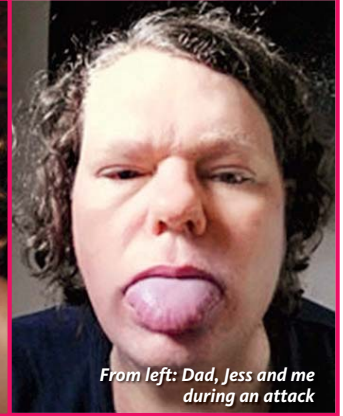




A family curse



Ryan suffers terribly



From left: Dad, Jess and me during an attack

Treasuring the GOOD DAYS

We could all die in our sleep, but we don't dwell on it

Tania Bogoyevitch, 45, Sunnybank Hills, Qld.

One of my earliest memories is riding my tricycle with my older brother. Suddenly, I lost my balance and fell face first onto the handlebars. "Are you all right?" my dad asked, helping me up. I nodded, trying to be brave. I was only four. The next morning, I woke up and couldn't open my eyes. I started screaming. "Your eyes are swollen, sweetie," Dad said. "Remember you fell off your tricycle yesterday?" Mum said. A realisation dawned on me. "Am I like Daddy?" I asked. My father suffered from a strange condition where his face swelled up. "It looks that way," Mum replied, sadly. It began to happen regularly. I'd knock my hands or feet somehow and they'd end up swelling. We didn't have a name for it, but Dad knew from experience

that the swelling lasted for a day or so before it went down again. A year later, I was helping Mum change my baby brother Matthew's nappy when we noticed that his feet were swollen. "He's got it, too," I said. Within five days the swelling had spread through his whole body. Our doctor had no idea what it was. It never seemed to affect my older brother, but Dad, Matthew and I got it all the time. Once, when I was nine, Dad's face swelled up like a balloon. I watched in horror as he tried to sip his tea, but his lips were so swollen it dribbled straight out his mouth. His tongue was hanging out and he started gasping for breath. He couldn't speak and his face was pale. "Dad's airways are closing," Mum said, panicking. She reached for the phone to call an ambulance but Dad shook his head furiously. He didn't like going to the hospital.

After several hours, the swelling went down. "That was scary," he said, when he could finally talk. Then, when I was 10, Dad found an immunologist who'd heard about similar cases in America. Matthew, Dad and I got tested and were all diagnosed with a rare blood condition called hereditary angioedema or HAE. We're missing a protein in our blood, which causes swelling all over our body. If our throat or bowels swell up too much, we could die. There was no known cure or prevention, only medicine to reduce the swelling.

Stress or knocks could trigger an episode. Once an attack came, it could last from 12 hours to several days. My dad's family got tested and none of them had it, so doctors thought it started with a mutation in his genes when he was conceived. It was a pretty shocking diagnosis, but we tried not to let it rule our lives. One morning, I woke up with a tight feeling in my throat. Mum and Dad took me straight to hospital. Because worrying made it worse, I was lying there with my eyes closed, trying to relax when I overheard a doctor. "If she can't make a sound in the next 10 minutes, we'll perform a tracheostomy."

"There was no known cure"



Dad (left), me, Matthew (right) and my kids (back) - we don't let our condition rule our lives



I reached out and held my doctor's arm. Inside, I was screaming, but all I managed was a tiny whisper, "Please, don't cut me."

He looked into my eyes and said, "Okay."

Thankfully, the swelling reduced and a few hours later, I was allowed home.

Somehow, I made it through school and at 18, I met and fell in love with Peter.

We got married and always knew there was a chance any kids we had could get my condition.

We decided to risk it, but during my first pregnancy I suffered my worst attacks.

At 20 weeks I had to go for a blood transfusion because the swelling was so bad on my face and throat, but I had an allergic reaction to the blood and nearly choked to death.

Thankfully, Jess was born safely, but when she was one, she was diagnosed with a milder form of HAE.

She had occasional rashes and tummy aches but on the whole, was a happy and healthy bub.

Three years later, I fell pregnant again. My feet swelled up so badly I felt like I was walking on broken glass.

Our son, Ryan, was born with severe HAE.

"I'm such a bad mum," I said to Peter, racked by guilt that I'd made my children sick.

"You love them," Peter said. "That's all that matters."

Despite my illness, I'd had a happy childhood, so I was determined to do the same for my own kids.

There are days when all three of us are sick together. But there are days when we can go to the movies or shops and spend time as a family.

Dad's now 73 and still has attacks. He, Matthew and I carry around an emergency injection, which we can use when an attack happens.

But it hasn't been cleared for children yet so unfortunately, whenever they get ill we have to take them to hospital for blood transfusions.

Jess gets swelling in her



stomach, hands and feet, and this year, has had to go to hospital four times.

But poor Ryan has been to hospital every week this year. He is in constant pain and misses out on so much.

They're both such troupers though, and have lovely friends.

Recently, Ryan asked me what would happen if he began swelling up in his sleep.

"We'll deal with it if it happens," I said.

The truth is he could die. We all could.

But we have to trust we are going to be okay. After all, my dad has lived a good life into his 70s, so we know we can do the same.

Some people may think our family is cursed, but our condition has brought us closer. There's nothing we wouldn't do for each other.

Also, instead of feeling bitter, we choose to treasure the days when we're well.

***For more information on HAE, please visit www.haeaustralia.org.au**



WE PAY MORE!
up to \$2000
for YOUR story

See coupon, at right.