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STORY: NIC BARNARD

*Federal MPs have joined the push
to increase Australia's organ donation rates.*

nted: More Miracles

THE headlines on the House of Representatives' first—and as it turned out, last—Friday sitting were all about disruptions, suspensions and a cardboard Kevin Rudd.

But before Speaker Jenkins called time on the theatrics, there came a series of moving and thoughtful speeches on an issue too rarely discussed and which seems to catch Australians in two minds.

The issue was organ donation, and Australia's sorry record in offering organs for transplant, despite the nation's world-leading status in transplant technology and near universal public support for organ donation.

It was raised under private members' business by Melissa Parke, the newly-elected Labor MP for Fremantle (WA), but its sentiments were echoed in speeches from both sides of the House.

Ms Parke's point was simple, and illuminated by some stark figures: last year, there were just 198 donors across Australia; their organs saved or improved more than 600 lives, but the waiting list for transplants stands at almost 1,900.

"Each year, thousands of Australians [are] dying or suffering blindness or the debilitating experience of being hooked up to a dialysis machine for several hours every few days for want of healthy organs," she told the House.

Australia's rate of organ donation is 10 per million in the population—one of the lowest in the developed world. It compares to 35 per million in Spain (the highest rate in the developed world) and to 21.5 per million in the US. Waiting lists are so long, that some Australians fly overseas for transplants.

"It is an appalling situation when Australians in desperate need of an organ feel they must travel overseas to obtain one," Ms Parke said.

And yet, she noted, some 94 per cent of Australians have indicated their support for organ and tissue donation. "We now need to convert that very high level of approval into action."

Ms Parke's call for action was well-timed: it came at the end of Australian Organ Donor Awareness Week, and just days after the release of the final report of the National Clinical Taskforce on Organ and Tissue Donation, commissioned by the previous government in response to concern at the continuing low level of donations.

The report's key conclusion was the need for agreement on a national system for identifying potential donors and approaching relatives for permission, backed by better data collection, and training for hospital staff.

It also called for a national campaign to drive home a simple message to the public about the importance of organ donation and dispel popular myths.

The overhaul of the donor system has already begun. Easter saw the announcement of the disbanding of Australians Donate, the government-funded peak body, following a separate independent review last year which found that, despite its work, there remained "a highly fragmented system that lacks effective coordination and cohesion".

Donation rates have barely changed in the past 20 years. In some respects, this disguises an improvement: deaths from traffic accidents and strokes—two of the major sources of

organs—have nearly halved in that time. More than 30,000 Australians have received organs since the first kidney transplant was carried out in 1956.

But demand for organs is likely to grow as incidences of diabetes and obesity and other lifestyle-related diseases increase. Particular work in promoting organ donation needs to be done with Indigenous communities, which have the lowest rates of donation, but some of the highest rates of kidney and liver disease.

The taskforce recommended a target of improving the rate of donations by 50 per cent. The benefit would come not just in lives saved or extended by treating an extra 370 patients a year; it would also save the public purse almost \$26 million, according to a 2006 report.

As the taskforce's report said: "Organ, eye and tissue donation should be regarded as a natural and routine aspect of end-of-life considerations."

Ms Parke, a former lawyer with the United Nations, has taken a long interest in the issue of organ donation. But her speech struck a chord around the chamber.

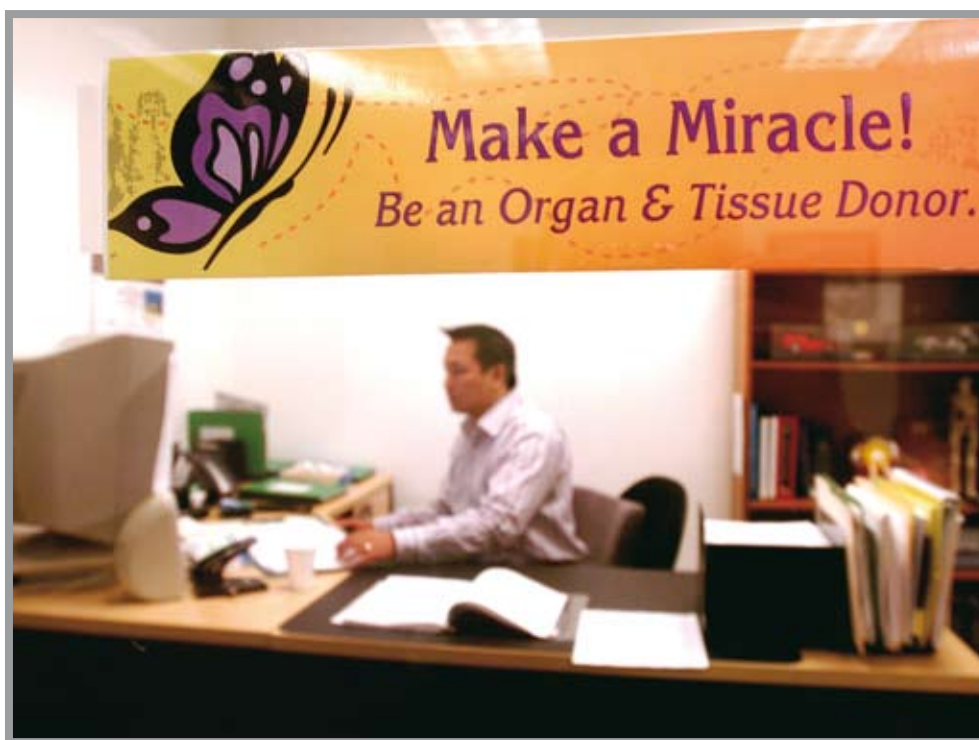
Margaret May, Liberal MP for McPherson in Queensland, reminded MPs that joining the organ donor register was not enough: "I cannot stress strongly enough that, if you register, it is a subject you must talk over with your family and your loved ones."

Families of the dead and dying were placed in a "heart-wrenching" position of being asked for consent for their loved one's organs to be used, she said. The most common reason for declining was that they did not know it was their relative's wish.

"Even if someone has registered their wishes on the organ donor register, a family member may still override that wish. If your family knows and understands your wishes, following through with your wishes will not be such a hard decision for them to make when you pass away," Mrs May said.

ENCOURAGING DONATIONS:

Campaigns in the United States have helped increase organ donation rates. Photos: apimage and Jupiterimages





CELEBRITY SUPPORT:

Sports stars such as cricketer Shane Warne have been used to help boost organ donations in Australia.
Photo: aapimage

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For Gregory Hunt, the Liberal MP for Flinders in Victoria, there was a personal connection. His cousin Christopher died in a skiing accident in 1992, aged 25, and his organs saved the lives of several people (see ‘Hope can be restored’).

Mr Hunt, whose wife is a neurosurgical nurse who has worked in transplant surgery, urged the government to consider an opt-out system for what he called Australia’s “magnificent organ donor register”—or failing that, reform of drivers’ licensing systems to make signing the register part of getting a licence.

At present, Australians opt in to the donor register—that is, by joining the register they make an explicit statement that they wish their organs to be used in the event of their death. In Spain, citizens are presumed to have given consent unless they have opted out.

This oft-touted proposal was considered by the taskforce, which came down against the idea, arguing that huge improvements could be made without taking such a drastic step. It pointed to the US, where donation rates are more than double that of Australia, without any opt-out system.

The most important challenge in meeting this goal is addressing Australia’s fragmented health service—based on

states and territories, with a high number of stakeholders working at different levels of the system.

The taskforce called for a national donation and transplantation authority, comprising clinicians and governments to oversee reform and coordinate activity.

But it will require more than collaboration between states and territories. It will also require new ways of working in and between the emergency departments, intensive care units (ICUs) and organ donor agencies on identifying potential donors and coordinating with transplant waiting lists.

Those involved in transplant services at all levels will be required to “think nationally but act locally”.

A national set of standards or “triggers” should be developed for identifying potential donors in all emergency wards and ICUs. In emergency units, this would broadly involve identifying patients who have been placed on artificial respirators and who have irrecoverable injury. In that case, the ICU would be contacted for support in making end-of-life decisions, including organ and tissue donation.

In ICU the triggers would identify patients with severe irreversible injury; the absence of several brainstem reflexes; or suffering from disease which was spreading to the point where it would be appropriate to withdraw life-sustaining treatment.

In such cases, the local donor coordinator or agency would be notified, and the Australian Organ Donor Register should be checked before approaching the next-of-kin.

These national triggers would be matched by national criteria for transplant waiting lists, and agreements on organ allocations between jurisdictions and hospitals.

Hospitals should also develop their own protocols, the taskforce recommended. Officers should be given designated roles in the donation process, and states should invest in bereavement counselling to support families.

Such a program would build on the work of a pilot program, the National Organ Donation Collaborative, which has brought together staff in 22 hospitals to find ways of improving practice. A similar initiative in the US lifted donation rates by 30 per cent over four years.

Ms Parke noted the taskforce's report in her recommendations to the House—and urged MPs to do what they could to encourage donation in their own electorates. But she also drew attention to a darker side to organ transplants.

She talked of her work with the UN in Kosovo on people trafficking, where she became aware of the “horrible” international trade in organs and the growing phenomenon of transplant tourism.

The recipients are almost always from the wealthiest nations in the world—Ms Parke mentioned Australia, Canada, Israel, Japan, Saudi Arabia and the USA—while the live donors are from the countries where poverty is endemic, such as Pakistan, India, Bolivia, Brazil, Iraq, Moldova, Peru and Turkey.

“The WHO [World Health Organisation] and other bodies have raised concern about the dangerous consequences of the international organ trade, both for live organ donors, most of whom are coerced into it through extreme poverty or force, and for recipients who may undergo surgery in substandard conditions and may not survive the transplant process,” she said.

She also detailed China's alleged harvesting of organs from executed prisoners—a practice which contributed to most of the 12,000 kidney and liver transplants performed in 2005, according to WHO figures, with many non-Chinese citizens as recipients. •

You can join the organ donor register online at www.medicareaustralia.gov.au
Remember to discuss your decision with your family.

Those involved in transplant services at all levels will be required to “think nationally but act locally”.

HOPE CAN BE RESTORED

Organ donation is an issue that touches the lives of many—not just the recipients but their friends and families, and just as importantly the families of those who have donated.

Several MPs spoke of constituents whose lives had been saved by organ transplants, or those who were still waiting, but none had closer experience than Flinders MP Gregory Hunt.

He spoke movingly of his uncle's decision to donate the organs of his 25-year-old son Christopher—Mr Hunt's cousin—after the young man died in a skiing accident in 1992.

“For some days he was on life support, and during that time my uncle David Hunt, whom I love very dearly and who is perhaps one of my harshest critics and challengers, had to make a very powerful decision—that is, to release the organs of his young son,” Mr Hunt told the House.

“It has been a very difficult period for David since then, but the one sustaining element that he has had is that those

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organs which were taken from his son, my cousin, gave life to many people. Not all organs were taken. A decision was made that the corneas were too personal, but the principal organs were taken.

“I cannot tell the House to how many people they gave life but I know it was to a significant number. That story is the story that occurred 198 times around Australia last year.”

He added: “It has never been easy for my uncle or for our family, but the fact that there was some good, a profound good, which came from this passing and this process means, to me, that it is one of the most significant things which anybody in our society can do.”

Other MPs told stories of their own constituents. Melissa Parke told of Fremantle bluegrass musician Jim Fisher who received a liver transplant and, despite feeling initially like he’d been “bashed by Mike Tyson for a week”, was now back playing the pubs with his band, the Sensitive New Age Cowpersons.

“He speaks with a humble awareness of how lucky he has been to receive a liver and how he had to wait only nine months to receive his transplant, while he has seen other people die waiting for transplants. Jim is well aware that it was not only the generosity of his donor but also Australia’s free public health system that contributed to his still being alive today.”

Annette Ellis talked of two cases in her Canberra electorate—a 10-month-old “dear little possum” in need of a liver transplant, and an older woman with a rare lung disease who is hooked to an oxygen machine for 24 hours a day.

She also read a moving letter published in the *Canberra Times* newspaper, from the father of a 17-year-old boy who died suddenly and whose organs saved the lives of five people.

The family had discussed donation and were ready to make the decision in tragic circumstances.

“We miss him every day and suffer the loss and feel the despair of losing him deeply still. We are consoled that part of him lives on in the people he saved,” David Mitchell wrote in his letter.

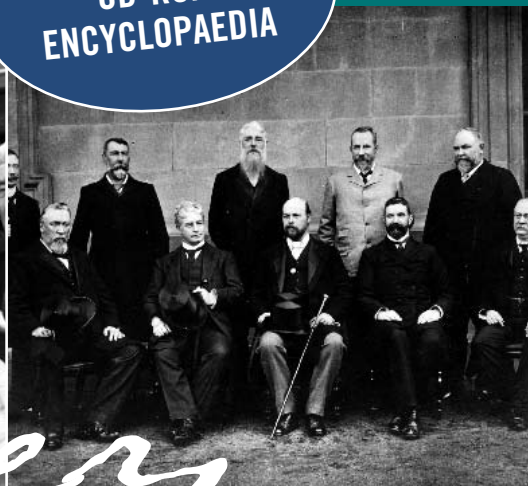
Luke Simpkins (Cowan, WA) talked of the zest for life shown by organ recipients at the annual Australian Transplant Games. “Hope can be restored and there is life after great adversity if we get organ donation right.” •



ZEST FOR LIFE: *Organ donation ensures life after adversity. Photo: Jupiterimages*

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