Speech

Address By

Her Excellency the Honourable Quentin Bryce AC CVO
Governor-General of the Commonwealth of Australia

On the occasion of

Opening of Parkinsons Australia National Conference

Brisbane
13 July 2012

Ladies and gentlemen
Good morning, and a special welcome to visitors to Brisbane. It’s always lovely to come home. This city is known for its perfect winter, and you will feel the warmth of the sunshine and the Queensland hospitality.

President, Parkinsons Australia Mr John Bird,
CEO, Mr Daryl Smeaton
Delegates

I want you to know how delighted I am to be with you this morning, for the opening of our very significant gathering

- The Triennial conference of Parkinsons Australia.

Better knowledge: Better outcomes
It brings together researchers, neurologists, GPs, pharmaceutical manufacturers, and the people who are the experts in the field, PWP s and their carers. This is a vital event for everyone in the Parkinson Family, and one of enormous import to our country. Some facts and figures are pertinent at the outset.

My friends:
I know that most of you will be familiar with these sobering statistics, but I want to set them out because Parkinsons is still much misunderstood by the broader community, and this national meeting gives us an excellent opportunity to raise awareness of its spread and its symptoms.

An insidious disease, powerfully described by Dr Lynne Pezzullo as a chronic, progressive, incurable, complex and disabling neurological condition. One in 350 Australians is affected by Parkinsons Disease and the number is growing. Every day 30 people are diagnosed with Parkinsons.

We are talking about Australia’s second most common neurological disease after dementia. The average person lives for about 12 years after diagnosis, though many Parkinsons patients live with the disease for well over 20 years. 20% of people affected are of working age. This disease is more common than prostate, bowel and many other cancers, yet 200 years after its discovery by John Parkinson a cure is still to be found.

Ladies and Gentlemen:
There have been giant advances in quality of life in the last 40 years with new medications to address symptoms, but nevertheless it is a disease on the rise. The 2011 Pezzullo Report conservatively estimated that over 64,000 Australians were living with Parkinsons Disease, with 80% aged over 65. With a rapidly ageing population, the implications for Australia, and our health care system, are plain and stark. Parkinsons is projected to increase 4% over the next 20 years. These figures affirm the common perception that it is an older persons ailment.

However the Pezzullo Report noted that some 2,000 sufferers were only in their 30s and 40s. This is a cruel condition that can strike without warning. Or worse, the early warning signs are ignored or overlooked even by health professionals.

My friends:
Today and tomorrow you will be discussing key issues in plenary sessions led by distinguished researchers –

- Causes and impacts
- Advances in surgical treatments
- Advances in drug treatments

There are some exciting developments which throw into sharp focus the need for funding – fundraising for research. I know there are many here who work hard in innovative ways, tapping into every sector in our community for the resources we need to push for the breakthroughs. Presentations will be given on the tough challenges that come with depression and anxiety, young onset issues, the additional needs relating to forming relationships and rearing children, as well as asset acquisition and financial planning.

On the agenda too:

- Vitally important day to day practical matters
- Balance and falls, nutrition, speech therapy

I’m pleased to note that specialist nursing for PWP is included in your agenda. I have observed with enormous interest and respect the development of specialist nursing faculties in the profession in the UK and Australia in recent years. I remember the introduction of Breast Nurses here, based on the Macmillan system in the UK. Highly valued by women with breast cancer, and by their practitioners, breast nurses are now caring for women in remote areas through the Royal Flying Doctor Service. As many of you will know, they are supported by the McGrath Foundation. The Movement Disorders Faculty of the Royal College of Nursing has advised that there are 34 nurses who can be considered as specialists. I hope we can build on this.

My friends:

Your conference is a precious time for listening, learning, reflecting, developing ideas, experiences, renewing energy, enthusiasm and friendship. I know that the Parkinson family is good at these things, giving, supporting, getting through tough times, sharing. I feel I belong to it now. Last year my sister was diagnosed. The dearest person who has been my role model, confidante, bossy boots elder sister all my life. I felt saddened, alarmed, broken hearted when she told me – perhaps a selfish response, then I gave myself one of those lectures we need from time to time and determined that I would learn everything I could about Parkinsons – research here, around the world, treatment I’ve spoken to dedicated, committed scientists, practitioners and therapists in many disciplines. I’m impressed with how much information is available, and also by the leadership of the Parkinsons Associations across our country.

I’ve learnt that there are achievements and advances to celebrate, but there is a lot of work to be done to alleviate the growing burden of Parkinsons Disease. The lack of awareness in the general community, and in many parts of our health services, goes right to the core of what we have to get on with to address the challenges and needs of those suffering, their carers and their families. I have been inspired and uplifted by the patient perspectives I have pored over in recent weeks. We owe a particular debt of gratitude to men and women who teach us about what Parkinsons really means with openness, honesty, generosity; gritty determination, shining through. Stories that add another dimension to our understandings. Stories that speak of planning for the future, but making the most of every day and enjoying life to the best of your ability. Stories about the subtle changes.

- “I wait expectantly for what lies around the corner, not fearfully, expectantly.”

About what it feels like – Being scared, falling into a heap. So often I observe a little humour tucked away on the edge. I see these qualities that I admire again and again in people with Parkinsons, quiet courage, dignity, but I see too awkwardness, embarrassment, a withdrawal from social life. The lack of co-ordination, tremor, impaired balance and slurred speech, spilling a drink, breaking a plate, a stumbling entrance can all erode confidence and lead to reclusiveness and low self-esteem. The community needs to be educated and to help defuse such episodes with compassion and understanding. Parkinsons needs champions. It needs advocates – out there, as well as in here.

I know well that Parkinsons Australia sees its principal service in that light – in advocacy, being there as the voice of PWP – representing the needs and interests of PWP to all levels of government, seeking improved funding for services, research and awareness, in providing understanding. I congratulate you on your sustained commitment, your dedication to your mission. I am honoured to be your Patron and I assure you I will add my voice whenever I can to support and encourage you in what you do every day.