

“Syndrome X”

**The Silent Plague
Threatening the
World’s oldest
Culture**

by Jeff McMullen

“Use every breath”

When world swimming champion, Ian Thorpe visits some of the Northern Territory's remote aboriginal communities for the first time his raw and honest assessment makes nation-wide headlines.

Years of persistent lobbying by the AMA fail to sway our Federal Government and get scant attention in the mass media, but a sporting hero makes Middle Australia listen. Is this a lesson on effective message making to improve the health of all Australians? If we had stronger leadership at the highest levels would our nation continue to ignore the gravest health emergency we face today? The truth is that the cluster of chronic illnesses known as '*Syndrome X*' afflicting so many of the 460,000 indigenous Australians has long been a front-page story begging to be written.

Ian Thorpe's gut reaction, during a short visit last year to some of the isolated Jawoyn communities east of Katherine, is that it is hard to believe he is still in Australia. The separation of black and white is unsettling. Poverty he has seen in many nations. But here is hunger and terrible sickness in the heartland of our wealthy country. The inequity is striking through the eyes of an athlete who has enjoyed every opportunity for a healthy life. He is looking at some of the unhealthiest children in Australia, with illnesses like TB and rheumatic heart disease, as well as anaemia and malnutrition on Third World levels.

A sensitive man, quite humble about his place in the pantheon of sporting gods but aware of his own superb health through a dedication to nutrition and physical fitness, Thorpe towers over most of the aboriginal children stunted by their wretched start in life.

In Wugularr, Manyallaluk and Barunga, he smiles at them, swims with them in their waterhole and trades stories, although this is sometimes hard when up to 80 per cent of kids in remote communities have serious hearing impediments because of 'glue ear', middle ear infections neglected from infancy. These children will never hear a teacher standing at the front of a classroom.

In the stillness of the afternoon children with little to do wander the streets. Ian asks why there are so few sporting facilities or swimming pools in remote aboriginal communities? Good question.

Dr Fiona Stanley and a West Australia research team* revealed last year that building a 25 metre salt water pool in such isolated places could bring an extraordinary reduction in ear disease that leads to deafness, as well as dramatically easing *pyoderma*, 'skin sores' that contribute to chronic renal failure in the aboriginal communities and the highest incidence of acute rheumatic fever worldwide. Earlier studies of the handful of salt water pools in the Northern Territory support the W.A. finding that this single intervention could dramatically improve hygiene and health, reduce petty crime and even boost school attendance, especially if there is a 'no school, no pool' rule.

I recall, with great admiration, the late Charles Perkins and his 'Freedom Rides' in the 1960's, how he challenged the segregation and racism that barred aboriginal people from pools in many country towns. Charlie wanted to build pools too. But the dream died with

him. We know that Australians can build the finest Olympic swimming complex in the world. Can we also build 25 metre, salt water pools to improve the health of our sickest children?

During our travels in the Northern Territory it is disturbingly obvious that many aboriginal children are extremely small for their age. Malnourished mothers are giving birth to babies that are seriously under-weight and do not thrive. This disadvantage at birth gets worse throughout a life of poverty.

As young adults they begin to show symptoms of renal failure, diabetes, strokes, hypertension and heart disease, the epidemic that is '*Syndrome X*' now sweeping through several generations of aboriginal people.

Irene Fisher, of the new indigenous-run Sunrise Health Service, based in Katherine, explains that as a result of this cluster of chronic illnesses aboriginal life expectancy has fallen twenty years behind the rest of Australians.

"This is horrific," Ian says. ""What can we do to help?"

Championing better health for all Australians and raising his voice to call for action to deal with the one true health crisis our nation faces, seems a natural response for this 21-year-old. He is one of the greatest swimmers of all time because he sets his own high standards.

Here is a sports star that understands there is value in fame if you convert it into benefit for *others*.

It was his good nature, value system and sense of purpose, which led me to join this champion's team, accepting an invitation to become a Director (gratis) of *Ian Thorpe's Fountain for Youth Trust*, formed after the Sydney Olympics to support equal health for all Australian children.

We agree on many things that matter. It is time to use every breath to make a difference, in or out of the pool.

My long career as a television story-teller and what I have seen in other parts of the world convince me that indigenous Australians, with the oldest continuous culture on earth, are now facing their most serious health threat since Europeans first brought epidemics of disease here over two centuries ago.

“Guns, Germs and Steel”

It was what I saw in the Amazon that opened my eyes. Thirty years ago as an ABC foreign correspondent I made some of the world's first documentaries about the slaughter of Brazil's highly endangered tribes.

In his famous book, 'Guns, Germs and Steel', the Harvard Professor, Jared Diamond, described the scenario that has led to the decimation of indigenous peoples across the New World.

With cinematographer, David Brill, in the mid-1970's I witnessed this destructive pattern, brutal, thoughtless and devastating.

Along the twisting tributaries of the mighty river an indigenous population estimated to be around five million when the Portuguese arrived, has been reduced to a mere two hundred thousand survivors. So much has been lost in the Amazon but to many Brazilians this is the inevitable consequence of 'progress'.

In Central America, filming for *Four Corners*, David Brill and I hiked across the mountains into Guatemala where at least 240,000 of the last indigenous majority in the Americas fell victim to genocide. I came to see this pattern of "Guns, Germs and Steel" as predatory species behaviour, threatening indigenous people almost everywhere.

In the 1970's, Native American communities too were in serious trouble, sinking deeper into poverty and poor health. During my two decades as an ABC foreign correspondent I filmed numerous reports from the lands of the Navajo, Hopi, Oglala Sioux and other 'First Nations' where the social determinants of ill health were almost as grim as among indigenous Australians.

After militants of the American Indian Movement took over the trading post on that infamous battleground, Wounded Knee, South Dakota, I met indigenous doctors who told me about the rapid health collapse among their people. I was introduced to the remarkable but largely ignored discoveries by medical researcher, Dr Weston Price, whose work is carried on today by the Price-Pottenger Foundation in California. His studies of many indigenous populations around the world clearly established another feature of the sinister pattern. When forced to abandon their traditional diets and rapidly switch to a vastly sub-standard version of European nutrition, Native Americans, Aborigines and others have degenerated physically at an astonishing rate. Tantalisingly, Weston Price argued that maternal health and improved nutrition could reverse this process fairly rapidly*.

Today, Native Americans are rapidly closing the health gap and are just 3.5 years behind the life expectancy of the rest. More autonomy for indigenous people, a better relationship with their federal government, acknowledgment of long ignored treaties, better jobs and more economic development, improved schooling, 'affirmative action' led by newly-educated indigenous lawyers, doctors and teachers, and, especially, adequate investment in urgent primary health care, has brought about this extraordinary improvement in the lives of these First Nations people. In Canada, a similar commitment to education and health sees the Inuit about 7 years behind the life expectancy of the rest. In New Zealand the gap is just 5-6 years and the Sami of Norway have drawn level with the rest of that nation.

Australia's grim record on health care for indigenous people is by far the worst of any developed nation.

“Coming Home”

After more than half my life spent overseas, my first report on coming home to Australia's *Sixty Minutes*, late in 1984, was about the atrocious state of aboriginal health.

I went to Amata, an isolated desert community in Central Australia, where the elders were despairing that so many children, sick at heart and seemingly lost, were suffering terrible brain damage through petrol sniffing. Adults too, crazed on this 'tin can dreaming', were bashing themselves and others to a pulp. At the time, Aboriginal elders were pleased with the confronting power of that film. Governments pledged support to give aboriginal children some alternative to a life that began and ended in crippling disadvantage. But petrol sniffing is still widespread in remote communities. In Amata and many other places I have learned that it is not enough to merely document a tragedy.

Just as I once heard some white Americans predict that nothing would stop the decline of their indigenous people, many Australians seem resigned, even accepting of the inevitability of a disaster. In both countries some medical specialists have argued that it is a genetic weakness that makes indigenous people so vulnerable to the end stage renal disease showing up in epidemic proportions.

“Blame the victim,” said Shane Houston, one of the brightest Australians working in the field of indigenous health. Now Assistant Secretary of the NT Office of Aboriginal Health, it was Shane who first showed me around the impoverished camps of Central Australia in the 1980's.

“It is inequity. This is the root cause of so much aboriginal ill-health.”

We were looking at some of the hundreds of isolated aboriginal communities that still today do not have proper water supplies and sanitation, at dilapidated shacks and humpies, and children who were sick and hungry. Poverty is a terrible trap. Welfare is a slow poison, as useless as misguided charity, because both produce dependence. The only real change will come when indigenous people are treated like equals and allowed to take control of their destiny once more. This has not happened because Australia has not provided all of its citizens with an equal opportunity for primary health care, education, housing, employment and a life of dignity.

“Aboriginal people,” Shane Houston said, “are viewed by too many in the Australian community as an unwelcome burden on the nation. Governments say they have spent a lot of money on aborigines but where do you see the results in this squalor? So the mainstream concludes that aboriginal health is a waste of money. It is all the fault of the poor blacks. My people are somehow expected to just extricate themselves from this maze of life-threatening conditions. And if we can’t manage to do that then many white people will shrug and say our end is inevitable.”

“The key to Syndrome X”

In the Jawoyn communities, east of Katherine, Ian Thorpe and I see how fast ‘Syndrome X’ is cutting the heart out of an entire aboriginal generation. Diabetes affects one in every two of these adults. As we look around we are confronted by a frightening truth. There seems to be no one here my age and at 56 I always think I am about half way through the innings. Among the Jawoyn even the community leaders are afflicted by chronic illnesses and the life expectancy here has plunged to just 46 years.

“People have no idea what is happening to their bodies,” says Chronic Disease Nurse, Joy Pascal. “They don’t just have one disease, they have three or four or five of these chronic illnesses.”

“End-stage renal failure is nine times higher among indigenous people”, Olga Havnen, of *The Fred Hollows Foundation* tells us. “But in remote communities where living conditions and primary health care are appalling then the spread of this kidney disease is even greater and in truly epidemic proportions.”

“Is there a cure?”

“A kidney transplant is one option but there’s a shortage of donors. The usual treatment for indigenous people who make it to hospital will be renal dialysis which will cost about \$100,000 per year to maintain a person in the last stage of their life. We are going to pay for the neglect of the past. Obviously intervening early to prevent this level of illness would be far better. But there is no accountable system for delivering effective health

care to aboriginal people and for ensuring that enough money is spent where it is most needed.”

Ian Thorpe’s Fountain for Youth Trust has formed a partnership with *The Fred Hollows Foundation* and the *Sunrise Health Service* to improve maternal and infant health in the Jawoyn communities. The importance of this approach, dealing with the underlying causes of the health crisis not merely the symptoms, is underscored by ground-breaking research by a combined American-Australian research team.

The early speculation that a genetic quirk is causing indigenous people to fail to process kidney-weakening sugars has been rejected.

After examining kidneys in autopsies on whites, Afro-Americans and indigenous people, a team from Melbourne’s Monash University, Menzies School of Health Research in the NT and University of Mississippi, has linked the plague of kidney and heart disease to the extremely high rates of low birthweight babies among some populations*.

The lower a baby’s birthweight the fewer nephrons in the kidney, with a greatly increased risk of scarring and subsequent kidney failure, high blood pressure and heart disease. After birth you can’t catch up on nephrons. The hand you are dealt will determine your level of risk and this will increase dramatically through poor nutrition and obesity.

Surely, here is the key to unlock the mystery of ‘Syndrome X’?

Hunger in our country, a Third World level of malnutrition, poverty and poor health among indigenous people, is endangering their babies even *in utero*. Their kidneys are programmed for failure. Other diseases of poverty, like scabies, also can produce streptococcal infections that contribute to the epidemic of kidney disease. One illness intersects with another, and then another, until there is a sickening implosion, with thousands dying prematurely.

The obvious way to attack ‘Syndrome X’ is not to wait for a bigger avalanche of patients into our hospitals with a rising expenditure on dialysis, but to urgently improve the health and nutrition of expectant mothers and the 10,000 aboriginal babies born each year.

“A Blue-print for Action”

The Australian Medical Association has invested years of thought and effort on this, led by Professor John Deeble, who constantly updates his sharp estimates*. He currently believes an additional \$250 million dollars a year must be urgently spent on primary health care for indigenous Australians. To slow the epidemic of chronic disease, Professor Deeble further recommends an additional \$50 million on screening, health promotion and education.

The Federal Government's response reveals the state of denial - or perhaps it is amnesia - gripping this nation.

I wrote to the Federal Minister of Health, Tony Abbott, asking why the government has not responded adequately to these and other urgent recommendations from the best medical experts on 'Syndrome X'.

By 2005, the Minister's team said, the total expenditure on indigenous health "would rise to \$264 million per annum – a real increase of 90% since 1995-96".

But look at the gap!

The AMA's report card* on indigenous health indicates that more than double that amount needs to be invested in primary health care to head off a disaster.

If we wait we will consign another aboriginal generation to fall victim to 'Syndrome X'.

Is it time for doctors and medical specialists who have far greater understanding of this health emergency to take bolder action. We should demand true leadership at the highest political levels. Together we must inform Australians that rather than giving aboriginal people 'too much' we have invested too little in their health. According to Shane Houston, we should be spending on a 5:1 ratio for patients who are five times sicker than the rest of us.

As a simple first step, more GP's could put up posters in their surgeries to promote indigenous health, as this also sends a signal that aboriginal people are welcome. Around the edges of our largest metropolitan areas where most indigenous people live and in country towns too, 'Syndrome X' is rapidly destroying lives. These patients, our working poor, need to be encouraged (by bulk billing for example) to seek treatment.

Australian Indigenous Doctors Association President Louis Peachey has pointed out that there are shamefully few opportunities in any of the professions and health services for indigenous people. We have just 55 aboriginal doctors when there should be at least 1260 for fair and proportionate representation. Dr Peachey also argues that indigenous health issues should be compulsory postgraduate study*. We have a professional responsibility to understand the critical areas of illness in our nation and to urgently accelerate the education of indigenous people to lead the fight on the front lines of this crisis.

Syndrome X is a silent epidemic because as a nation we have not yet raised our voice in a real battle cry. We have not yet shown the commitment to deal with so much death among our own people. These are our children. Yet we have not invested the time, money and concentration to face up to the plague that threatens them.

I don't expect you to just take my word for it. I am not a doctor. I am a storyteller. But ask Professor Jim Hyde (President of the Public Health Association of Australia/NSW branch) who says that while our nation has plenty of medical *problems*, only indigenous

Australians are facing a genuine health *crisis*. Ask the AMA President, Dr Bill Glasson or his predecessor, Dr Kerry Phelps, who ended her time in that post deeply distressed that so many years of work shaping a strategy to tackle the indigenous health crisis has brought so little action by Government. Dr Fionna Stanley and the NSW Governor Marie Bashir, an eminent child psychiatrist, have repeatedly pointed out the national disgrace of allowing the forty per cent of indigenous children under the age of fifteen to put up with health problems found in no other developed nation.

Patrick Dodson summed up the consensus among aboriginal leaders and independent medical authorities when earlier this year he launched a campaign for ***Health as a Human Right for Indigenous Australians***. “Only the most urgent Government action”, said Australia’s Father of Reconciliation, “could change the inequality that has created this health tragedy in our own backyard.”

“A Cry from the Heartland”

Nellie Amunda, an elderly aboriginal woman in a torn cotton dress stained with the red dirt of Central Australia, crooks a finger and points out the tree and the grassy place where she was born out here under the stars.

There is silence. We listen to the wind. The land itself speaks to us now.

My family has been invited this day to share a path where the Ancestors walked.

Cave Hill, in the Western Desert, several hours by four wheel drive on a gravel road south of Uluru, is not only the site of some of the most spectacular rock art in the world, it is a place where the first people of this land can clearly explain what life means to them.

Here, yesterday, today and tomorrow are fused into an all-powerful sense of place.

Our children, Claire, 10, and Will, 8, are soon entranced by Nellie’s wistful smile and her clear memories of other youngsters who once ran across these rocks and dunes. Their life was hard but her people roamed free. The men hunted ‘roo. The women foraged with their digging-sticks for bush-tucker: roots, seeds, wild fruits and berries. This is not to romanticise their constant struggle for survival in one of the harshest environments on earth. But the people of the Western Desert once were lean and strong. This was noted by some whites on first contact. I have also seen the first black and white film ever recorded in these parts and noticed the bodies, brown and muscled.

This old lady today is heavy and unwell. It is not the custom to ask why. Nellie is also barefooted and her leathered feet are badly cracked.

“Amunda, you need new shoes,” says Claire. “You could have mine but they are too small.”

“Thanks,” the smiling face replies. “No shoes for long time.”

Nellie Amunda’s first language is Yankunytjatjara. Her husband, Dicky Minyintiri, speaks the neighbouring dialect, Pitjantjatjara. I am told that each of these slightly different Western Desert dialects takes its name from the word the people use for ‘coming or going somewhere’.

All of life is a journey across this land where events, past, present and future, are governed by the Law set down in Creation Time, the Tjukurpa. No one is bigger than this Law.

Dicky, a small man not much taller than our children, breathes hard as he leads us across the flat stone ‘footprints’ where the Seven Sisters fell from the sky and ran to take shelter in the cave we are approaching. Animated and eyes flashing, Dicky lives the story as if he can see these Ancestral figures over Will’s shoulder.

Will is respectful of the old man’s ability to survive out here so far from other people. We kneel at a shaded rock hole and scoop up the cool water, just as people have done here for longer than anyone can remember.

Dicky wears an old Northern Territory police hat, something useful borrowed from the white-fulla’s Law and he grins as he recalls seeing his first white man, a strangely dressed ghostly figure riding an even stranger animal. Dicky and other young aboriginal boys were not afraid at that moment but they wondered what the white man was doing on their land.

Black and white we crouch together in the low roofed cave and at the very edge is a more recent painting of the man on horseback, the rider’s body fused with the animal’s. As far as our eyes can see into the gloom there are stories like this painted in ochre.

My American born wife, Kim, stares at the faded symbols, some verified at around twenty thousand years old. A culture existed here before humans ever walked on the American continent. For fifty thousand, maybe eighty thousand years, the ancestors of Dicky and Nellie have thrived in the Great South Land. No other continuous culture comes close to this unique achievement. This is an awesome realisation for every newcomer.

Dicky explains to the children the mapping of the waterholes, the stories of the hunt, the history of how his people survived conflict, climate change and famine. Kim and I have travelled these deserts before but we wanted our children to understand why as a family we are lending a hand to these communities. The children themselves started a literacy project to organise books for the first tin shed pre-school in one place. Claire and Will

clearly appreciate the privilege of meeting traditional owners like Nellie Amunda and Dicky Minyintiri.

Among perhaps a handful of living aboriginal healers with extensive knowledge of the Law, Dicky has had a hand in his people's marvellous record of survival. This knowledge gives him considerable standing among the Pitjantjatjara. His medicines include plants now studied by western pharmacologists. But a good deal more of his powers are founded in the role of 'the clever man' who can work out how a person's illness is sometimes caused by them ignoring the Law. When the aboriginal healer looks today at what is happening to the health of indigenous Australians everywhere, at the great sickness sweeping the heartland of this country, the only possible explanation is that life is out of balance with the Law.

Ian Thorpe's Fountain for Youth Trust is directing approximately half a million dollars over three years to health/education work in the Jawoyn communities of the Northern Territory. To support this partnership with the Fred Hollows Foundation and the Sunrise Health Service, tax deductible donations may be sent to :
Fred Hollows Foundation, Locked Bag 3100, Burwood NSW 1805 or
Ian Thorpe's Fountain for Youth Trust PO Box 402 Manly NSW1655

Healing Hands. This new campaign stressing health as a human right is organised by ANTaR, *Australians for Native Title and Reconciliation*. The priority is to tackle underlying causes rather than just symptoms. To find out more go to www.antar.org.au or call 02-9555 6138.

References

1. Benefits of swimming pools in two remote Aboriginal communities in Western Australia, Director, Dr Fiona J Stanley et al, University Western Australia. *British Medical Journal* 23.8.03.
2. Indigenous Health and Nutrition. The Weston A. Price Foundation. PO Box 695 Northbridge NSW 2063. www.WestonAPrice.com
3. Professor John Deeble's costings on Primary Health care for Indigenous People. AMA Public Report Card 2003.
Email ama@ama.com.au
4. Indigenous low-birthweight and kidney disease risk. Study by Professor John Bertram of Monash University et al, Menzies School of Health Research NT, and Uni of Mississippi. *Pub. Journal Kidney International*. 2003.
5. End Stage Renal Disease statistics and life expectancy figures from Fred Hollows Foundation Indigenous Health fact Sheets 2004.
6. Indigenous Doctors. Louis G. Peachey, President Indigenous Doctors Association. *E-Medical Journal Australia*, April 2003.