

Darkness to light – the fight to beat TB

A former patient remembers early days of treating tuberculosis

Retired journalist Brian Jarvis and Chris Dell, a TB survivor from the late 1950s, put questions to Ann Shaw, a former pulmonary tuberculosis patient about her four years in Craig-y-nos sanatorium in Wales in the early 1950s, followed six years later for further treatment in Sully Hospital, near Cardiff. Towards the end of the interview, Ann introduces Pamela Hamer, another long-term child patient admitted to Craig-y-nos but suffering from TB of the spine.

Craig-y-nos Castle, on the edge of the Brecon Beacons in South Wales, was the home of the world famous opera singer, Adelina Patti. After her death in 1919, it became a tuberculosis sanatorium, mainly for children and young adults. Despite a romantic-sounding location, this is not the setting of a fairy tale – the gothic castle is a building with a dark secret past.

As patients, many children spent years at Craig-y-nos, separated from family and friends, and subjected to regimes that seem barbaric today. Tuberculosis affected the whole community – physically, socially and emotionally. The disease and the unfortunate victims were often stigmatised and never spoken about except in hushed whispers.



Before moving onto the interview, please watch a 12-minute documentary in which some TB survivors (including Ann and Pamela) return to Craig-y-nos in 2017 and relive the memories of their childhood. This award-winning film was made by students on the Documentary Production course at Stirling University directed by Maria Craig who kindly gave permission for it to be shown here.

<https://vimeo.com/218963856>

An interview with Ann Shaw, a former child patient at the sanatorium

I understand you've had tuberculosis. Tell me when?

In 1950 when I was nine I had tuberculosis. My local GP first thought it was 'growing pains'. He was mistaken as TB was not easily recognised then.

How did you feel then?

I felt very tired and was coughing up blood. As a nine year old I was not scared because I was not in any pain, just the tiredness and coughing. The doctor then sent me to see a specialist to find out what was wrong.

Did he say it might be TB?

Yes, he told my parents it was TB but the words meant nothing to me. None of my school friends had it and there was none in the family. Looking back I think I caught it from the farm girl who was staying with my brother and me. When she coughed I breathed in the TB bacteria which then infected my lungs.

Where were you sent for treatment?

At nine in 1950 I was admitted to Craig-y-nos children's sanatorium in the Swansea Valley, South Wales.

Tell me something about Craig-y-nos, it was a Castle?

Yes, it was a mock Gothic castle, the name meaning "Rock of the Night" famous because the opera star Adelina Patti used to live there. But I was terrified. It looked like something out of a horror film with mist swirling around the turrets.

How did they greet you there – were they friendly and welcoming?

No, certainly not! I remember my mum getting told off because she had brought some of my dolls and toys in a cardboard box, and the nurse told her to take them away because I wouldn't need them. I had been given a new doll, a blonde one with blue eyes and curly hair and I cried because I wanted to keep her. The nurse relented but only on condition that it stayed up on the mantelpiece near my bed. I was never allowed to touch her.

What do you remember of the staff there – were they kind to you?

We had a terrifying woman doctor, an Austrian Jew called Dr Hubbard with short-cropped hair and gold teeth. She dressed like a man but wore stockings and frightened everyone. There was a ward sister who did show some kindness. As children we looked to the orderlies and nursing assistants for comfort. Some we called Auntie – they became like mothers to us.

Were they all children in the ward?

No, I was the youngest in the ward. Most were teenagers. I still don't know why they put me there because children of my age were kept in another ward. Maybe because there were no beds available in the children's ward.



Happier times with younger children at a Christmas party in the Glass Conservatory, 1928.

Did the doctors and nurses tell you about the treatment to come?

The only thing they told me was I must lie on my left side all the time on the bed that was raised on 12-inch blocks. That was it.

Were you very ill with much pain, or just uncomfortable?

No, I was not in any pain though it was uncomfortable to lie in the same position all the time. If I tried to sit up, the nurses shouted at me to lie down again.

Were you frightened?

Yes, at nine years of age I had no idea what was wrong with me and even if they said it was TB it would have meant nothing. I soon realised though that whatever it was, all the other girls had it too. They were all coughing but didn't seem bothered about it. In fact this was something of a comfort. I thought whatever it is that's wrong we have all got the same thing. But what really frightened me was the strict regime. They made us eat all our food and it was horrible. It was cold by the time it reached our ward. I had lived on a farm and was used to fresh food and home cooking. Suddenly I was given food that I had never seen before like grey porridge, cold fried eggs and kippers. Once I found a snail in a lettuce leaf and the nurse told me to carry on eating while the snail slithered round the edge of the plate. The coldness in the ward was alarming. We only had two thin red blankets. Because it was a castle there were bars on the windows instead of glass so the wind whistled through making a noise.

What treatment did you receive?

The initial treatment was bedrest, lying on my side 24 hours a day with bed tipped up on 12-inch blocks. After two years when I could no longer provide sputum samples for testing I was subjected to an awful procedure called a 'gastric lavage'. However once I was allowed up and ready for discharge they discovered TB on the other lung, so it was back to bed with medication for another two years. Fortunately the new antibiotic streptomycin became available which saved my life. I was in Craig-y-nos for four years and one day.

Were you given any school lessons in hospital?

For the first two years I had no schooling because I was considered too ill. Then one day a teacher came along and tried to find out what standard of education I had reached. She decided I hadn't reached any so abandoned me. I enjoyed reading books though. Once a week a trolley came round and we could choose a book to read. There was a library in the basement which the teacher kept locked. However I was the only one thin enough to squeeze through the bars of the windows to the library, break in and unlock the door to let the other girls in to borrow books. On one occasion my friend, Rosemary, tried to squeeze through the bars but got stuck. After that she wouldn't try again.



The headmistress giving the boys school lessons out on the balcony.

Were family allowed to visit?

Visitors were only allowed one weekend every month. Because I was admitted at the beginning of March I had missed the visiting allocations so I didn't see my parents until four weeks later in April. When I saw my mother I burst out crying and cried solidly for two hours wanting to go home. Because family visits were monthly, and as I was in for such a long time, I didn't get many visitors. Only my mother came to see me regularly. I never saw my brother and my father stopped coming – the girls asked me if he was dead. I didn't know what to say.



Visitors are allowed only once a month but this blue tit was welcome anytime.

Did you get bored?

We relieved the boredom in several ways. Despite the grim surroundings there was a happy atmosphere in the ward. We invented our own entertainment, often dressing up and telling each other stories and having regular sing-songs. The treatment was long but we didn't think of it as treatment because none of us felt ill. It was more like an orphanage or, some of us thought bitterly, a kind of child prison. There were about 16 girls in my ward. The beds were very close to each other. Many years later I re-visited Craig-y-nos and couldn't believe they had so many beds in my ward. Once I was allowed up, and able to go out into the grounds, we had great fun exploring the castle and even climbed up onto the roof.

Did you make any friends?

Girls made friends with others in the ward and I became close to the girl in the next bed to me. These friendships acted as a lifeline and made the stay bearable. It became obvious that we all had the same disease and none of us seemed bothered about it, so I was not afraid. It never occurred to me that I might die, though looking back I must have been close to death because I was coughing up a lot of blood. As soon as I was put out on the balcony, which was open to all the elements even in winter, my life improved considerably. I became one of the "snow children" and would wake up in the winter with snow on the bed. We were each given green tarpaulins to protect the bed. At least it was waterproof.

What was it like, leaving hospital?

Leaving Craig-y-nos and getting back into family life was just as traumatic for me as going there in the first place. I had become institutionalised and hated the closeness of the family instead of being among a group of 20-30 girls. While in the sanatorium I had earned a reputation for fighting and was considered tough. At home I became the “poor sick child”. Adjusting to life on the farm was difficult, especially going to school. I was nearly 14 before I started proper schooling. After a while my mum took me back to Craig-y-nos to see the girls again and suddenly I realized that I no longer belonged there, neither did I belong at home.



At long last Ann (left) and her friend are allowed out of bed to explore the grounds.

What happened then?

At 19 years old I applied for a position at the teachers training college in Bristol but a condition of acceptance was a clean X-ray. That's when they discovered that my TB had returned. More frightening than the disease was the fear that I would become an outcast from society because I had already struggled since leaving Craig-y-nos to fit in with family life. So six years later I was admitted to Sully Hospital, near Cardiff. It was a modern hospital pioneering a new and more humane way of treating TB patients using the latest drugs as treatment. I spent six months at Sully followed by three months in Pinewood Hospital at Crowthorne, in Berkshire, a student rehabilitation centre. The discovery of the antibiotic streptomycin had revolutionised the treatment of TB. Instead of it being a long drawn-out sentence – even to death – patients started to recover, some quickly.

When you look back?

On the whole, now at 77, I have had a good life and enjoy excellent health. I became a journalist working on newspapers in London, Lancashire, Yorkshire and Scotland, latterly on the Glasgow Herald as a Feature Writer. I think my experience as a child in a sanatorium toughened me up for life in journalism. If I hadn't had TB and moved away from the farm I doubt if I would ever have become a journalist.

What about TB today?

Streptomycin combined with other drugs was the break-through, from late 1940s onwards, that almost stopped TB in its tracks in the West. When I read about its resurgence today, because of drug-resistant strains, it fills me with sadness. One of the difficulties treating the disease is that you often do not feel ill, until you are very seriously ill. Then there is a long treatment process. It is no wonder many people give up, start treatment, improve, and then opt out. Recently I have had knee replacement surgery. Now in my late Seventies, this has been far more painful than anything I ever experienced with TB. In view of TB's dreadful and malign history - what a surprise!

Are you still in touch with any former patients?

Yes indeed! I created a blog asking for any TB survivors from Craig-y-nos to contact me and share their stories in a book I was writing with Dr Carole Reeves, a medical historian from University College, London. We were overwhelmed by the huge response and able to publish "The Children of Craig-y-nos" with photographs from the early days at the sanatorium. One of the survivors, Pamela Hamer, has become a close friend and here is what she told me.

"I was seven years old in 1947 when admitted to Craig-y-nos. At first my doctor thought I had 'growing pains' but the severity of the condition was later confirmed as TB of the spine. I was the youngest on the ward, frightened and in great pain. They strapped me down into a plaster bed without a pillow. Although there were about eight other children on my ward I couldn't see what was going on around me because all I could see was the ceiling. When eventually freed from the plaster bed after two and a half years, I could at last make friends with the girl in the adjacent bed. I had no schooling during my confinement and was left in total ignorance about my condition and treatment. I was ten years old before being discharged but unable to go to school, so my father sat with me for hours teaching me the basics."

Publications:

The Children of Craig-y-nos by Ann Shaw and Dr Carole Reeves.

Searching for Sully by Ann Shaw about her second stay in hospital when TB returned.

Black Notley Blues by Chris Dell, a TB patient in Black Notley Hospital (1958/59).

Further details on www.stortdoc.com