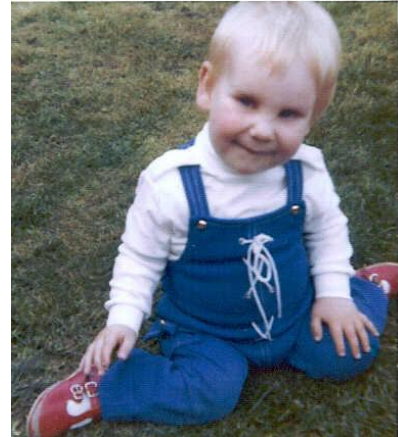


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Andrew's Story (32 years old) Jan 2004

Our second child Andrew was born on 7th May 1971, and was a healthy 9lb in weight. However, in the days that followed Andrew started to get weaker as he would not feed or keep any baby milk down. I also kept noticing that there seemed to something wrong with his eyes, compared to those of my daughter when she was born. After 6 weeks Andrew attended the children's clinic for a normal check up and they diagnosed cataracts in both eyes. Andrew could drink diluted cows milk, and water and this kept him going.



At 11 weeks old Andrew had his first eye operations to remove the cataracts. As the months went on Andrew did not attempt to walk or talk, and we were transferred to GOSH when he was about 18 months old. After many tests and visits to GOSH Andrew was diagnosed at 2 1/2 years old as having Lowe's syndrome, but that his life expectancy was no more than 4 years old. This was devastating news for my husband and I. My world fell apart; he was a lovely little boy, cheeky, full of fun and loved life. We just had to be positive and take each day as it came.

Andrew was always ill with bad colds, had cysts on his gums and was always being sick. Life was a continuous round of hospital visits, either to the local paediatrician or to GOSH or Moorfields eye hospital.



Somehow, Andrew pulled through all of this and gradually gained strength. It was hard work as he had temper tantrums and continually broke the arms off his glasses. He even had his own draw at the opticians with replacement spectacle arms in it. Andrew went to a school for the partially sighted from 4 years old and left at 16. He then attended a special needs unit at college for a further 3 years.

From the age of 17 years we started looking at the long term to see what was needed to meet Andrew's needs once college finished as his temper and outbursts were only getting worse. We were aware of the [Home Farm Trust](#) and liked the way it catered for people with special needs. It offered sheltered accommodation and a chance for Andrew to develop at his pace and not at our expectations of him.

After much tussling with the local council who would not agree to finance him unless he had a place, and the Home Farm Trust who could not offer a place unless he was financed, we eventually got both parties to agree positively. Andrew started when he was 19 in a communal home, with 24 hour support. After two years he moved to a shared house where he was encouraged to mix more with the community. In the last 6 years Andrew now lives in a bungalow with one other person, where he gets support during the day.

Andrew works one day a week in an Oxfam shop, attends college for touch typing, goes to an Art group and works in a charity art shop. He also attends his local Evangelical church every Sunday, and has made many friends and is well known in his local community. This may look as though Andrew is very academic, but he enjoys the company of others and likes to live as full a life as possible.

He also travels a lot on the local bus routes on his own and is a very independent person, to the point where he feels that any help is interfering with his way doing things. Andrew gets a lot of lumps on his back and face: He has had 2 removed surgically, and has another 2 still needing further attention. He has had 2 toes on each foot amputated as they were chronically distorted and painful in shoes. He has knobbly fingers and stiff knee joints. Andrew suffered a Deep Vein Thrombosis nearly 3 years ago, and at the time would not have it treated as he had a distinct hate of needles and injections. Two years ago it swelled up again and I believe because of the pain and fear of its consequences, he agreed to the treatment of stomach injections and warfarin tablets. Now he has overcome the fear of needles and willingly has regular blood tests to check his warfarin levels. A milestone.

Although he has had all of this and Lowe's syndrome to contend with, Andrew still likes to have a laugh and joke with people, an occasional lager shandy and loves listening to music on his record player .

I think of Andrew and not Lowe's syndrome, it's the only way I cope. He is young for his age and I tell people to think of him as Andrew and not as a 32 year old man.

So far he has proved all the doctors wrong and I keep hoping that this will continue for as long as possible. I am so proud of his achievements.

Andrew talks every day to my husband on the phone, and thinks the world of him, and I know how much it must hurt him to have a son with Lowe's. Sometimes, I feel guilty as the carrier, but it has made me a stronger person.

My daughter has had her DNA genetic test and was not found to have the gene, and has given us two lovely granddaughters, and Andrew is their godfather as well as their uncle. He loves them both dearly.

I hope this story may help others dealing with Lowe's.

Joan -Money 20th January 2004

19 may 2007 update - Andrew, Lorraine and Oscar visit Andrew



In May 2007 Andrew, Lorraine (Lowe Syndrome Trust) and Oscar Thomas (13 with Lowe Syndrome) visited Andrew with his family at his home in Evesham and Andrew took them on a tour of Evesham and to his favourite restaurant and tearooms.

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