‘I’M TIRED OF DISCUSSIONS ABOUT MENTAL HEALTH THAT MISS EXPERIENCES LIKE ALEC’S’

Reporter MARCUS HUGHES wants to see more recognition of schizophrenia. Here he talks candidly about his brother who suffered from the mental illness and who took his own life

MY OLDER brother died when he was 25 years old.

He didn’t have cancer, a congenital heart defect, or chronic lung disease, but he was at times seriously unwell.

Starting in his teenage years, Alec suffered numerous bouts of psychosis that robbed him of his ability to look after himself, relate to others, think clearly, and live his life happily.

He would have hallucinations and develop delusions that were obviously far away from reality for most of us, but felt deeply real to him.

He was diagnosed with schizophrenia, and spent varying amounts of time in psychiatric wards and at home where mental health services would work to bring him back to a manageable state of mind.

My brother took his own life more than seven years ago. There is no heartwarming ending to Alec’s story.

He died leaving behind brothers, sisters, parents, grandparents, aunts, uncles, cousins and friends who love and miss him.

With the right treatment and support, many people who experience psychotic illnesses like schizophrenia live happy and productive lives.

But I’m tired of hearing discussions about mental health that so frequently miss experiences like Alec’s.

And until we find the language to talk about the uncomfortable reality of these illnesses, the people who live with them will continue to struggle to find their place.

My brother and I grew up in a loving home in Gaer, Newport.

There was a big seven-year age gap between us, but he was a kind, generous and patient big brother so those years felt a lot fewer most of the time.

Alec was intelligent, creative, and took a natural interest in a wide range of things. In school he was particularly good at maths and physics but I remember him getting top grades in nearly everything.

At home he was constantly busy with music or art.

As a teenager, Alec made animations using an old Super 8 film camera years before that vintage look gained a hipster vogue on Instagram.

These might appear a bit messy and scratchy to look back on now. But to me they demonstrate the best of Alec and who he was.

Alec also drew in sketchbooks, wrote short stories, and made musical compositions on his computer.

A childhood superhero character of his, known as Pantman, is famous in our family to this day.

Pantman’s creation can be credited to one neat early observation of Alec’s – namely that a regular pair of pants, when applied in the correct orientation to the face, makes for a rather effective superhero mask – reminiscent of Spiderman.

Alec was talkative in the right circles, well liked, and had a close group of school friends. However, some elements of social interaction were always challenging for him.

He was in his latter teenage years when he first developed symptoms of mental illness.

I was 10 at the time, so there are plenty of details I don’t remember or couldn’t have fully understood.

It began slowly. He started behaving in unusual ways and talking openly about strange thoughts he was having. On a few occasions, he appeared to have become scared while out in the street and felt he needed to run away from something that was threatening him.

Alec was just 17 when he was admitted to a psychiatric ward at St Cadoc’s Hospital in Caerleon for the first time. I find it difficult to contemplate how scared he must have been.

Treatment was provided and he got better, going on to do his A-levels in college and starting his university degree.

Not every day was bad. I have happy memories from every time in Alec’s life. As I became a teenager he introduced me to music he liked and took me to see bands.

But it became clear that not all his symptoms went away entirely. He was eventually diagnosed with schizophrenia.

Schizophrenia is a mental disorder that causes psychotic symptoms. These include hallucinations, delusions and disorganised thinking, behaviour or speech.

Hearing voices or other sounds is a common hallucination, but they can be experienced through any sense – hearing, sight, smell, taste, or touch.

Someone with these symptoms is said to be experiencing “psychosis” or a “psychotic episode”.

Psychosis can also be a symptom of other conditions, such as bipolar disorder and severe depression, or anyone could experience a psychotic episode as an isolated event.

Alec could be relatively well for long periods of time but the antipsychotic medication he was prescribed often had unpleasant side effects. They could slow his thinking and make him feel sluggish, difficult for an intelligent and naturally sparky, productive person like him.

While those drugs could control his illness for a time, things always seemed to go wrong.

It could be difficult for those around him to detect at first because the early symptoms of psychosis could appear to be quite positive. He might have a surge of energy or suddenly become very outgoing.

Alec had always taken an interest in religion and theology, but during the start of one episode he spent a lot of time in church, prayed, and began taking religious texts very seriously.

On the face of it, this is fine. Billions of perfectly healthy people across the world sit down to pray every day. Alec’s interest eventually fed into his confusion and he developed delusions of religious grandeur.

During this time in his early twenties, he would run away from home often for days in the height of winter. He wouldn’t, or couldn’t, feed himself or find shelter. Missing persons reports were made and thankfully he never came to any serious harm.

When people who are so ill they become a risk to themselves or others they are sometimes kept in hospital against their will. This is known as “sectioning”, in reference to a section of the Mental Health Act 1983 – the law that gives medical professionals the power to take away a person’s right to refuse treatment temporarily.

Those being sectioned might believe they aren’t unwell at all, or they might think the hospital is doing something to make it worse.

Alec was sectioned on a number of occasions, sometimes for months at a time. An acute episode would be followed by a long period where Alec would be withdrawn and isolated, even though the worst symptoms of psychosis had been brought under control.

Because of the relapse, he would often have lost some of the progress he might have made, like a job.

This meant getting better could seem like starting all over again and I’m sure that contributed to a feeling of hopelessness.

During those periods, I found I would lose touch with him. He would feel distant even though he was only in the bedroom next to mine.

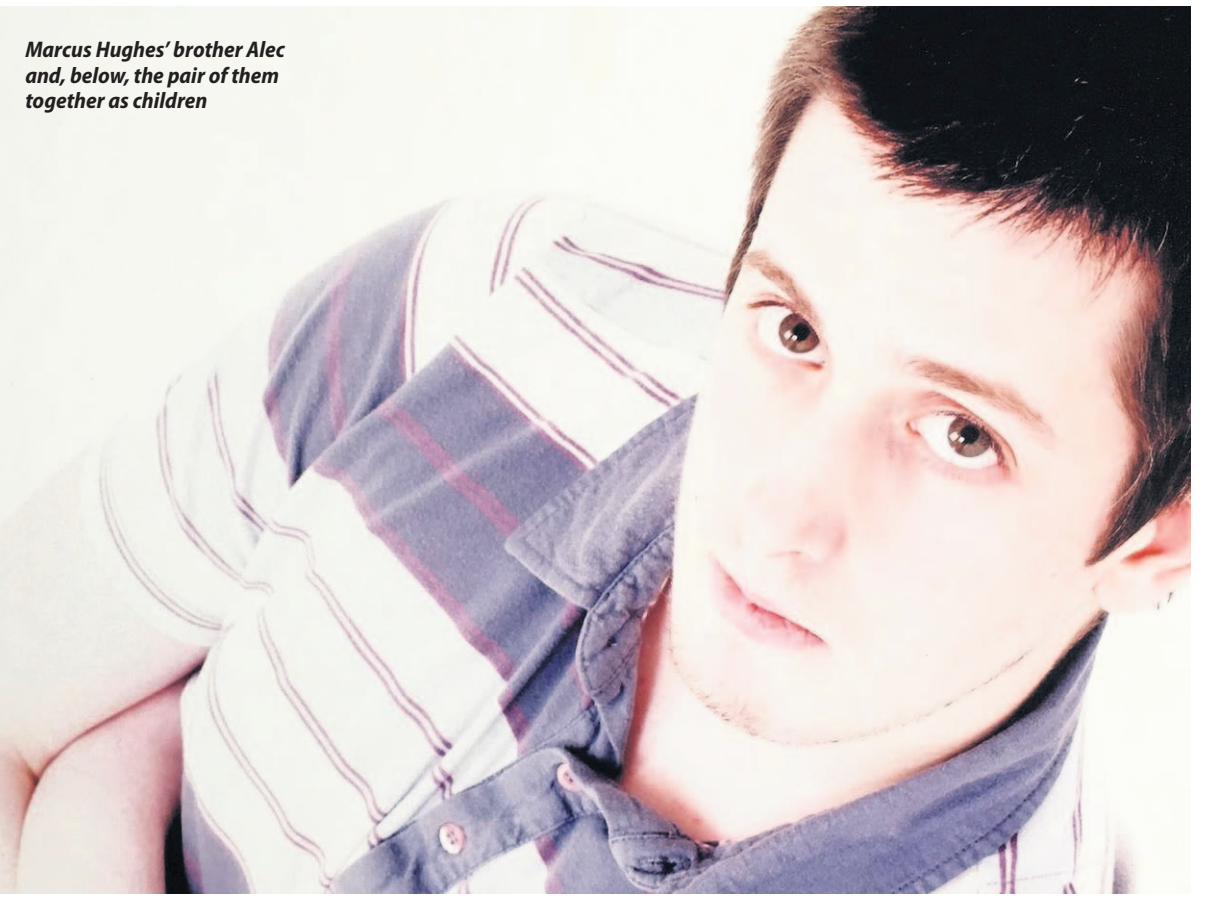
Of course I always knew growing up that people with severe mental health problems are at a much greater risk of suicide. I knew it like I’m distantly aware planes sometimes crash while I walk through airport security. It happens, but not to us.

When I was 18 years old I was told my brother had taken his own life at the house where we grew up together.

Bereavement like that changes you, but even after seven years I find it very difficult to put into words exactly how it makes me feel.

When I talk about it, I usually stop

Marcus Hughes speaks about the death of his brother Alec ROB BROWNE



Marcus Hughes' brother Alec and, below, the pair of them together as children

almost mid-sentence here because I can't find anything else to say.

I love him. He's dead. I miss him.

A great deal of progress has been made to increase awareness of mental health issues, and breaking down stigma. But I'm still struck by how infrequently I hear about experiences similar to my brother's.

The World Health Organisation estimates that schizophrenia affects 21 million people worldwide. According to Mind UK, research in England suggests four people per 1,000 experience symptoms of psychosis in any given year.

People with schizophrenia are two to three times more likely to die early than the general population. Mental ill-health has a bearing on the physical, so this is often due to cardiovascular disease, metabolic disease and infection.

Many people are affected by schizophrenia, and many live happy and full lives. But stigma can push already marginalised people further into isolation. If you are afraid what people might think of your diagnosis – you hide it.

And if you don't feel it's acceptable to be a little bit mad – you will try to pretend you aren't.

While researching this piece I came across a Facebook blog written by Stephen Debar.

He has been writing about his illness in order to bring it to the attention of others.

Stephen, now 57, first started experiencing symptoms of psychosis in his late 20s, and has been diagnosed with schizophrenia.

He can recall in vivid detail the exact day he first felt its effects, but admits his illness could have been present for years before that.

"It was November 5, Bonfire Night, 1989, when all this began," Stephen said. "I was coming in from walking the dog and there were two people on the front doorstep of the house next door. One of them I knew from school, and they started talking about me saying I couldn't stand up for myself.

"I ignored them and just walked in and ended up punching the wardrobe in anger."

Stephen, who grew up in the Lancashire town of Fleetwood, was always interested in the outdoors and wanted to be a forestry ranger. A lot of his delusional thinking centred around believing he was in the SAS.

"I have wondered if the reason I like bushcraft and things like that is because of my illness," Stephen said.

"But then I think if someone goes to church and they hear people saying they are god, should they stop going to church?

"It's the same with football. People [who are experiencing delusions] go to football matches and think they are Bobby Charlton. They shouldn't stop going to the football match should they?"

Like my brother, Stephen has spent some time in psychiatric wards and said he spent a long time isolated in his own home. But he has been managing his illness for decades and has made a lot of progress.

Stephen Debar

Stephen told me that for a number of years he couldn't make eye contact with anyone. But with therapy he has managed to change that behaviour and now he is able to look people in the eye.

Two years ago, he got married and moved to Colwyn Bay with his wife, Jenny. He now enjoys spending time with his grandchildren.

Stephen also does voluntary work, but describes managing his schizophrenia and type one diabetes as like a full-time job.

He still finds using public transport difficult because of the intrusive paranoid thoughts he experiences.

"I think people fear it, people who haven't got it," Stephen said. "The only way to get around that is to educate people.

"It has disabled me really. I couldn't do what I want in life. It's taken away more than 20 years of my life that I can't get back.

"In some ways I'm as healthy as I've ever been, but I still have blips."

Glenn Page, senior policy and campaigns officer at Mind Cymru said: "Psychosis is more common than most people think.

"Research from England suggests that around four people per 1,000 experience symptoms of psychosis in any given year.

"There are a lot of misunderstandings about what it means to experience psychosis. Lots of people wrongly think that the word 'psychotic' means 'dangerous'.

"The media often shows people with psychosis behaving like this, even though very few people who experience psychosis ever hurt anyone else and in fact are much more likely to be victims of crime themselves.

"This creates a negative stigma that makes it more difficult for people experiencing psychosis to get the help and support they need.

"For many people, there is no quick and simple treatment for psychosis.

"However, there are services available that can help and with the right treatment and support, it is possible to manage the symptoms of psychosis and recover."

■ **For confidential support the Samaritans can be contacted for free around the clock 365 days a year on 116 123.**