

## Seriously creative: managing chronic conditions in the heart of Western Australia

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Associate Professor Christine Jeffries-Stokes was born in Hobart and completed medical training at the University of Tasmania before moving to Western Australia in 1987 to complete paediatric training and a Masters in Public Health. Christine became involved in community arts in Perth. In 1991 she became involved in a medical research project in maternal and infant health that was to be the first of many projects that bring together her arts and medical experience. She is married to Geoffrey Stokes, a senior man of the Wongutha Tribe and lives and works in Kalgoorlie in Western Australia.

Annette Stokes is a senior woman of the Wongutha Tribe of the goldfields of Western Australia. Annette was born in Kalgoorlie and spent her early life travelling around the goldfields with her family living in the bush, and on stations. She trained as an early childhood education worker, then as an Aboriginal health worker, moving into research in 1995. She was awarded the Fiona Stanley Medal for Medical Research in 2005.

Annette is a musician, artist and community arts worker, coordinating the Wongutha Birni Aboriginal Arts and Cultural Centre in Kalgoorlie.

MS ANNETTE STOKES: Thank you very much, James. Good afternoon, everybody. Also, Pat, thank you for that, and the Minister. Firstly, I would like to give God all praise, glory and honour here this afternoon and to acknowledge the true traditional owners of this land. We've got a team here that came with us and I'd like to acknowledge Lockie McDonald and Steve and Annie, and our special community members Catherine Howard and Allison Dimer.

This photo here is of my father and grandparents making their first contact coming into the mission of Mount Margaret, and also Christine's father and her parents in Tasmania. Now, my father and Christine's father were around about the same age and so here are some of the changes that happened in our lives, and here's a story that will go with it.

A hundred years ago when my father was little, the Wongutha people lived in the bush. They went hunting for food, drank water, walked around a lot and had happy, stress-free lives. Then they moved into the mission where they still went hunting but were also given flour, salt and sugar as part of their diet which raised their sugar levels. They didn't walk around as much as they did but still had happy lives. Then they moved into towns where hunting became impossible and, instead, they drove cars, bought food at the shop and ate Cherry Ripe, Coke, two-minute noodles and barbecue chips. They lived in tin shacks with no heating or cooling. Life was very hard and stressful and people started to die too young. This is when diabetes developed.

So what about now, the next generation, our children? Going to the basketball carnival, my sister-in-law noticed most of the children had signs of early onset diabetes – darkening under the arms – then we began talking about how we can stop this diabetes epidemic in our children and family. We decided to start the Western Desert Kidney health project which will travel through the 10 communities in the goldfields to screen people and educate them about what causes diabetes and kidney disease and how to prevent these diseases.

DR CHRISTINE JEFFRIES-STOKES: We're not really going to talk a lot today but we are going to show you some beautiful things, because this project grew out of despair and misery and hopelessness in our community. Annette and I are sisters-in-law and we were going to lots of funerals, and people were talking about how diabetes and kidney disease is killing our family. And why is this happening? Is this a curse on Aboriginal people? Because it seems that, even if you do everything right, you still get diabetes and kidney disease and it still affects your pregnancy, your children, yourselves, your friends, your family and causes so much death and loss of potential.

And so we started thinking about what is it that's causing this and, really, one of the biggest issues is the insulin levels. And so we developed this process of thinking about what causes it and then what you could do

about it. So a quick run through the science of this – so high insulin levels – probably indigenous groups have an excessive response to carbohydrate because a traditional diet probably had about 45 per cent of calories from native animal fat, and most of the rest of the diet was actually protein, particularly in desert areas. So the high insulin level causes the acanthosis nigricans or darkening under the armpit and all the complications that we are experiencing in our community.

So where does that come from? But what causes those things? Sugar is obvious, but the change in diet has been dramatic and rapid and very dramatic. Soft drink probably plays a big factor – and that’s probably a worldwide factor – change in lifestyle – you saw Annette’s grandparents, how fit and lean they were – and stress. And stress is probably the biggest factor that affects people’s ability to care for themselves and their families. And so we thought about that in the historical context because, in our region, it’s very recent, as you’ve seen.

But what if you could change all of that? And how could you change all of that? So we developed the Western Desert Kidney health project. Initially, it was Annette’s idea, working with me, and it’s become a big collaboration between the health service in the region, including Bega Garnbirringu, the Aboriginal medical service, the GP network, the Health Department but, more importantly, it involves all of the community through the Wongatha Birni Aboriginal Corporation working with individual communities.

MS ANNETTE STOKES: So we’ve got two trucks that will travel the 10 communities in the goldfields and screen everyone for diabetes and kidney disease and teach them how to reduce the risk. We bring in a team of expert artists to help them produce their own health promotion material and also motivate and inspire them. The first truck is the art one, and the second one is built out into a clinic, and I think this one’s the children one?

DR CHRISTINE JEFFRIES-STOKES: Yeah, that’s similar to ours.

MS ANNETTE STOKES: So the same as this.

DR CHRISTINE JEFFRIES-STOKES: So we come into a community. We screen everyone for the risk factors for kidney disease and diabetes, and then we teach them – and, at the same time, we teach them about what causes it, empower them, and educate them so they can work out ways to change things in their community, and then they produce their own health promotion materials working with our artists, like this one.

VOICE-OVER: At another time in another place when I was a little girl, a strange thing happened. There was this little tooth fairy named Alfie. This is Alfie’s story. Every night Alfie would fly off into town with all the other tooth fairies, lots and lots of tooth fairies. That’s the funny thing: humans think there’s only one – ha. Their wings beat so fast they glow. Their job was simple but, oh, so very important – to leave money for the tiny teeth that the little girls and boys had left under their pillows, or in glasses of water next to their bed, while they dreamt big dreams.

One night Alfie had gone into town laden with his bag of silvers for all the tiny teeth. Alfie was late flying back home and all the other tooth fairies began to worry about him. They waited and waited but there was still no sign of him. All the tooth fairies decided to go and look for Alfie. It was a very dark night but all the tooth fairies kept searching. Suddenly, one tooth fairy screamed, “Alfie is over here.” He had crashed into a big tree and had injured himself badly. “Let me check his little black box,” said the mechanic tooth fairy. All the fairies have a black box like the big aeroplanes that fly in the sky and, when they check the black box, the fairies will find out why Alfie had crashed. The mechanic tooth fairy opened the little black box and he was so shocked. “Oh, my goodness, no wonder Alfie crashed. His little black box is so full of sugar,” whispered the mechanic. Alfie had sugar diabetes and it had caused him to become overweight. The mechanic tooth fairy checked Alfie’s eyes. Alfie was a bit blind too.

“How did this happen and why? All the tooth fairies are healthy. We all eat good food like fruit and vegetables and drink plenty of water, and we never eat rubbish.” All the tooth fairies went quiet, then they heard a little voice in the back. It was Ella, one of Alfie’s best mates. “Every night when we go into town to get all the tiny teeth, Alfie goes to the burger shop and buys big burgers and chips and cool drinks and Cherry Ripes – lots of Cherry Ripes,” said Ella. “I’m so sorry. I tried to tell him that he’ll get sick and might go blind, or he might end up on a dialysis machine because his kidneys will stop working, but he told me to shut up and mind my own business,” said little Ella. “Ella, it’s not your fault. You tried to tell Alfie but he was too pigheaded,” said the

mechanic. "Let's take Alfie back to the special healing tree and get him checked out." So the tooth fairies took little Alfie back to the special healing tree.

Some time later Alfie came home. Before they set off into town for the night to collect all the tiny teeth, all the tooth fairies gathered for a big meeting. "So you all need to listen up big time," said the mechanic. "You'd better not tell us what to do again. We're sick of you telling us what to do," said one of the cheekiest tooth fairies with a missing front tooth. "Yeah," said a tall tooth fairy with long hair. "I can't tell you not to eat burgers, drink Coke and chomp all night on Cherry Ripes. What I can tell you though is" - - -

"Stop – stop – stop this," shouted Alfie. "I've been there. I ate lots of Cherry Ripes. I drank Coke every day. I would sneak off every week when I had enough silvers in my pocket to buy burgers and, because I did not know, I will always have this sugar problem. But I also know I can look after myself and stop things getting worse. If I look after myself I can collect tiny teeth for years and years and years to come. The healing tree has powers but it can't fix everything. There's only one person that can fix you and that's yourself." Late into the night they talked and talked and they decided as a mob that they would slow down on the junk food, drink lots of water, exercise heaps and heaps and stress less. After all, they had an important job to do.

You see, it's me. I am Alfie. Over the years I can't remember how many teeth I've collected – thousands and thousands and thousands – all because the whole mob of us decided to eat better, drink water heaps, exercise and stress less. No one said it would be easy but we had to or kids would never have anyone left to collect their tiny teeth. Have you ever wondered what they do with all those teeth? That's another story.

Even today, if you sit still late at night after all the lights go out away from the street lights in the shadows in the park, you just might see us, all the glowing tooth fairies hovering into town. So just before you put your head down to sleep, look.

MS ANNETTE STOKES: So just going on the little shows there, the sand animation, I'm a Wonga lady from the goldfields and – when I grew up – what we used to play with is a wire and we used to make it into a story lamp so – it was called a milbindi(ph) – and we used to tell stories on the sand and make up stories and draw pictures of things. And it was like also when tribes were travelling through the lands, rock holes to rock holes, they would ask for directions and, if you couldn't give that direction, you'd draw it on the ground on the sand. So with the milbindi and the sand animation, it's very important to us because it's a special way of getting the message out, and for us to do these animations it was so that we can show our families and people could understand the message of good health in diabetes. Thank you.

DR CHRISTINE JEFFRIES-STOKES: We've got one more to show you but I just want to tell you that up the front here is Allison Dimer who wrote that story that you've just seen, and Catherine Noble who did the narration. The pictures for it were done by the children from Kurrawang school and CAPS school in Coolgardie, and Steve Aiton, who's the animation artist, is here as well today. Now we have a brand new one to show you which was done by the children at Norseman school. The story was written by Naomi Wicker(ph) who's a 12 year old girl. After she heard about what we were talking about she wrote this story and, with Steve, the children made this one.

VOICE-OVER: There is a place not far from here where a brave little emu was born, so let me tell you a story of the lost emu. One bright cloudy morning, a mother and father emu were getting ready for their new family. The mother had all the eggs ready in the nest and, one by one, they hatched. All the chicks took off together but there was one lonely egg, and the little emu hatched all alone.

This little emu grew up by himself. He had nobody to show him what to eat or what to drink. He would try to eat all kinds of things, and he even ate a gold nugget. Soon the little emu began to feel a bit sick from eating all the wrong foods and, after walking a long way across the big salt lake, his body started to feel so ill. Lucky for him and echidna came along. The echidna was a friendly fellow and he said, "Emus are supposed to eat doomberries(ph). Come with me and I'll show you where they are." The little emu followed the spiny friend to a big quandong bush full of juicy red doomberries and he had a good feed.

"I used to see the emus here all the time," said the echidna. "Excuse me for a second." The little emu felt better straight away but, just then, a goanna came along. "It looks like you need to drink plenty of water," said the goanna. "Follow me. I'll show you a good place," and they walked to a nice big rock hole. "Always drink

plenty of water so your kidneys are nice and healthy,” the goanna mentioned before leaving. So the emu got down and had a nice big drink and felt much better. A long time passed and the emu had been doing what the echidna and goanna had taught him, and walking to the rock hole every day gave him plenty of exercise.

One day near a salt lake he saw another emu running in the distance so he followed that emu all the way to town. He was new to town so he asked a horse for directions, but the horse was just standing there and didn't say a thing. So the emu walked down the street. Just in the glimpse of his eye he seen the other emu go past. It was heading back out of town with something in its beak. He followed him right to a rock hole and, as he got there, he seen the half-eaten chips, the Coke, the donuts and packets of sugar that were in the rock hole. It was that little emu's family.

The little emu was shocked. They all looked very sick, especially the smallest one with the curled up beak. The rock hole no longer worked and the emus were not drinking water any more. The emu didn't like what he saw so he ran to the bush to live a healthy life that he knew. But just as he was running along, he couldn't stop thinking of that little sick emu. He decided to go back. "Come with me," he said to his little brother. "I'll show you how to get healthy again." And he took that sick emu away and he taught him how to eat doomberrries and taught him how to drink plenty of water at the rock hole.

After a while they both went back to their family. The family of emus were amazed to see that small sick emu looking healthier. Our brave little emu came up with an idea. They got rid of the Coke and the junk food and cleaned out that rock hole. Then as a mob they dug down deeper and deeper until the water flowed out once again. So as a family they all agreed to stop with the junk food and Coke and, after a nice big drink of water from their very own rock hole, they followed that emu to that nice big doomberry tree.

DR CHRISTINE JEFFRIES-STOKES: We'll just let this roll with an original song that was written for this story. And we invite you now to be part of this story of desperation and despair which has turned into not only individual but community redemption and hope. Up the front here there's some handouts. These are on YouTube and the kids are watching every day. So if you find it on YouTube, please leave a comment so they can have a look at it and spread this further and further and you'd see, like the ripples in that rock hole, going out reaching the whole community. Thank you.

