

# Worlds apart?

In its latest report on how Parkinson's is managed around the world, **EPDA Plus** spoke to two key disease authorities in South Africa and discovered a country faced with numerous high-profile economic, cultural, political and health-related challenges. As a result, many people with Parkinson's are going without the treatments and care they should be entitled to

**S**outh Africa has a population of about 45 million people. At present, about 40 million of them don't have the financial resources to afford a private healthcare plan and, therefore, rely on the availability of doctors from the state sector. This is roughly on the same lines as the UK's National Health Service (NHS) only vastly less funded and largely dependent on a tiered system of clinics, district hospitals and academic centres (of which there are seven for the entire country).

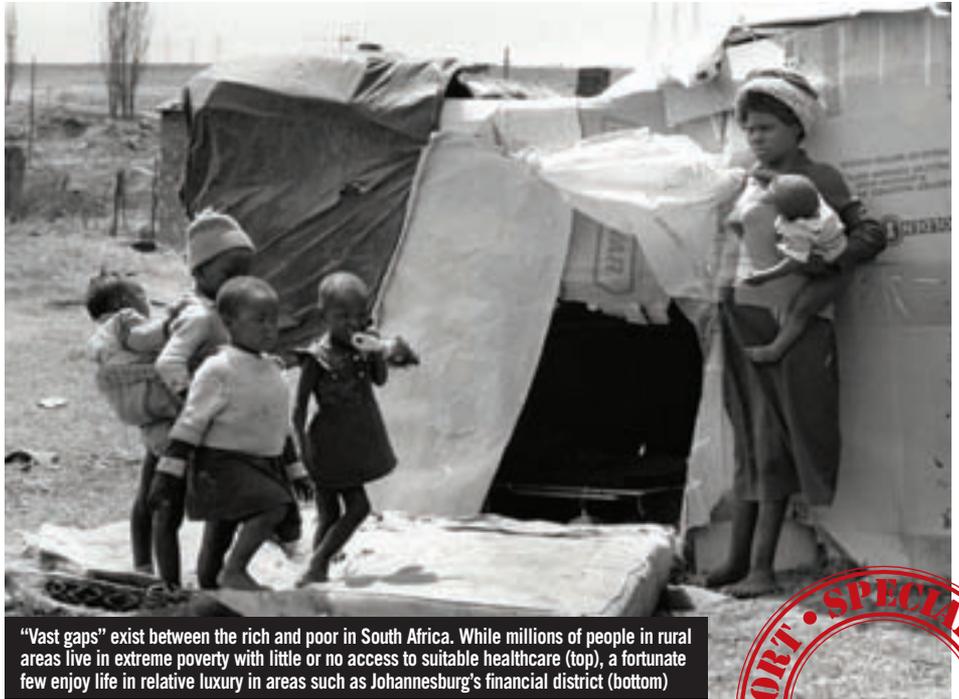
The country is also sadly lacking in neurologists, especially in the state sector – about 25 bear the responsibility for 40 million people. Although there are geriatricians in South Africa, they are in even shorter supply than neurologists.

Private healthcare insurance, meanwhile, is expensive, costing around €250 to €350 a month for a family of four. And if you consider the total amount spent on healthcare in South Africa, a significant chunk – about 60% – is devoted towards private healthcare even though this covers only a minority of people in the country.

Like other countries, South African healthcare costs continue to spiral and it appears inevitable that some kind of middle ground will need to be achieved whereby the average factory worker gets a better healthcare deal than they do presently.

Fortunately, the South African government is looking into this issue intensively and is proposing a 'National Health Insurance' plan as well as a number of pilot healthcare programmes that are due to start shortly.

Such a plan would ideally be modelled on the NHS, but for a relatively poor country, starting such a bold initiative in the 21<sup>st</sup> century is likely to prove far more difficult than the UK government found in 1948. However, as healthcare is intimately bound to socio-economic conditions, it is worth considering that massive cash injections have resulted in



"Vast gaps" exist between the rich and poor in South Africa. While millions of people in rural areas live in extreme poverty with little or no access to suitable healthcare (top), a fortunate few enjoy life in relative luxury in areas such as Johannesburg's financial district (bottom)



the electrification of 3.5 million homes in the last two decades, together with similar improvements in housing.

Nevertheless, vast gaps between the rich and poor remain in South Africa, and it is sobering to point out that if you have Parkinson's and cannot work, a typical state disability grant would amount to about €100 a month – a minimal figure.

Of course, South Africa, on the whole, has a far younger population than many of its European counterparts, while the healthcare problems African nations face are significantly different, especially given the extent of the HIV epidemic in the region. Nevertheless, there are a large number of people with Parkinson's (PWP) and, by and large, their requirements for treatment are pretty similar to those living in Europe.

**CERTAIN SIMILARITIES**

In terms of pharmaceutical treatments, the South African private sector situation is quite similar to that of many European countries – with the exception of drugs such as apomorphine and duodopa, which are scarcely used.

Well-qualified neurosurgeons carry out deep brain stimulation although follow-up sessions and maintenance of the equipment can be troublesome. The state sector, meanwhile, offers combinations of levodopa and one or two of the dopamine agonists as well as amantadine and anticholinergics. Due to the relative lack of efficacy of some of the current COMT inhibitors, however, they are rarely used.

One could argue that providing a single dopamine agonist is not good enough in the modern world. But given that a number of countries in sub-Saharan Africa do not provide any levodopa replacement to PWP at all, the current South African approach is probably quite proactive. Slow-release versions of Sinemet or Madopar would be useful at times, though.

In 1997, the EPDA launched its global Charter for People with Parkinson's to raise the profile of Parkinson's and enhance the public's awareness of the disease. Among other things, the Charter stated that PWP had the right to be referred to a doctor with a special interest in Parkinson's. But, as outlined above, given the tiny number of neurologists and geriatricians in South Africa – let alone those who are skilled in the treatment of Parkinson's – this aim hardly seems achievable in the foreseeable future.

Since the fall of apartheid in 1994 and the resulting influx into urban areas, many millions of South Africans still live



*"A terrible paradox": Soccer City in Johannesburg (bottom) cost the country around \$440m while much of the population lives without sufficient healthcare resources (top)*

*“South Africa is a country of terrible paradoxes. It provided a well-run soccer World Cup in 2010 but the diversion of resources away from healthcare as a result probably resulted in more than one mortality for every goal scored”*

in isolated villages in rural areas where healthcare is frequently inadequate.

Admittedly, this is hardly a problem unique to South Africa – Australia and Canada, for example, face similar challenges. While there are potential solutions to these challenges, such as financial incentives, telemedicine and rural medical schools, the fact remains that the priority for current South African healthcare authorities remains the treatment

of preventable disease – particularly on a primary health care level and trying to ensure the health of children and women. Indeed, the general consensus in the country is that it is hard to reasonably argue we need more neurologists when presented with such a tidal wave of overwhelming need.

Another problem is the fact that we all live in a ‘global village’ and that South African professionals – both doctors and nurses –

are in high demand and provide the 'mobile workforce' that international governments with healthcare crises are looking for.

#### PAYING THE PRICE?

South Africa is a country of terrible paradoxes: on the one hand, it was able to provide an efficient and well-run soccer World Cup in 2010, but on the other, the diversion of resources away from healthcare as a result of that sporting event probably resulted in significantly more than a mortality for every goal that was scored.

In a time of global recession, every little bit counts and everything has its price. And while the management and care of the elderly and PWP's is certainly of consequence to the national Minister of Health, the truth is he has other priorities on his mind.

However, where the government does not (or cannot) act, this creates an opportunity for non-governmental organisations to step

in. But there is another 'but'. Although South Africa has a number of well-run, able and proactive Parkinson's support groups – in particular the Parkinson's Disease and Related Movement Disorders Association of South Africa (see box) – the total combined number of members is only thought to be a few thousand. In other words, the South African Parkinson's 'voice' is simply too small to ensure that changes are made or that the national health policy is pointed in a particular direction.

#### THE WAY FORWARD

Of course, it's all very well to list a litany of complaints, so what about solutions? The obvious first step is to follow the UK Parkinson's disease nurse specialist (PDNS) model. Considering many of the most important Parkinson's treatments deal with the disease's non-motor symptoms, it can be argued that a PWP does not always

need 'fancy' or expensive medicines to improve their quality of life. Instead, a caring individual who is familiar with their patient and who can come to their assistance quickly when needed is incredibly important.

PDNSs certainly exist in South Africa but, sadly, they largely fill the vacuum that exists in rural areas. What is required is well-trained, competent nurses who can work together with the admittedly slim network of interested neurologists and geriatricians.

We have no shortage of skilled nursing staff; what we lack is the acceptance that trained PDNSs could make a massive contribution to improving the lives of South African PWP's. ■

This article was based on a discussion with Professor Jonathan Carr PhD, head of the Division of Neurology at the Tygerberg Hospital and the University of Stellenbosch in South Africa.

## THE PARKINSON'S DISEASE AND RELATED MOVEMENT DISORDERS ASSOCIATION

"We are the only national organisation working exclusively to support people with movement disorders (including Parkinson's) in South Africa. We formed in 1970 but have expanded rapidly since then. Our mission is the conquest of Parkinson's and the alleviation of the distress it causes. After a long and hard struggle, our new website is now up and running ([www.parkinsons.co.za](http://www.parkinsons.co.za)).

"Sadly there are no accurate Parkinson's-related statistics available but we believe there are approximately 18,000 people with Parkinson's (PWP's) across the country.

"Bearing this in mind, we have about 5,000 members and we support each and every one of them by providing Parkinson's education resources, information days, symposia, more than 20 regular support group meetings around the country and various forms of media including our quarterly *Movement Matters* magazine. Our board of medical advisers also offer telephone consultations to anyone in need of help. We answer any questions asked of us but these mostly cover medication, symptoms, quality of life and non-motor symptoms issues. We very much have an open-door policy. Anyone can contact us.

"Sadly there is always room for improvement in the management of Parkinson's in South Africa, especially with regards to raising awareness and

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**Karin Willemse**



getting the government, the media and the pharmaceutical industry more involved.

"In my humble opinion, we need more people to speak out publicly about the disease, especially from celebrities with Parkinson's. We do not get any government grant and our main sponsor is the National Lottery, but awareness is our most powerful tool and high-profile funding is required to do this.

"Our national health policy is different to Europe and the US. We have 'prescribed minimum benefits' which offer protection for members of official medical schemes. But not everyone is eligible for such schemes.

"As Professor Carr explains, we do not have many PDNSs as sponsorship is simply not available. But I agree, they would definitely help our PWP's. At present, a consultation with a neurologist can cost anything from €70 to €180 – a lot of money for most people.

"Remember that there is a large population of underprivileged communities in rural and semi-rural areas where people never get to see a neurologist. This poses a huge obstacle for the association and we are currently working on a road show that, providing we get the funding, will actually go into these areas to help awareness, knowledge and care."

**Karin Willemse is director of the Parkinson Association SA.**