

## Sample texts from the chapters

Meeting people

Family

Siblings

Growing up

Love affairs

Losses

### „I am not your little sausage dog“

Looking back

I only really noticed people with Down's Syndrome quite late in life. I'd just moved house and was getting to know my new surroundings. I was pregnant and tried to do as much walking as possible because at work I sat at my desk all day. I used to bump into the same woman time and again with her two children. In my eyes the woman was ancient, she was probably only 50 or 60. As for her children, I couldn't even hazard a guess, they were definitely over 20, maybe even over 30 or 40. I never wanted to look too closely. Like two little pet dogs they trotted behind their mother, overweight, a bit cumbersome, all dressed in grey. They seemed handicapped in some way and I felt truly sorry for the poor woman.

Then my son was born and diagnosed with Down's Syndrome. I struggled to shake off the image of those three people and get a grip on my own life. One thing still stays with me to this very day – I get very uneasy if I ever I sense that Matthias has got left behind or is trotting behind me. Nowadays it's become a bit of a game, I look at Matthias or take him by the arm and he says; „I know, I'm not your little sausage dog“. Wherever did he get that expression from?

Hanni Holthaus

### Walter

A community service volunteer describes his experiences

I first met a „Mongoloid“ – Walter – when I was just starting my community service in a home for mentally handicapped adults. My residential group was made up of eleven men with varying degrees of mental handicap. Epileptics, spastics, people with mental disability resulting from premature birth, and a Down's Syndrome sufferer. For Walter, our first encounter was entirely without prejudice. During our coffee break he smiled at me continuously and winked at me mischievously; somewhat embarrassed, I smiled back at him. Taking this as a sign of encouragement he started stroking my arm – it took a great deal of will-power on my part not to snatch it back. When it came to saying goodbye, Walter gave me a sudden – and for me extremely unexpected – kiss on the cheek. I wanted to run to the nearest sink and wash myself, as if Down's could be catching.  
(...)

Stefan Baumgartner

### What a stroke of luck!

Prenatal diagnostic and its consequences

Before I got pregnant, my husband and I agreed that there's never any guarantee of a perfect child. In our discussions, I was adamant that I'd carry the child to full term, even if it was handicapped. Obviously it never occurred to me that I might actually have a handicapped child. My husband couldn't agree with such an uncompromising position and hoped he'd never have to face such a reality. But things turned out differently.  
(...)

Daniela Schulze

### „I want to keep my baby!“

Down's Syndrome and motherhood

Last year in October, our 15 year old daughter Kim started behaving strangely. She was incredibly clingy, had terrible mood swings, cried a lot, was always hungry and stopped getting her periods. After a few days of nagging suspicion we went to a gynaecologist on October 22, 2001. He confirmed that Kim was in her eighth week of pregnancy...

Ute Wilke

## The sound of music

Marlene is in her third year primary school where she's learning the recorder. Konrad (who's two and a half and into everything) gets hold of this extremely interesting instrument and tries to get to grips with it. Marlene catches him and I hear the following conversation with her brother: „Konrad give me back my recorder right now, it was really expensive. When you're my age you can learn the recorder too.“ There was a small pause, followed by: „It would definitely help your mouth coordination!“

Claudia Heller-Vitouch

## I don't mind if he gets married

Twelve-year-old Judith talking about her brother

*What do you like about your brother?*

He's really nice and sometimes lovely too. I really like it when we play together with our soft toys.

*What don't you like about him – what gets on your nerves?*

When he tickles me and holds me tight by my arm! And I don't like it when he argues about the telly. We always have to watch what he wants. And when we argue, he always wins!

*What do you think your future will be like, when you're both grown-up?*

I want him to be a doctor. I want to work in a hotel. We'll live in a flat together. And I don't really mind if he gets married. When I get married maybe I won't live with him. Or maybe I will. We'll have to see.

## Actually my sister is perfectly normal

Ten year old Taddaeus talking about his sister

*What do you like about your sister?*

Whenever we're playing a game together with all the family in the evenings, which she can't play, she never grumbles. She sits there with us anyway and has fun watching us. She never gets cross because she can't join in, she's just happy that we're playing.

*What don't you like about her- what gets on your nerves?*

She eats really noisily and grinds her teeth really badly! And she always wants to watch what she wants to watch on the telly, never mind whether I'm there, or anybody else.

*How do you think your sister finds you?*

I think she thinks I'm ok – yes, even though I tell her off quite a lot, I think she likes me

Both these interviews were conducted by the children's mother Angelika Pollmaecher

**„Who am I?“**

Self-contemplation

I have Down's Syndrome. But then that gives me two advantages and disadvantages. The first advantage is that I have a nice place to live in Buchbach and that I'm more independent. And that I am lucky in love. I wish everybody was lucky in love. When I was a child I couldn't read or write. But I learnt how to, through my bible-study, and now I can and I understand the stories in the Bible about religion. When I play sport and when I play board games, I've learnt how to be a good loser. I don't really know if I enjoy it. But it's much worse to lose someone you really love in real life. I often think about my father Albert, who's dead. I learnt a lot of things from him. Some people say that I'm just like my father, and I agree. My father used to like reading the Old Testament and the Book of Wisdom. And he liked going to the theatre and to the opera, and out to dinner. And I do too. He told me I had to help my mother. I look after her exactly like my father used to. He can be proud of his son Patrick. I can't think of anything else.

Patrick Goerres

**Love is at the heart of things**

Ines Heitzmann on her love for Patrick Goerres

(...)

*Why did you choose Patrick?*

I was quite sure I wanted Patrick. I fell in love with him. He's a handsome man. I always smiled at him, and he smiled at me. And then we had our first kiss. And then I said you're so gentle and lovely. And I was very gentle too. I am drawn to him like Cupid who shot the arrow....

Ines Heitzmann in an interview with her mother

**Johannes – in seven months he explained his world to us**

The end of a short life

(...)

The operation itself went smoothly and without any complications. But two hours later Johannes' heart stopped beating. All attempts to save his life were unsuccessful. I'll never forget the words of the senior consultant in the children's intensive care unit: "Johannes didn't want to go on" he said. I was so shaken and confused, I couldn't understand what he meant. Why should Johannes want to leave us? We were all so happy, and we loved him so much! It was much easier to believe in a medical error. But a post-mortem gave us no new answers. Johannes had simply died of causes for which there was no medical explanation.

(...)

Katja Weiske

**Mourning and letting go**

Entries from a diary

(...)

2nd May 1996

I've been freezing since you died  
I'm freezing because you've gone  
I didn't know how real the warmth  
could be that a person radiates  
Life and the world have grown cold  
and your little star is so far away  
(...)

Dorothee Lehmann