

Ashleigh - life with leukaemia



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Jim and Sharon Eastwood had already had a harder start to family life than most couples, Sharon writes;

“Jim and I were married in March 1990 and like most couples we took it for granted we could have children.

To our joy I fell pregnant in August 1990, but that joy turned to sorrow the following February when our son was still-born.

Between 1991 and 1999 we had many miscarriages, fertility treatment and two tries at IVF. We applied for adoption and lived in hope that we would be blessed with a baby.

In July 1999 we decided to go away on a world trip. Before going I rang our social worker to ask her to take our names out of the pool as we'd been waiting nine years and I thought it was time we accepted that we would never be blessed with a baby. She suggested we leave the decision until we got back.

We had a great time catching up with Jim's family and his niece offered us her flat in London for the weekend. After a busy day sight seeing, we returned to the flat to get ready for an evening at a West End theatre.

There had been a message waiting on Jim's mobile for most of the day, but he hadn't answered it as I'd made the rule that there should be no work over the weekend. Jim was really wanting to check it so in the end I gave in.

It was our social worker in NZ asking us to contact her urgently as she had wonderful news for us. We had been picked by a young couple to adopt their little daughter. Of course we just heard baby – then we heard her say “BUT... this little girl has DOWN SYNDROME”.

Jim and Sharon decided to adopt this little girl. They went and picked her up from her parents when she was eight weeks old and called her Ashleigh. Sharon wrote about the early days for the ‘Our Stories’ booklet of the NZDSA Welcome Pack.

They enjoyed the everyday life that comes with a child with Down syndrome. Sharon tells of the joy she found in; “teaching her and watching her learn to roll over, sit up, crawl, walk, produce her first sign and then first word.”

She was busy with visits to and from “speech therapists, physiotherapists, dietician, doctors, dentists, CCS and Social Welfare” and loved “meeting other mums

at the South Auckland coffee mornings.”

Sharon remembers Ashleigh's “first day at Potter's Early Childhood Centre, watching her grow and learn to be independent and the mornings when she ran off into the Centre and waved good bye.”

She sums up these years: “The joy and love this little girl brought us cannot be put into words. WE were finally a family.”

In September 2002, the family attended the launch of the NZDSA Welcome Pack in Auckland and Hamilton, and told Ashleigh's story, but Ashleigh had a cold and was not really very well.

The local medical centre told them nothing was seriously wrong, that maybe Ashleigh had hay fever or asthma.

By early October, she was not improving. Sharon writes, “Ashleigh was sick and was not getting any better. She was pale and tired, covered in unexplained bruises and a strange rash. She had a high temperature and her cold was getting so bad she could hardly breathe.

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The family was sent to ward 27b at Starship hospital, the haematology/oncology ward, and the next day Ashleigh had bone marrow taken under anaesthetic. Bone marrow produces blood cells, so by looking at it, a doctor can diagnose which type of leukaemia a child has. Ashleigh was found to have ALL (acute lymphoblastic leukaemia).

Jim and Sharon were given lots of information about leukaemia and encouraged to learn as much about it as

possible.

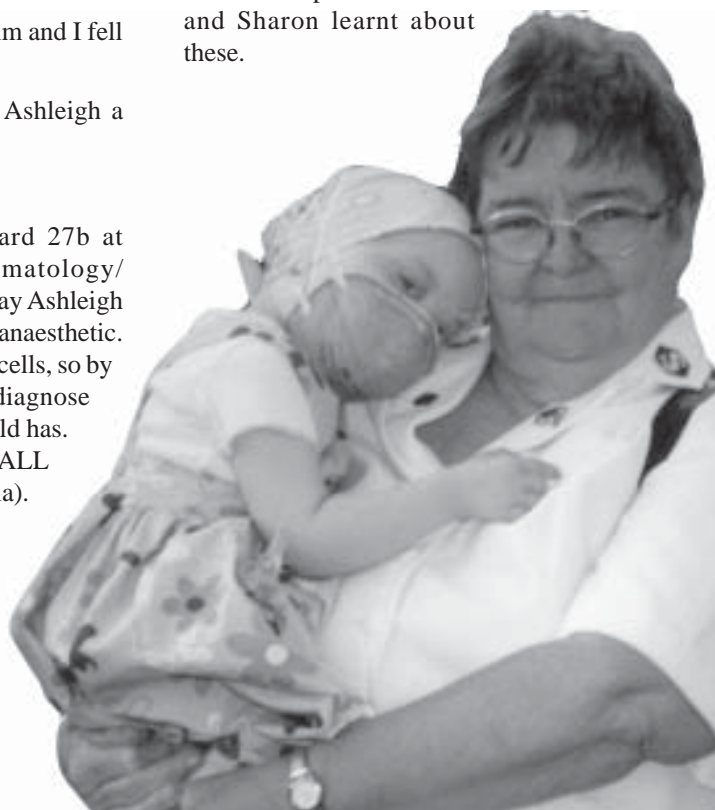
They discovered leukaemia is commoner in children with Down syndrome than other children, and occurs in about one in a hundred of children with DS. Some forms of leukaemia are specific to Down syndrome and it is important to find out which type of leukaemia a child has, as treatment and outcome vary.

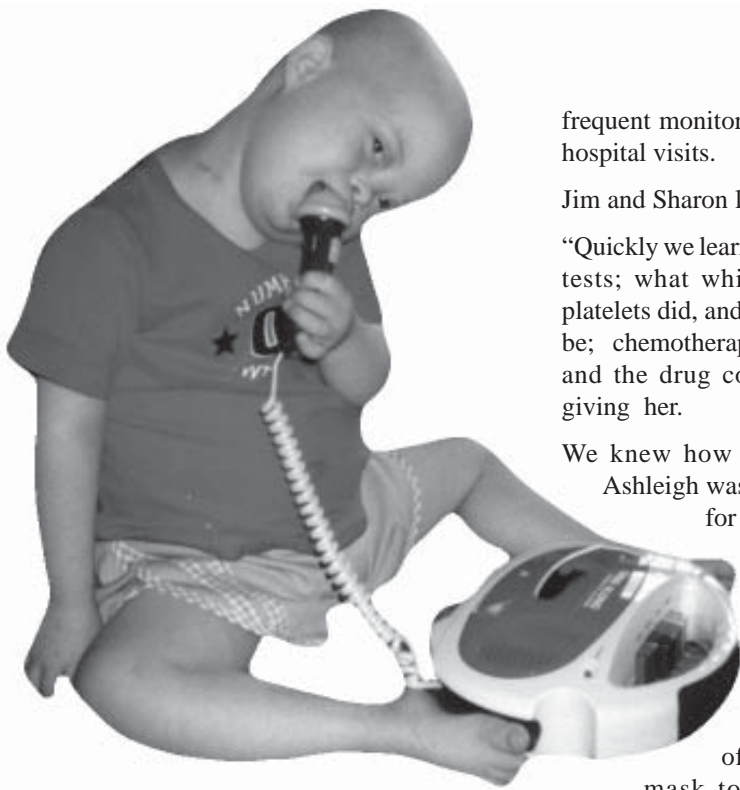
ALL (as Ashleigh has) is the commonest form of childhood leukaemia overall, but children with DS often have acute megakaryoblastic leukaemia, a leukaemia which is very rare in other children.

In leukaemia, lots of abnormal white blood cells are produced by the bone marrow which is then unable to keep up its usual production of normal blood cells. Because Ashleigh didn't have enough red blood cells she was pale and tired. Because she didn't have enough normal white cells, she had an infection and high temperature. Because she didn't have enough platelets, her blood didn't clot properly so she had bruises and a strange rash.

It was also explained that leukaemia is not a death sentence. With treatment, almost all children with leukaemia will go into remission, meaning no leukemia cells are left in their blood or bone marrow. Treatment has to be continued for months or years and the vast majority of children will then continue in remission (the term ‘cured’ is rarely used).

Ashleigh needed to start treatment immediately, but the chemotherapy drugs are very powerful with major side effects, so it was important that Jim and Sharon learnt about these.





There was so much to learn and take in, as well as coming to terms with the diagnosis of leukaemia.

Sharon was very grateful for all the support she received. She says, "Thank goodness that Jim is a calm and strong person as I would not have made it through the first few months. Both our families have always been there when we need them, offering love, support and prayers, especially my mother Jan."

Jan had already given much love and support since Ashleigh's arrival, but now she came to the hospital most days and would stay with Ashleigh so Sharon and Jim could have the occasional break.

Friends from the Down Syndrome Association also offered lots of help. The local group organized meals for the family and sent cards and gifts. Sharon writes, "We'd like to thank all our friends we have found through the Down Syndrome Association, there are just too many to thank by name."

Support offered via the hospital was very important too. Doctors and nurses gave love and reassurance, and Jim and Sharon met many wonderful families on the ward or in clinic.

The Children's Cancer Foundation and the Eastwoods' church family at the Pukekohe Salvation Army also offered helpful support.

As expected, Ashleigh soon went into remission and after two weeks was allowed home to continue treatment there, with

frequent monitoring at home and regular hospital visits.

Jim and Sharon learnt fast.

"Quickly we learnt about: blood and blood tests; what white cells, red cells and platelets did, and what their levels should be; chemotherapy; steroids; side effects and the drug cocktails they would be giving her.

We knew how to look for signs that Ashleigh was unwell, how to prepare for theatre procedure every month [when Ashleigh would have a bone marrow test or lumbar puncture under general anaesthetic].

We knew the importance of getting her to wear a mask to avoid infection, and rushing her to Starship when her temperature was over 38."

Ashleigh was learning too: she needed a portacath inserted in her chest, so that drugs could be given to her more easily. Ashleigh calmly practised what would happen with a special doll from the Play Therapy Department of Starship.

Sharon knew Ashleigh would lose her hair and at first was very concerned about this. It was hard too, when she was told Ashleigh couldn't mix with other children because of the risk of infection. Ashleigh couldn't go to her early childhood centre or the local Down syndrome group any longer and Sharon missed the contacts and support she'd had with other mothers.

There were also "the endless days and nights in hospital when Ashleigh was sick. It all sounds rather scary, and at the time it was."

But now the family is one year and three months into the two year three month treatment for ALL. After that, once "chemotherapy has stopped for six months and if there are no signs that the leukaemia has returned the portacath will be removed. Then there are yearly doctors' visits and blood tests for the next 7 years."

Sharon says now, Leukaemia is "a part of our daily routine and life must go on.

I know and accept that what Ashleigh goes through is necessary and it's only another one year and three months and Ashleigh will be ready to start school and this nightmare will be behind us."

The family have coped with Ashleigh losing her hair, and seen it regrow. Ashleigh continues to learn and develop and looks healthy, no longer sick and frail as she did at diagnosis.

Sharon is looking forward to the day when, "Ashleigh will be declared leukaemia free at the age of 10."

In memory of Ashleigh's grandmother, who passed away Jan 2004. She lived in the UK but was always with us in thought, letters and phone calls. The joy Ashleigh gave her will never be forgotten.

Medical content checked by Paul Harper specialist haematologist.

photos;
title page, Ashleigh now looks healthy again, December 2003
previous page, with Granma Jan soon after treatment began
this page, 1. hair loss is a side effect of some chemotherapy drugs, January 2003
2. Jim and Sharon with Ashleigh

