

'Making Connections' NSW Premier's Forum on Spinal Cord Injury & Conditions

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(Note: text has been clarified and subtitles have been added in the editing process).

Well ladies and gentlemen, I can hardly believe I'm here. It's a real thrill to be down under. I never thought I was going to come when I was on my feet. So I'm even more thrilled to be here, arriving after thirteen and a half hours sitting down.

No worries

The theme of the Forum today is making connections. But I have to say something about the Australian people, a country that I've observed through my acquaintance from overseas and in my short time down here. Australians face the same challenges as the rest of the world, but there's something very unique in the Australian character. When faced with adversity it seems to me that Australians lump adversity into only one of two categories: either it's 'no worries' or it's 'a bit of a worry.'

But nothing beyond that. In the States we talk about impending doom, immediate catastrophes, and cataclysmic outcomes. You don't do that down here, and I think that is perhaps built into the national character and has developed over the centuries. But nevertheless it's an inspiration to the rest of us as we face whatever challenges come before us, either personally or as a country.

Making Connections

Going back to the theme of making connections. I have first hand experience with that, beginning with my injury. When I was injured the base of my skull was literally disconnected from the top of my spinal column and my head was only attached by muscles and tendons and ligaments. Dr John Jane, a great neurosurgeon at the University of Virginia, had to make a very basic connection. He had to put my head back on my body. And the care with which he did so enabled me to go forward and live the life I'm living today, with great expectations for a better life in the future. He would have been perfectly justified back in 1995 to be more dismissive of my situation. But he gave me the best care so that I'd have the optimal outcome. In fact, when I was placed on the table for surgery it took ten people one hour to turn me over. The reason they took that much time was because they didn't know the extent of my injury. They wanted to make sure they didn't do any further damage. And for that I will always be grateful. So making connections for me began with my relationship with a great neurosurgeon, and then it continued with the people with whom I work day to day, facing each day going forward.

Nursing

I think more credit should go to nurses. They're very much under appreciated. In fact in the U.S. there is a critical shortage of nurses because they're underpaid for what they do. So a lot of young people think "Why should I become a nurse?" But the ones who've made that commitment to nursing mean everything to the patient. They're the ones we talk to in the middle of the night. They're the ones who are with us through the ups and downs. They're the ones who challenge us to do more. They're the ones who are always available. If we're lucky, we get that quality of nursing care.

Sometimes nurses are just sent from an agency. A lot of patients - probably many of you here - can relate to this. An agency just sends out a nurse who doesn't even know you. They fulfil their obligation to provide a nurse, but particularly when you're vent -dependent a lot of nurses don't know about that. It's not right for just an agency nurse to show up, someone who doesn't have a relationship with you.

I've been lucky to hire nurses independently. Many of them have been with me since I came home from rehab in December of 1995. They've stayed and our connection has become personal as well as professional. They're really members of our extended family, and for that I am extremely grateful. For their time, their commitment and the care that they've given me, which has enabled me to do more than was expected of someone in my condition.

Insurance

In the United States insurance is quite different than it is here. I understand that many times because of excellent health policies in Australia, an individual can stay for as long as a year in a rehab centre. In the States they try to kick you out as soon as they can, and then they give you limited care when you get home. I was told I could only have nursing for 48 days, and after that my family would have to take over. Then I wasn't going to be allowed any physical therapy whatsoever, because they told me I'd never move below my shoulders. So for a while, a physical therapist would come once or twice a week and would work on my shoulders. But that was useless because I could already use my shoulders. I wanted more.

So we stopped that relationship because it was not the right connection. It was not a fair connection. One of the things I have been campaigning for in the States (and I think it applies to other parts of the world as well) is simply for the medical profession, as controlled by insurance companies, to do business in a different way. Don't treat patients by giving them the very minimum care. Don't treat patients just by statistics. Don't deny basic services simply because that's how you think you're going to save money. Insurance companies need to know that because of advances in medicine they will profit --- and improve their image --- by giving patients more. Not by indulging them, but by giving them the best shot. That means paying for proactive therapy. It means providing electrical stimulation. It means paying for sessions on a bicycle that can allow patients to maintain skin integrity and cardiovascular conditioning and good circulation and bone density. All of those are crucial aspects of living with paralysis.

A paradigm shift needs to take place - at least in the United States. I can't speak for other countries around the world, but it's a real problem for us. I'll give you an example: when I filed a claim for a back up ventilator my insurance company said "No". They told me that someone could just give me air with an ambu bag, manually forcing air into my lungs, for as long as necessary until another ventilator arrived. Where I live, that could have been five or six hours.

The reason they automatically deny is because only 30% of people who are refused goods and services fight back. The rest of them simply roll over. The 30% who fight back have to write letter after letter, hire lawyers and threaten to sue in order to get results. Why is that necessary? There should never be an adversarial relationship between health care providers and patients. It is wrong. It is wrong that we should be battling each other. We should be making a connection there that allows both sides to win. Insurance companies can succeed --- in fact they will profit more --- by treating their patients properly.

Family

Other important connections are within the patient's family and in the relationships with other caregivers who are not professional. When insurance companies won't provide necessary care close relatives are brought by necessity into the life of the one who suffers from a disease or disability. That can be very rewarding. It can also be extremely challenging and difficult because of the intensity of the experience. Dealing with severe pain. Dealing with spasticity. Dealing with the daily care. Dealing with a patient who needs to be turned every two hours.

All of you who've had children understand I'm sure. At first you think the newborn baby is a little miracle, as cute as can be all wrapped up in a blanket. Then he keeps you up every night and after a while you go nuts. Every parent has experienced that. The same can happen with a patient as well.

So we need to develop a system where families are not torn apart by having to shoulder the whole burden of caring for someone who is seriously ill or disabled. There has to be a support system for the caregivers, particularly family members, so that families can enjoy as much of a normal life as possible. Paralysis is a life-changing event. But it should be something that can bring a family together with more love; more sympathy; more understanding than before --- rather than splitting it apart. I've seen both. We need to find resources for families so they don't burn out and they can maintain the healthy, loving connections that will allow them to face the future.

Science & Research

Another essential connection is between scientists, researchers and patients. Once I spoke at a symposium of 2000 neuroscientists in New Orleans. A lot of the brightest minds in the world were there. But many of them are PhDs rather than MD PhDs and they spend most of their time looking into microscopes studying cell biology. That work is very important. But I remember saying to

them; “You know what I’d like? Every now and again when you’re on the way home from work, stop by a hospital. Stop by a rehab center and watch a patient with paralysis just trying to sit up or move a finger. Then go back to the laboratory and ask yourselves how your work connects to real live human beings who are suffering, perhaps just down the street from you”.

In the past, there wasn’t a lot of hope so researchers could take their time. In fact when they applied for funding, often they would apply for a grant that would get them just enough money to make a little bit of progress. Then they would apply for another grant to make a little bit more progress. Pure research would become their life’s work.

Pure research is fine. But in our area, research means practical applied research. And it should be conducted with the same urgency that we expect when we call the fire department. You don’t want firefighters to engage in a theoretical discussion about what might be happening at a burning house. You want them to arrive immediately and put the fire out.

Not so long ago there wasn’t any expectation that scientists could put the fire out. That’s all changed for the better. Dr. Wise Young, present at this Forum, has been toiling in the field since the time when spinal cord research was considered, “the graveyard of neuroscience”. Wise Young was one of the pioneers, a forward thinker who always believed that something could be done.

In 1995 he said in an interview, “At first there’s hope, but over time hope ebbs

And finally it may fade all together”. A few years later he told me that in order for me to walk nerves would have to regenerate from below my injury all the way to the end of my spinal cord.

Just recently Wise Young and other scientists have said they must now discard almost everything they know. All the conventional wisdom that has accumulated over the last 20, 25 years about the spinal cord - about its ability to regenerate, about its ability to remyelinate, about its ability to respond to exercise. We have to make a new connection to the present reality, which is that the spinal cord can be repaired. The spinal cord is smart, the spinal cord probably only needs to be regenerated in the area of the lesion because there are many intact connections further down that can be reawakened with exercise and other therapies. We can already plan for a day when people who are presently confined to wheelchairs will be able to get up and leave them behind.

At the Reeve-Irvine Research Centre, at UC, Irvine, California, they have a very ambitious programme going in stem cell research. They’re pretty much on the cutting edge of what’s happening with stem cells. Last month’s newsletter had a whole page specifically dedicated to human trials, telling patients and their care givers what a human trial is. Phase one for safety, phase two for efficacy, phase three --- more than three hundred patients to prove that a treatment is truly viable, in order to gain approval by the Food & Drug Administration (FDA).

Hope

Already scientists are working with the FDA to design human trials that may begin as soon as a year or two from now. Connections have been made that were once thought to be absolutely impossible. Scientists have been willing to give up old ways of thinking. We’re all here today in an atmosphere of collaboration that is creating real hope. Hope is not optimism or wishful thinking; hope must be built on a solid foundation of knowledge and discovery. When I think back to those words that Wise Young said to me, “Over time hope fades” --- they’re no longer true. Now we know that over time hope grows. Hope for real change and for recovery is here and alive today. This meeting is about where we stand --- no pun intended --- and how were going to move forward in practical terms, for a better life for tomorrow. It will come.

Let me say again how honoured I am to be here. At this point I’ll be very glad to answer any questions. Thank you.

Questions & Answers

Jane Charlton: *Christopher, what therapy or procedure has most helped you so far?*

Well, I've had no medical procedure but I believe that I've made progress because of constant exercise. Perhaps I've challenged the old wisdom that you'll only get recovery about a year or so after injury. I think many patients believed that because of so few of them were given the opportunity to exercise beyond that time. I've had the privilege of exercising virtually everyday since 1995 and I began to get recovery of movement and of sensation five years post injury. I don't think that I'd be an isolated case if others were given the same opportunity.

But my progress won't mean anything unless it translates into the same opportunity for others. That means making electrical stimulation, aqua therapy, bicycles, treadmill therapy - making that care affordable and available to the patient population as a whole. Clearly, exercise seems to make connections between the body and the brain. And perhaps the body itself has energy and memory that can be used to achieve recovery.

When I am not encumbered by gravity I am able to move my arms, move my legs, move my feet. All of which was never supposed to happen. And of course, the psychological benefit of finding that something new moves or gets stronger gives me the will, would give anyone the will to keep going in preparation for further recovery. Science and exercise must come together to achieve the best possible outcome.

Camille Manley: *Christopher, do you believe many patients leave hospital ill prepared for the emotional and mental impact. And what can we do to change this?*

I think everyone's hospital experience and rehab experience is very different, and I think that the timing is very important. I know that when I was in intensive care, it was only 4 or 5 days after the surgery, I was in very low spirits. Trying to come to terms with being a spinal cord patient, with no idea what my future would be. And somebody cheerfully came into the room and talked about various colour choices for my wheelchair. I wasn't ready to hear that. I wasn't ready to hear "wheelchair".

Then a psychologist came in --- and I think perhaps she'd been working with children for too long because she talked to me as though I was a two year old and about "all the wonderful opportunities I'd find in life". I told her either to speak to me as an adult or get the hell out of there. She never came back.

It's important to tell patients the truth, but only when they're ready to hear it. You don't want to mince words, but it's very important for psychologists, doctors, nurses, physical therapists and even family members to be very sensitive to the patient's state of mind and emotional wellbeing.

Michael McDermott: *Mr Reeve, do you think there is much likelihood of success in growing new spinal nerves that are severed?*

Yes I do. As I understand it, the standard way of experimenting on mice and rats is by actually severing the spinal cord. That means most experiments create an injury that is worse than many patients actually suffer. Stem cells have been used on rats with a complete injury and they have recovered quite successfully because their stem cells have been able to create neuronal and axonal bridges across the gap. "Bridging the gap" is the phrase that is used, and the gap you're talking about is the gap of a complete injury.

So I do not think that in the future people with complete injuries are going to be excluded from this journey of recovery.

James Sidebottom: *How do you and you family cope with the intrusion of cares 24 hours a day?*

You hope that people will come along that become friends. Who become like members of your family, who are extremely sensitive. What we do in our family is to create a professional relationship that eventually becomes a personal relationship. Then it's like having extended family around. You can't cross that barrier immediately, nor should you --- but over time the people who stay are the ones who feel like family. And then their presence doesn't feel intrusive.

I have a theory that might sound naïve, but it works for me. I feel that even though there are six billion of us on the planet, really we're just one huge family. We're only strangers if we decide to ignore one another or if we see someone suffering and decide to look away. But if our attitude is one of compassion, realising we're all part of the same big human family, then we reach out and that make that connection more easily.

Annie Selman: *Mr Reeve, why not focus on adult stem cell research as a priority rather than embryonic?*

Well, there is a lot of focus on adult stem cells - and there should be. But I wouldn't say it should be the number one priority. First of all adult stem cells are already treating certain diseases --- for example, adult stem cells taken from the bone marrow are used to treat bone marrow cancer. Adult stem cells taken from the umbilical cord are used to cure sickle cell anemia. Scientists have been able to take adult stem cells and change them into neurons, but not to implant them in animals and get the creation of new tissue, which is part of what is required to heal spinal cord injury.

So if you were to say, because of controversy, let's only focus on the adult stem cells, scientists might spend five years trying to make adult stem cells behave like embryonic stem cells and fail. And we will have lost precious time. Thousands of people will have died in the meantime. It seems to me only reasonable to proceed on all fronts. When you're waging a war --- and we are waging a war against disease and disability and the attendant suffering --- in waging that war, you want to marshal all the forces you possibly can. That means adult stem cells, embryonic stem cells, and stem cells derived by nuclear transfer, which is also known as therapeutic cloning. And there are other technologies as well. There is the olfactory gland, there are Schwann cells combined with peripheral nerves, there's microchip technology being worked on and more. All of this should be done because no one knows for sure what the outcomes will be and what the timeframe will be. But to say "let's make adult stem cell a priority because they cure already a couple of diseases and they're not controversial" would be a mistake.

Amanda Kaest: *Hi Chris. If electrical stimulation is so beneficial to your therapeutic programme how will this be made available to Australians?*

Patients shouldn't have to go down to the bottom and suffer blood clots and pneumonia and skin breakdowns and all of that before they get the treatment they need. It should be started from day one as soon as they can possibly tolerate it after surgery. Once again it comes down to the National Health Service, insurance companies and health care providers. They should see the benefits, the cost effectiveness of providing top quality care.

In the first few years after my injury I had blood clots, pneumonia, ulcers, skin infections, broken bones and more. I spent many days in the hospital, which cost my insurance company quite a bit of money. But in the last four and a half to five years I haven't been hospitalised, due to the quality of my home care. I think insurance companies should realize that keeping someone like you or me out of the hospital by providing quality equipment and care is in their best interests. Again, it's all about education.

Chanelle Flavell: *Mr Reeve, how have your family and friends helped you to overcome the emotional and physical obstacles that have developed as a result of your injury?*

My first reaction when I became aware of my injury was guilt. Getting over that guilt was possible because my family accepted me in spite of the fact that I was going to --- and we were going to --- have to live a new life. I was very, very lucky in that regard.

I think that what you have going into a situation like this --- once again, in terms of connections and the relationship with your family --- will be intensified by the experience. If the connections, the love, the bond is strong you're likely to do well and become even closer. If, on the other hand, the connections are bad, if there are issues in the family, if there's discord or poor communication, then an injury will make things worse. I've seen people abandon family members who have suffered a serious injury. I met a young woman with ALS (Amyotrophic Lateral Sclerosis) whose parents didn't want anything to do with her, and she died without ever seeing her parents again.

My recommendation to anybody at any time is to honour, cherish, and nurture your relationships with family and friends. Always. It will stand you in good stead in case something terrible happens.

Chris Spanos: *Christopher, what was it like to travel on an international flight to Australia as a quad?*

The longest I'd done before was seven hours from New York to London. The prospect of going from New York to Sydney at first was daunting, because it's five and a half hours New York to LA, then thirteen and a half down here. I recommend you move Australia a little closer. Just up a bit towards the equator if you don't mind. And bring all the other islands with you.

I am very very grateful to Qantas for the efforts they made. I'm glad they didn't have to rebuild the aeroplane for me. In fact, no seats were taken out of the first class area. On the left side of the aircraft there's a little area for a basinet to put a baby in, and that's where they put my ventilator. I had a longer hose than normal, and the seats recline all the way, so I enjoyed great food and great entertainment, a good night's sleep and arrived well rested and with my skin intact. It was tremendous.

Rehan Ahmad: *What would your message of hope and support be to those who suffer from spinal cord injury?*

Well the main message of hope is that there is hope. Not just optimism, not just wishful thinking, not just theory. There is applied science going on all over the world right now to treat patients. I would like to dispel the myth that embryonic stem cell research or research using nuclear transfer, also known as therapeutic cloning, will not produce results for ten to twenty years. That's not true. In a chess metaphor, we're already looking at the end game. The end game is not going to take ten, fifteen or twenty years or forever to finish. It will happen much more quickly if we unite around the world to make it happen. Because ultimately who has the power? People have the power. Not industry, not politicians --- people have the power. And we need to address human suffering with the kind of urgency we would expect of the fire department if a building is burning. And that can happen. Don't let anyone tell you it's some pipe dream. It can happen and will happen much faster than you think.

Jess Evans: *What are your current activities in your endeavour to help disabled people around the world?*

Well I'm working on a number of fronts. One thing that I'd like to make clear - I've been talking a lot about research but I'm the Vice Chairman of the National Organization on Disability (NOD) in the United States, which is the foremost organization to answer and provide quality of life needs for people living with disabilities. Now that means, for example, enforcement of the provisions of the Americans with Disabilities Act. This was passed back in 1990, but there are many places that are not in compliance - and one thing we do is bring attention to that. The NOD also is in charge of the veteran's hospitals around the country, so I work to ensure there is good therapy for veterans. I want people to understand that I believe in care today and cure tomorrow. I am not simply sounding the one note of research: both are equally important. Both must be accomplished at the same time.

Much of my time is spent as chairman of the Christopher Reeve Paralysis Foundation, raising money for the best researchers around the world. I'm pleased to say that we fund research here in Australia, in particular a project on autonomic dysreflexia conducted by Dr Brock at the Prince of Wales Research Institute --- for which we hope to raise a great deal of money tomorrow night.

And then lastly, but perhaps most importantly, I work in connection with a group called the Coalition for the Advancement of Medical Research. That is a grass roots movement comprised of more than 80 disease groups in the US who have banded together to try to pass progressive legislation that will help fund and legalise the best research. We're doing it at the federal level and we're also doing it at the state level.

I'm reminded of what happened at home, back in the days of the Reagan administration. In the early 80's the federal government spent zero dollars on AIDS research. In fact, many of our elected officials said that AIDS was God's revenge on people who lived a certain lifestyle. It took a grass

roots movement that was formed by local chapters, local activists who campaigned across the country and eventually a quilt was stitched together with the names of men, women and children who had died of AIDS. That quilt arrived in Washington and was placed on the great lawn --- it could be seen all the way from the Capitol to the Washington Monument.

And from that point on, AIDS research began to be funded by the US government through the National Institutes of Health. Today the NIH spends approximately \$1.8 billion annually on AIDS research. Tremendous progress has been made in the US in halting the progression of AIDS and HIV. And how did it happen? Because people took action.

We're doing the same thing in terms of research that will benefit not just someone like me sitting in a wheelchair with paralysis, but people suffering from Parkinsons and Alzheimers and ALS and MS and Cancer, Leukaemia, Heart Disease... the list goes on and on and on. That's the promise of stem cells. The states initiatives began in California last September when they passed a law that allows their scientists to conduct research on stem cells derived from any source: that means adult stem cells, it means human embryonic stem cells derived from embryos that would otherwise be discarded as medical waste from *in vitro* fertility clinics, and therapeutic cloning. There is a thriving biotech industry that will become involved in California and there is a wealth of scientific talent throughout the state university system. So California has pioneered the way. Now legislation is pending in New Jersey, where there is also a thriving pharmaceutical industry waiting to become involved. Similar legislation is pending in New York, Massachusetts, Ohio and Wisconsin.

We believe that with grass roots support, led by our coalition, with the help of politicians who are willing to listen and perhaps change their minds, we will be able to create momentum that the federal government will not be able to stop. Opinion polls have shown that 68% of the American public support all forms of reasonable research, including therapeutic cloning. So once again, this is what the people want.

I often wonder why it takes a direct emotional connection for our elected officials or prominent members of society before they are willing to help us. Back in the eighties Nancy Reagan was opposed to federal funding for AIDS research. Now her husband has Alzheimer's and deteriorated to the point where he doesn't even recognise her. Now Nancy Reagan is lobbying very actively for federal funding for stem cell research. Where was her compassion before? Why do most of the politicians who are sympathetic to our cause know somebody with cancer or Alzheimer's? Is it because Senator Harkin's nephew has a spinal cord injury that he cares so much? Is Senator Dodd an ally because of a long history of blood disease in his family?

We all belong to the *same* family. It's not so hard to do the one thing that will change everything: we just have to imagine, even for one thoughtful moment, what it is like to be somebody else. Thank you.