



Rachel Bishop and her son Roman.

LONG ROAD To Recovery

SA families currently have to travel interstate if their child needs heart surgery, writes **John Thompson-Mills**.

It's the biggest killer of children under five and the most common birth abnormality, but for 80 per cent of cases the cause is unknown. And there's no cure available in South Australia. Childhood Heart Disease (CHD) can range from a hole in the heart to something much more complex. Each year more than 100 South Australian children suffering from CHD must travel to Melbourne for life-saving surgery that until 2004 was available in Adelaide.

Planning this trip to Melbourne places massive pressure on families, as there are many decisions to make. Do both parents go? What about their other children? The house and pets? How long will they be away? Accommodation? How much will it cost? What about work?

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Previously, there was a renowned cardiac-surgery unit in Adelaide, founded in the 1970s by pioneering surgeon D'Arcy Sutherland. Surgery was conducted at the Royal Adelaide Hospital (RAH), with pre- and post-operative services at the Women's and Children's Hospital (WCH). But this changed in the early 1990s when the Variety Club funded the establishment of a paediatric cardiac-surgery unit at the WCH. It dealt with simple open-heart procedures, and the more-complicated cases were sent to the Royal Children's Hospital (RCH) in Melbourne. But in 2004 the unit closed, forcing all South Australian families with a child affected with CHD who needs surgery to travel to Melbourne.

Dr Jayme Bennetts, head of cardiac surgery at the WCH, and acting head of cardiac and thoracic surgery at Flinders Medical Centre, says it's been a struggle to find out exactly why the unit closed. "There was basically a worry about dwindling numbers, and this was being complicated by justification about continuing a service," he says.

Rachel Bishop's now-six-year-old son Roman was diagnosed with CHD in utero, during Rachel's 20-week prenatal scan. She says having to go to Melbourne for Roman's treatment reinforced the seriousness of his condition. "We knew that it couldn't be dealt with in SA and this made us feel apprehensive as it's generally not something you can plan for," Rachel says. "You're told you might have to go in the next couple of weeks, then they say actually it's tomorrow. And then you're on a plane."

Roman, Rachel and her partner Ed Pikusa have been to Melbourne six times in the past six years. "Our first trip was for almost six weeks, with Royal Flying Doctor Service transfer both ways because Roman was so sick," Rachel says. "We also had an aborted trip because Melbourne is so busy, you often get cancelled. You rock up, do all the testing, turn up first thing in the morning, and at 10am they say sorry, no beds available. Just come back again tomorrow morning and see if you can get in. Once we had been there for nearly three weeks when they said 'we're not going to be able to get you done', so we came home for three weeks and then went back again."

The trips are only partly subsidised. Flights are paid for, and the South Australian Government has a Patient Assistance Scheme, but it doesn't include accommodation. Rachel and Ed have spent 94 nights in Melbourne, paying almost \$12,000 on accommodation. After one trip, they met with SA Health Minister John Hill who "kindly increased the subsidy", but Rachel says the system is not equitable. "That's the one sore point; depending on where you live, different States have different budgets," she says. "In WA, the government has a bigger resource base than SA, so if I was there I wouldn't have to pay for accommodation. I don't expect to be out of pocket because the surgery isn't supplied in my State."

An organisation that helps families in these situations is HeartKids SA. Set up in 2007, it employs a part-time support coordinator at the WCH and will soon have another at Flinders Medical Centre. HeartKids State Manager Kerry Southwell says the program works well. "Our family support coordinator starts talking to families as soon as they come into the program," she says. "We offer telephone support, run events for the kids such as playgroups, and also give families \$120 in travel assistance."

After working in Sydney and Canada, Dr Jayme Bennetts returned to Adelaide in 2006 with the aim of re-establishing a paediatric cardiac-surgery unit. Now he's all but given up. "I think there's room for a lower-complexity cardiac-surgery

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service in SA (20-30 cases per year), but I'm one of the few that holds that view," he says. "The social costs and difficulty with transferring to Melbourne, for a service I believe is reproducible here in Adelaide, is almost impossible to quantify; because how do you measure those things?"

Dr Bennetts' opinion is at odds with SA Health's chief medical officer, Professor Paddy Phillips, who believes that the case load doesn't justify an Adelaide-based service. "It's well recognised that a certain case-load level is required to remain expert in this area," Professor Phillips says. "South Australia does not generate the required number of cases, which is why we refer to centres that do."

The good news is that the Victorian Government will open a new RCH later this year. Stage two of the development includes a 90-room hotel built on the old hospital site. Demolition starts next year, with the 3.5-star facility due to open in 2014. So while South Australian children with CHD face a long trip to better health, at least they'll be close to their families as they take that journey. ●