



Baby Sam struggled to feed at first

doctors at the Royal Cornwall Hospital in Trillick, Cornwall, told me that the amniotic fluid around my child had reduced.

'We need to induce you next week,' they said.

The day before I was due to have the procedure, however, I went into labour naturally. On 15 October 1997, I gave birth to a little boy. We named him Sam.

'He looks just like you,' I said to Peter proudly.

Sam was a healthy 6lb, but had jaundice and struggled to feed. They kept him in hospital for three days. Even after he came home, he had blood tests every other day.

After one visit, the hospital rang. 'We'd like you to bring Sam back in,' a voice said. 'We suspect there is something wrong with his heart.'

The news was a complete bolt from the blue.

'He's going to be all right, isn't he?' I said to Peter, worried.

'Of course,' he reassured me.

While we waited for a paediatric cardiologist, the hospital tube fed Sam and decided to test him for Down's syndrome.

'Problems with the heart can be part of the condition,' a doctor said.

Although of course I'd heard of Down's, I knew nothing about it.

When the test came back positive, I told myself not to worry about it.

*It's Sam's heart that matters at the moment,* I thought.

Still waiting for a diagnosis, Peter and I decided to have him christened.

'Maybe that will cure everything,' I said.

But it didn't. He was diagnosed with three holes in his heart.

I wanted to break down and weep for my little boy, but I knew I had to be strong.

'What happens now?' I asked,

my voice trembling.

'Surgery,' the cardiologist said. 'But we need to leave it as long as we can so we have more tissue to deal with.'

With that, we were sent home.

The following days and weeks were very difficult. Sam went downhill fast. Fed every two hours, he'd then projectile vomit every bit of milk. When I held him, I could hear his heart making a scary swishing sound.

Finally, on 29 January 1998, when he was three months old, Sam went in for surgery at Bristol Royal Infirmary.

With my mum looking after Eleanor, Peter and I slept on the hospital floor, next to our son's cot.

The surgery was a success.

'Thank God,' I wept, hugging Peter tightly.

The day after we took Sam home, however, we learnt that Peter's mum Peggy had suffered a major aneurysm and needed surgery.

He rushed to Leeds to be at her side, while I set about finding out all I could about Down's syndrome.

There wasn't much available. One of only a handful of books began: *If you've decided to keep your child with Down's syndrome...*

*Too right I'm keeping him!* I thought, shocked, and snapped the book closed.

I couldn't run away from people's reactions, though. Some stared, others wouldn't look at Sam at all.

Worst of all was when people



Sam on his first birthday

When Wendy Uttley, 47, was told her baby had Down's syndrome, she longed for more support. So she decided to take action...

**Y**ou look like a pipe cleaner with a knot in it!' laughed my partner Peter.

I was pregnant with my second child, and I was finding it hard to gain weight having spent eight months breast-feeding my two-year-old daughter, Eleanor.

But I was delighted at becoming a mum again at 33. Everything had

gone so well with Eleanor. She'd blossomed into a bright little girl and was excited to be a big sister.

Into the second half of pregnancy, I was asked if I wanted the Triple test to check for chromosomal abnormalities in the baby.

'No,' I replied, just as I had when I was expecting Eleanor.

Four weeks before I was due,

Who will help **MY SAM?**



frustrating and lonely experience. 'The support here for kids with Down's is so limited,' I told Peter. I did, however, meet three families who had children with the condition. They were lovely people with great kids, but were also disappointed by the lack of resources. 'It has to change,' I said to Peter with passion.

It was while lying in bed that it occurred to me — I could be the one to make a difference. In the morning, I sprang from bed. 'I want to start a support group,' I told Peter. 'Not just coffee and a moan, but a proper support group for families of kids with Down's syndrome. I want to do it for Sam.'

Peter was all for it. Together with the other families I'd met, I started making my idea a reality.

I booked Haworth Road Methodist Church in Bradford for a Saturday meeting in September 2000, then designed some leaflets with information about the support group.

I left them in doctors' surgeries, hospitals, medical centres, shops and supermarkets.

I was used to a classroom, so it was scary to be out of my comfort zone.

But I only had to think of Sam to know it was worth it.

When Saturday came, I was full of nerves. I knew the families involved would be there.

Other families else? 'They'll come,' Peter said.

He was right. One family arrived, then another. Four families made it. While the kids played, the parents talked through their experiences.

The following month, we only just had enough chairs, biscuits and toy cars to go around!

The group grew, and Sam was flourishing. When he was three, I decided to start working on his counting skills.

'Well done,' I'd say to him, and he'd clap and beam at me with pride.

I introduced him to sign language, having learnt about it from Down Syndrome Education International. And with the help of a DVD by kids' TV favourite Dave Benson Phillips, Sam's communication really improved.

If this is helping my

son, how many other kids could benefit? I wondered.

I started structured activities, including signing, for the kids at the support group. I also gave talks on my methods to parents and in 2004 applied for the group to be a registered charity — Down Syndrome Support Group Bradford.

Wanting to restart my career, in 2005 I applied for various lecturing posts, but having been out of the loop for five years, I got nowhere.

After working as an associate lecturer for the Open University, I realised that I wanted to work with Down's kids. That same year, I successfully applied for a Big Lottery Fund grant.

'Now I'll be able to do some training,' I told Peter excitedly. It also meant the charity could move into a small office.

When I wasn't planning talks on teaching and home learning, I was organising days out for families. And the phone didn't stop ringing. It was exhausting. But knowing how important it was to kids like Sam kept me going.

In January 2009, the charity moved into bigger premises and was renamed Down Syndrome Training & Support Service Ltd, which really reflects what we do. Ten years on, it's still as hectic. I



Above: Sam's seventh birthday. Right: he hasn't let Down's syndrome get in his way



Top: me with the kids on one of our first walks. Above: Sam and me on my 40th

asked me: 'How are you?'

It made me dissolve every time. Meeting other parents in Truro who had Down's syndrome in their lives made a big difference to me.

I also visited Down Syndrome Education International, an organisation in Portsmouth that did research into development and education for children like Sam.

Peter's mum pulled through, but it was clear she couldn't live alone.

Peter and I had moved from Bradford to Cornwall four years earlier. Now the most obvious answer was to move back.

'Peggy can move in with us,' I said to Peter. 'And it will be good to have my mum close by too.'

It was a very big step, though. Peter was a househusband and we relied on what I earned from teaching maths at Truro College. I had no job to go to in Bradford, but Peter and I decided it was the right thing to do.

We moved in 1998. Social Services gave us a lot of support with Peggy, while Sam, almost one, was blossoming.

But being in Bradford was a



Left: the support group flourished. Right: Peter, Sam, Eleanor and me now



It struck me that I could be the one to make a difference

hardly have time to put my feet up with Peter, now 55, at home in Malvern Crescent, Keighley, West Yorkshire.

Over 200 families have registered with us. Along with teaching and activities, we offer an extensive library of information for parents.

Sam is 13 now and in mainstream education. It hasn't always been easy — I had to take him out of one school. He's a real character and a lovely boy who's never let Down's syndrome get in his way.

Having failed to renew our Big Lottery Fund grant, the charity relies on a legacy. But we still need help with core running costs, which can be up to £80,000 a year.

It's hard going, but I'm so proud of what we've achieved. Having a child with Down's syndrome truly changed my life — and I wouldn't have it any other way.

For more information visit [www.downsupportbradford.btck.co.uk](http://www.downsupportbradford.btck.co.uk)

**BIG CASH** paid for every true story we publish. See our story form on page 21.

Edited by: Julie Cook and Kerry Sutch Photo: Telegraph & Argus