

Health

The advice you need

Given six months to live!

But I'm still here, and fighting through with a smile

Reigan Walker, 21, Glasgow

At 11, I had a sickness bug like no other. Off school for three days, I couldn't stop being sick.

I was so disoriented. 'Who am I?' I'd mutter, my mum Colleen recalls. Worried, she took me to A&E.

In my own room, doctors worried that I was contagious.

After two weeks of MRI and CT scans, they had news.

'It's adrenoleukodystrophy,' a doctor explained.

Known as ALD, it is a rare brain condition causing fatty acid build-up.

It affects brain function – especially in boys.

I'd soon lose the ability to walk, talk and function.

It was an X-linked

genetic disorder, and we soon discovered that my mum was a carrier.

It can be fatal.

'We don't know how to treat it,' the doctor said, telling Mum that I had six months to live.

Refusing to accept it, she spent hours researching, and found

Dr Orchard, in Minnesota, USA.

He said my doctor was wrong, I had up to two years.

Plus, chemo, followed by a

bone-marrow transplant, could extend my life further.

He pointed us to some UK-based ALD specialists, and one was in Glasgow.

Mum reached out to Alex TLC – a charity for those affected by genetic leukodystrophy.

We weren't alone. There

True-life PATIENT CASEBOOK



were boys like me. With the charity's help, an emergency donor was found after a worldwide search. Four months after my diagnosis, I had 10 days of intense chemo.

Vomited 50 times a day, weighed 3st.

But the transplant was a success and my body started recovering.

I was going to live.

And finally, after six months in hospital, I went home and back to school.

ALD had some lasting effects, though.

My right side was affected, meaning I struggled to walk properly, couldn't cut food.

Before I was right-handed, now I was left.

Then, at 15, I came out as transgender.

While I'd been physically born a boy, I was female.

I started living openly as a woman – and that's when I became Reigan.

I'm currently having hormone treatments.

Oestrogen tablets and

testosterone blockers are safe and don't affect my brain function.

I'm saving for bottom surgery so I can finally feel comfortable in my body.

I still suffer mental-health trouble.

But I have great friends – including ones with ALD.

Alex TLC arranges annual holidays.

We meet up, have a great time hanging out with like-minded people.

People feel sorry for me when I say I'm disabled.

But I'm independent – despite a slight lisp, I'm chatty and friendly.

I can shower, cook, live a 'normal' life.

Things just take longer.

I'm studying Psychology at uni, too, so I can help people like me.

By telling my story, I hope to change perceptions of disabled people.

ALD has changed my life, but for the better.

And while I don't know what my future holds, that doesn't stop me smiling.

Me today – changing perceptions



After chemo and my transplant

More info?

For more information, visit screenourboys.org, and to make a donation for Reigan's surgery, visit gofundme.com and search Reigan Walker.