de to, der bliver dets far og mor,
må virke som mine hænder på jord.
Måske vil de først have svært ved at se,
at der kan være en mening med det,
at barnet ikke kan tumle og lege,
og at det kræver så megen pleje.
Men de vil nok efterhånden lære,
at det giver kræfter at måtte bære.
Guds kærtegn gør undertiden ondt,
og medgang alene er ikke sundt,
men modtager de barnet, som gave de to,
så bliver det en kilde til indsigt og tro,
og så kan det sikkert med tiden læres,
at livet er både at bære – og bæres.

The many helpers

When a child is born with Down's syndrome, the midwife/doctor has a legal duty to report it. This means that, with your knowledge, they will inform the social services department in your municipality that a child with Down's syndrome has been born.

Soon after returning home you can expect to be contacted by a case officer who can advise you about the help and support opportunities available for you and your family. These do vary depending on the municipality in which you live. Support can include extended contact with a health visitor, contact with a paediatric specialist, physiotherapist and speech therapist and extra doctor visits.

The paediatric specialist's task is to give guidance and advice on how you and your closest relatives can assist the child's development. Guidance can also later be given to the personnel at the child's institution. The specialist may also be able to put you in touch with other parents of small children with Down's syndrome.

The physiotherapist is one of the first healthcare professionals you will meet, because muscle weakness is one of the common features of children with Down's syndrome. Besides direct work with the child, the physiotherapist also advises on what you can do to strengthen your child's coarse muscular activity.

The speech therapist usually comes into the picture later on. Many children with Down's syndrome have difficulty in developing language and the speech therapist can advise you on helping the child's language on its way. Sign-For-Speech is an indispensable part of life for most children with Down's syndrome.

At this moment it might seem overwhelming to think about all the professionals who can talk to you about your child, and what you can do to give the child the best possible start in life. When and if you want more information about the child's development and the possible help available, you can request the leaflet "På vej" from National Down's Syndrome Association, (see the reading list). There are many parents who, after the first year of the child's life say: "Our home is getting like a railway station" and possibly think to themselves "And I am taking the next train out of here". A good piece of advice is: All the helpers are there for you and your child. If the help they offer does not suit you, then you can ask them to propose something else. If you think they visit too often, or there are too many of them, then ask for a break. You always have a choice, and you don't have to say yes to everything, even though everything is intended to be a help.

De mange hjælpere

Når du har født et barn med Downs syndrom, har jordemoderen/lægen indberetningspligt. Det betyder, at de med dit vidende har pligt til at underrette socialforvaltningen i din kommune om, at der er født et barn med Downs syndrom.

Ret hurtigt efter hjemkomsten kan du forvente at blive kontaktet af en **sagsbehandler**. Hun/han kan fortælle om, hvilke muligheder, der er for hjælp og støtte til dig og din familie. Det er forskelligt alt efter, hvor man bor, hvilke støttemuligheder man får tilbudt. En del af støtten kan være udvidet kontakt til sundhedsplejersken, kontakt til en hjemmevejleder/småbørnskonsulent fra amtet, en fysioterapeut, talepædagog, ekstra lægebesøg mm.

Småbørnskonsulentens opgave er at vejlede og rådgive i, hvordan du og dine nærmeste kan hjælpe barnets udvikling på vej. De kan senere vejlede personalet i barnets institution. Nogle steder tilbyder hjemmevejlederen/småbørnskonsulenten at bringe jer sammen med andre forældre til små børn med Downs syndrom.

Fysioterapeuten er ofte en af de fagpersoner, du vil møde først, da svage muskler er et af de gennemgående træk ved børn med Downs syndrom. Fysioterapeuten kan dels selv træne barnet, dels give ideer til hvad du kan gøre for at styrke dit barn grovmotorisk.

Talepædagogen kommer ofte lidt senere ind i billedet. Mange børn med Downs syndrom har problemer med at udvikle sproget, og her kan talepædagogen vejlede i, hvordan man hjælper sproget på vej. Blandt andet er "Tegn-Til-Tale" en uundværlig del af livet for de fleste børn med Downs syndrom.

Lige nu er det måske overvældende at forestille sig alle mulige professionelle, der kommer og taler om dit barn, og hvad du skal gøre for at give det en bedst mulig start. Når og hvis du ønsker mere information om barnets udvikling, og hvilken hjælp man kan få, kan du rekvirere pjecen "På vej" hos Landsforeningen Downs syndrom (se litteraturlisten).

Der er mange forældre, der efter det første halve til hele år af barnets levetid siger: "Vores hjem er blevet en banegård" (og måske tænker man også "... og jeg tager det næste tog væk".) Et godt råd er: Alle hjælpere er til for dig og dit barn. Hvis den hjælp, de tilbyder, ikke passer til jer, så bed dem om at foreslå noget andet. Hvis I synes, de professionelle kommer for tit, eller de er for mange, så sig fra. Bed om en pause. I har altid et valg, man behøver ikke sige ja til alt, også selv om det er ment som en hjælp.

Moving ahead

by Bodil Keiding

Loss and trauma therapist, Roskilde County Council

Expecting a child

Expecting a child is for most parents a time of joy, expectations and dreams. Usually the dreams about the child are positive, "It will be a perfectly healthy baby". You have been looking forward to the birth, so naturally it comes as a big shock to be told that the new arrival has Down's syndrome, a different child in many respects from the child you were probably dreaming about. The new situation is so unexpected and makes so different demands that many despair. "Why me?" "Why us?"

A mixed cocktail of feelings

Most parents are very confused because they feel both powerless and joyful over the new baby. You are unhappy that it is not the healthy child you dreamed of, but at the same time happy for the child you have got. It can be difficult to handle these mixed feelings. In this situation, grieving can be regarded as taboo, but in fact it is a very natural feeling when you feel you have lost a healthy child. It is important to remember that it is in grieving for what you have lost, that you find the seeds of joy in what you have gained. By coming to terms with and acknowledging your sorrow, you can begin to feel joy about the positive aspects.

Different reactions

There are many ways to react when you have a child with Down's syndrome. Some lose control of their emotions, for example crying without provocation or becoming angry without reason, or do strange things. Some become forgetful and anxious. The opposite can also happen; closing off, throwing yourself into work or domestic practicalities, anything to occupy the mind and shut out feelings. There is often a difference between the reactions of men and women, especially in stressed situations. When you are under pressure it is easier to misinterpret the other person's reactions as rejection and indifference. It is often easier for women to vocalise their feelings and cry than it is for men. Many men are more action oriented. They take care of practicalities, seek information about Down's syndrome or throw themselves into work. Differences in reactions do not need to provoke accusations that one is running away while the other is drowning in sorrow, but there is a danger of misunderstandings. The important point is that differences rarely – or never – express "indifference". We all do the best we can, right here and now. You and your closest relatives have to find out about having and living with a child who has Down's syndrome.

Having a child with Down's syndrome is a many-sided experience

On the one hand you might experience defeat or dashed hopes, while on the other you are filled with joy over even the slightest progress that the child makes. Parents of older children with Down's syndrome express it this way: "You can say that we have received a present. We have greater intensity in our life, and have become better at living in the present, because we know that nothing in life is ever certain".

Hvordan kommer man videre ?

Af Bodil Keiding

Tab- og traumeterapeut i Roskilde Amt

At vente et barn

At vente et barn er for de fleste forældre forbundet med glæde, forventninger og drømme. Som regel er drømmene om barnet positive. "Det vil blive sundt og rask", og man håber, at man bliver lykkelig i sin familie.

Derfor kan det naturligvis være et stort chok at få at vide, at den lille ny har Downs syndrom.

Barnet afviger måske på mange punkter fra det barn, man drømte om.

Den nye situation er så uventet og stiller så anderledes krav, at mange, men ikke alle, i første omgang bliver fortvivlede. "Hvorfor lige mig?". "Hvorfor lige os?"

En cocktail af følelser

De fleste forældre er meget forvirrede, fordi de både føler afmagt og glæde over den lille ny. Man er på en gang ulykkelig over, at det ikke er det raske barn, man drømte om, og samtidig lykkelig og glad for det barn man har fået. Det kan være svært at håndtere denne blanding af følelser.

I denne situation kan det opleves som forbudt at sørge, men det er en ganske naturlig følelse, når man har oplevet et tab af det raske barn. Her er det vigtigt at huske, at det er i sorgen over det, man har mistet, man finder kimen til glæden over det, man har. Dvs. at ved at bearbejde og erkende sin sorg, kommer man til at glæde sig over de positive sider.

Forskellige reaktioner

Der er mange måder at reagere på, når man får et barn med Downs syndrom. Man kan godt for en tid miste kontrollen over sig selv. F.eks. kan man helt umotiveret begynde at græde, blive vred uden grund, foretage sig underlige ting. Blive glemsom og angst. Der kan også ske det modsatte; at man lukker af, kaster sig over alt det praktiske, fordyber sig i arbejde, ja, gør alt for ikke at mærke.

Ofte er der forskel på mænd og kvinders reaktioner. Især i stressede situationer. Og når man er presset, har man lettere ved at misforstå den andens reaktioner som afvisning eller ligegyldighed.

Kvinder har ofte lettere ved at sætte ord på deres følelser og græde end mænd. Mange mænd er mere handlingsorienterede; de ordner praktiske ting, søger informationer om Downs syndrom eller fordyber sig f.eks. i arbejde.

Forskelle i reaktioner behøver ikke at give anledning til beskyldninger om f.eks. at den ene flygter og den anden begraver sig i sorg, men der er en fare for misforståelser. Det vigtigste er, at forskelle sjældent – eller aldrig – er udtryk for "ligegyldighed". Man må regne med, at vi hver især gør vores bedste, så godt vi kan lige nu.

Du og dine nærmeste skal sammen til at finde ud af at have fået og leve med et barn med Downs syndrom.

Det at få et barn med Downs syndrom er mangesidet

På den ene side oplever man måske nederlag eller skuffede forventninger, på den anden side fyldes man af glæde over selv små fremskridt, barnet gør.

Where can you get help?

If you need professional help to make progress, you have the opportunity to be referred to a psychologist through your GP or the hospital where the child is born. This offer is widespread and has helped many to come to terms with their feelings and to talk about how the family can move ahead. You can also talk to the case officer who can advise you on the range of help available in the county or municipality.

Forældre til lidt større børn med Downs syndrom, udtrykker det således: "Man kan sige, vi har fået en gave. Vi har fået større intensitet i vores liv, er blevet bedre til at leve her og nu, for vi ved, at der ikke er noget, der er givet".

Hvor kan du henvende dig?

Hvis du har brug for professionel hjælp til at komme videre, har du mulighed for at blive henvist til psykolog gennem egen læge eller det hospital, hvor barnet er født. Dette tilbud er almindeligt udbredt og har hjulpet mange til at bearbejde deres følelser og få talt om, hvordan familien skal komme videre.

Du kan også henvende dig til sagsbehandleren, som kan henvise til amtets og kommunens tilbud.

My older brother is handicapped

By Dan R. Schimmell

Consultant with The LEV National Association

I am the younger brother of a now very grown up man who is development compromised. He is my big brother and so naturally I have never experienced being in a family without a handicapped member. I think it has enriched my life in many ways, and given me a view of people which is characterised by greater tolerance.

Many parents become anxious about living with a handicapped child, especially if there are siblings. Many of the parents I meet have a very bad conscience in relation to the non-handicapped siblings – often without reason.

When I think back to my childhood, I do not remember my brother as handicapped. I remember him as the one he was and is, my big brother. When I got older I could see that there was something about him that was different. As a schoolboy I compared the things my parents did and didn't do for him and for me.

Three things especially are etched on my memory:

- *Parents' meetings*
- *"You should be grateful that you are not like your brother"*
- *Different rules*

Parents' meetings

Parents' meetings at my brother's special school were talked about for weeks beforehand. Things were twisted and turned. Arguments were formulated, accepted or rejected. Strategies were prepared and agreed – what my parents would like the school to offer my brother. And both my mother and father went there.

The contrast to the parents' meetings about me was striking. It was often agreed just the evening before which one of my parents would go – that was how it was.

I wish my parents had told me why they prioritised things as they did instead of just doing it.

"You should be grateful"

When we had meals in the kitchen, my parents would sit opposite each other, and me opposite my brother. I couldn't avoid seeing my brother chewing away noisily – it was quite annoying. On several occasions I grumbled about having a "ringside seat". Sometimes I was very persistent in my demands, causing my parents great annoyance. Their reply was always: "You should be grateful that you are not like your brother", and "you wouldn't want to be in his shoes". Hard words when you are just a boy.

I would have preferred that they had done something to change my brother's eating habits, made table rearrangements, doing something to ensure that everyone was considered, including me.

Different rules

I had a fairly unrestricted childhood, but there were still differences in the things my brother and me were allowed to do. It spelled trouble

Min bror er handicappet

Af Dan R. Schimmell

Konsulent i landsforeningen LEV

Jeg er bror til en nu meget voksen mand, der er udviklingshæmmet. Han er min storebror og i sagens natur har jeg aldrig oplevet at have en familie uden et handicappet medlem. Jeg synes, det på rigtig mange punkter har beriget mit liv, og givet mig et syn på mennesker, der er præget af stor tolerance.

Mange forældre bliver bekymrede, når de skal til at leve med at have et handicappet barn, særligt hvis der er søskende. Mange af de forældre, jeg møder, har kronisk dårlig samvittighed i forhold til de ikke handicappede søskende – ofte uden grund.

Når jeg tænker tilbage på min barndom, husker jeg ikke min bror som handicappet, jeg husker ham, som den han var og er, min storebror. Da jeg blev ældre, kunne jeg se, der var noget ved ham, som var anderledes. Som stor skoledreng sammenlignede jeg, hvilke ting mine forældre gjorde og ikke gjorde for ham og mig.

Der er særligt tre ting, der har brændt sig fast i min hukommelse:

- *Forældremøder*
- *"Du skal være glad for, at du ikke har det som din bror"*
- *Forskellige regler*

Forældremøder

Forældremøder på specialskolen hos min bror var noget, der blev talt om i uger forinden. Tingene blev vendt og drejet. Argumenter blev fundet, forkastet eller accepteret. Strategier blev aftalt osv. Alt sammen for at være klar – klar til at fortælle, hvordan mine forældre gerne ville have, at skoletilbudet skulle se ud for min bror. Altid skulle både far og mor af sted.

Kontrasten til møder, der handlede om mig var slående. Ofte blev det aftalt aftenen før, hvem af mine forældre der deltog – sådan var det.

Jeg ville ønske, at mine forældre havde fortalt mig, hvorfor de prioriterede, som de gjorde, i stedet for bare at gøre det.

"Du er heldig"

I køkkenet, når vi spiste, sad mine forældre over for hinanden, og jeg sad over for min bror. Jeg kunne ikke undgå at se min bror smaske sig gennem måltiderne – ret irriterende. Jeg brokkede mig ved flere lejligheder over, at jeg skulle have "første parket". Somme tider var jeg meget vedholdende i mine krav til stor irritation for mine forældre. Deres svar til mig var: "Vær glad for, at du ikke har det som din bror", og "du skal ikke ønske dig at være i hans sted". Hårde ord når man kun er en knægt.

Jeg ville gerne have oplevet, at de havde arbejdet offensivt på at ændre min brors spisevaner, lavet omrokeringer ved bordet, i det hele taget vist ved aktive handlinger, at vi alle skulle være der, også jeg.

Forskellige regler

Jeg havde vide rammer i mit barndomshjem, men der var også forskel på, hvad vi brødre kunne tillade os. Eksempelvis har det altid givet ballade, når jeg smed mig på gulvet – for min bror var det til tider en virksom måde at sætte sine krav igennem på.

for me if I threw myself on the floor – but for my brother it was an effective means for getting his own way.

Today I can see that the different rules were necessary. I just wish that my mother and father had explained that different rules existed, and why.

Looking back as an adult, I can offer some advice to parents in this situation: Give all your children the space to be as they are, and to develop themselves. Upbringing must be for everybody.

I dag kan jeg godt se, at det var nødvendig med forskellige regler. Jeg ville bare ønske, at min far og mor havde fortalt, at der eksisterede forskellige regler, og hvorfor de var der.

Når jeg i voksentilværelsen kigger tilbage, så har jeg et råd til forældre i denne situation:

Giv alle jeres børn plads til at være, som de er og til at udvikle sig. Opdragelse skal også være for alle.

The National Down's Syndrome Association

This is an association which was founded in November 2000. Our aim is to create the best possible conditions for people with Down's syndrome.

We work to:

- extend knowledge and create understanding of people with Down's syndrome and their families
- represent the interests of people with Down's syndrome and ensure that their rights are observed and developed
- support and guide people with Down's syndrome and their families
- contribute to a qualitative development of educational and treatment services

Our association is affiliated to the LEV National Association where we co-operate on all the conditions that concern development-compromised people in general.

What do we do ?

Through the National Association you can get in touch with people with Down's syndrome and their families.

- We publish information on Down's syndrome
- We publish a quarterly membership magazine "Down&Up"
- We hold national meetings with a professional and social content
- We help to set up local groups and provide ideas to existing groups

Membership of The National Down's Syndrome Association

Individuals DKK 75.00 per year
Families DKK 125.00 per year

Payment

Via PC Bank Art 73 no 89139538
By transfer to Jyske Bank account no. 5073 000140950-9
Do remember to include your name, address and telephone number.
Giro forms can be ordered on tel. 27 34 04 77 or e-mail: downs@downssyndrom.dk

You can see the list of people to contact in your county on our website www.downssyndrom.dk, where you can also see our current activities and search for information about Down's syndrome.

Landsforeningen Downs Syndrom

Vi er en forening, der blev stiftet i november 2000. Vores formål er at skabe de bedst mulige vilkår for mennesker med Downs syndrom.

Vi arbejder for:

- at udbrede kendskab til og skabe forståelse for mennesker med Downs syndrom og deres familier
- at repræsentere interesser for mennesker med Downs syndrom og sikre, at deres rettigheder overholdes og udvikles
- at støtte og vejlede mennesker med Downs syndrom og deres familier
- at medvirke til en kvalitativ udvikling i de pædagogiske og behandlingsmæssige tilbud.

Vores forening er tilknyttet Landsforeningen LEV, hvor vi samarbejder om alle de forhold, der vedrører udviklingshæmmede generelt.

Hvad laver vi ?

I Landsforeningen kan du få kontakt med mennesker med Downs syndrom og deres familier.

- Vi udgiver informationsmateriale om Downs syndrom
- Vi udsender vores medlemsblad "Down&up" fire gange om året
- Vi afholder landsmøder med fagligt og socialt indhold
- Vi hjælper med at oprette lokalgrupper og giver inspiration til eksisterende grupper.

Medlemskab af Landsforeningen Downs Syndrom

Enkeltperson 75,00 kr. om året
Familier 125,00 kr. om året

Betaling

Via P.C Bank Art 73 nr. 89139538
Ved overførsel til Jyske Bank kontonr. 5073 000140950-9
Husk at påføre navn, adresse og telefonnummer.
Girokort kan bestilles på tlf.: 27 34 04 77 eller e-mail: downs@downssyndrom.dk

Du kan se listen over kontaktpersoner i netop dit amt på vores hjemmeside www.downssyndrom.dk, hvor du også kan søge information om Downs syndrom og se vores aktuelle aktiviteter.

Local groups or associations

In almost every county there are local groups or associations which have been established by parents of children with Down's syndrome.

Purpose
The main purpose of a local group or association is to create a shared space where parents can help, guide and support each other with different problems. Naturally there are differences between local groups' activities; some have speakers and hold social events, while others may simply meet for coffee. But all members are in the same situation – they all have a child with Down's syndrome.

Local groups and associations provide the opportunity to:

- share experiences with other parents in the same situation
- tell each other about the help and guidance which professionals in the local area can offer
- tell each other about the kind of options and rights you have – especially financial rights
- collaborate on projects, for example to lobby the local authorities to provide shared caring
- share ideas on how to stimulate your child – both physically and mentally
- increase awareness of other children's development
- give your child equal playmates in the local area

It is up to you and your family how active you want to be in the association or group; the need is likely to vary over time. On The National Down's Syndrome Association website www.downssyndrom.dk you can find links to local groups and associations, as well as information about Down's syndrome. You will also find the telephone numbers of contact persons in your local area, should you have any questions or just need to talk to someone in the same situation.

Use us – we are here for you!

Downsyndromforeningen i Vestsjællands Amt

Downsyndromforeningen i Vestsjællands Amt blev stiftet i 1998 af nogle forældre til børn med Downs syndrom. Vi er i dag 25 familier i foreningen, og vores børn er mellem 0 og 7 år.

Aktiviteter
Vi har jævnligt legestuer forskellige steder, f.eks. i skoven, på stranden eller i børnehaver.

Vi afholder også fælles juletræsfest, fastelavnsfest og en årlig sommerfest.

Endvidere afholder vi forskellige foredrag for forældre og pårørende, og emnerne spænder lige fra indlæg fra en diætist til foredrag om søskenderelationer og bofællesskaber.

Medlemskab
Kunne du tænke dig at være aktivt eller passivt medlem af vores forening, kan du kontakte Lene Pedersen på telefonnr.: 57 61 48 17, eller klik ind på vores hjemmeside www.downvestamt.subnet.dk

Det koster kr. 100,- om året at være aktivt medlem og kr. 50,- at være passivt medlem.

Tilbud i Vestsjællands Amt
I Vestsjællands Amt har du en række tilbud, når du får et barn med Downs syndrom:
Hjemmebesøg af en småbørnskonsulent
Hjemmebesøg af fysioterapeut
Flere besøg af sundhedsplejerske

Useful web addresses

www.downssyndrom.dk
The National Down's Syndrome Association

www.lev.dk
Landsforeningen LEV (LEV - The National Association for development-compromised people)

www.handicap.dk
De samvirkede Invalideorganisationer (Cooperating Organisations for Disabled)

www.ds-health.com
Down Syndrome Health Issues – News and information for parents and professionals

www.downsnet.org
The Down Syndrome Educational Trust

www.ndss.org
National Down Syndrome Society

www.ndsccenter.org
National Down Syndrome Congress National Down Syndrome Congress
Down Syndrome Congress

www.dsrf.co.uk
The Down's Syndrome Research Foundation

www.downs.person.dk
The Copenhagen Association of Parents of Children with Down's Syndrome

www.downsyndrome.com
Search for Down Syndrome on the Internet

www.mosaicdownsyndrome.com
Mosaic Down Syndrome on the Web

Nyttige web-adresser

www.downssyndrom.dk
Landsforeningen Downs Syndrom

www.lev.dk
Landsforeningen LEV

www.handicap.dk
De samvirkede Invalideorganisationer

www.ds-health.com
Down Syndrome Health Issues – News and information for parents and professionals

www.downsnet.org
The Down Syndrome Educational Trust

www.ndss.org
National Down Syndrome Society

www.ndsccenter.org
National Down Syndrome Congress National Down Syndrome Congress

www.dsrf.co.uk
The Down's Syndrome Research Foundation

www.downs.person.dk
Foreningen Forældre til Mongolbørn i København

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Video (3 udsendelser om Morten og Peter, der har Downs Syndrom, TV2, 1995).

Anderledes, men dejlig
En oplysningsfilm om det at blive forældre til et mongolbarn. Udgivet af Mongolgruppen i Ringkøbing Amt (telefonnr.: 97 49 16 29/ 97 33 74 02).

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