

**CONCURRENT SESSION F –
CARING PARTNERSHIPS**

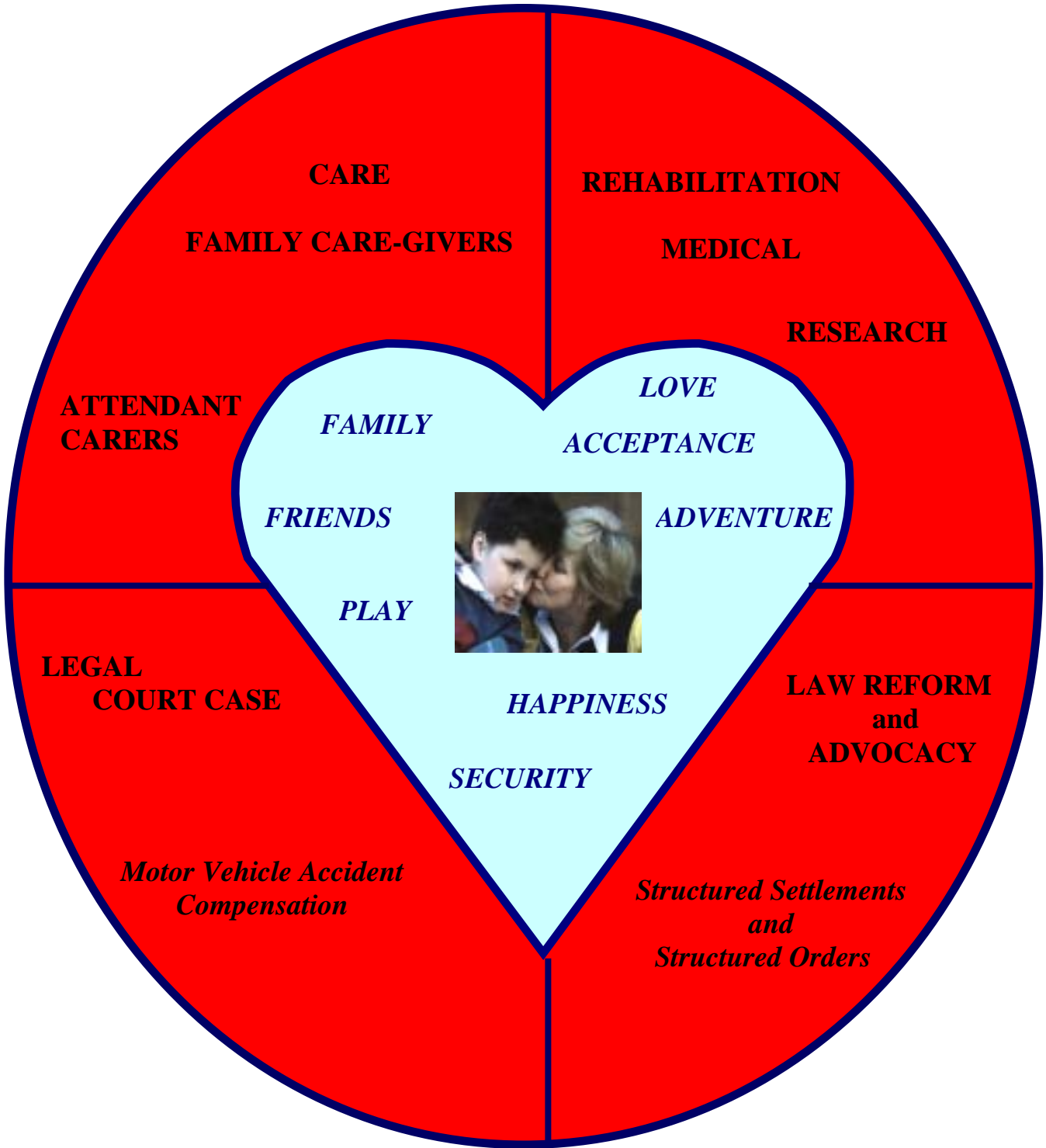
“ Jackson’s Love and Care while we await the Cure ”

**Presenter : Judie Stephens of Sydney
grandmother and carer
and law reform advocate of Dare to Do Australia www.daretodo.asn.au**

Some time ago, late November 1993 Judie Stephens who lives in Sydney was faced with the unthinkable. In a split moment, her life was changed forever. Judie’s daughter and son-in-law and three boys were involved in a motor vehicle accident. Both her daughter and son-in-law were killed. Jackson who was the youngest of the boys was three-months-old at the time and suffered extensive injuries. Jackson’s two older brothers recovered. Jackson’s two brothers now reside with their paternal grandparents. Jackson lives with his maternal grandmother who is Judie. Jackson has a closed head injury and is a high level quadriplegic with visual impairment. At the time of the accident, Judie was forty-nine years old when she and Jackson, as a three-month-old baby came together. This created a paradigm shift in her life. Jackson is now nine-years-old and thriving in a loving environment. Judie’s journey is not yet complete and she will tell you her story.

CARING PARTNERSHIPS

“JACKSON’S LOVE AND CARE WHILE WE AWAIT THE CURE”



“JACKSON’S *LOVE* AND *CARE* WHILE WE AWAIT THE *CURE*”

Presenter Judie Stephens

Maternal grandmother of Jackson Paul and law reform advocate

We are here today all seeking caring and healing connections. Everybody who is here in a wheelchair or who has a child or family member who has special needs all hope for healing connections. Hope because of stem cell therapy and other scientific discoveries that in ten years may ensure that we will all have the opportunity of further healing. Carefully contemplating this, I named my little presentation, ‘ Jackson’s *Love* and *Care* While We Await the *Cure*’.

Today a very special commitment was made. Our Premier Mr Bob Carr promised more funding for people with spinal cord injuries. The Motor Accident Authority of NSW has also committed three million dollars to ensure that those with spinal cord injury are given support in that very traumatic period between rehabilitation and settling back into their home following their injury. Thankyou. This great Forum will enhance our awareness about medical research and care. We will have the opportunity of international networking and new relationships. The focus is to support and educate us regarding care and medical science for those who have sustained spinal cord injury and conditions.

My grandson Jackson is the centre of my universe. You will see my illustration showing that a newborn baby would expect to have love and acceptance, supported by family and friends and other opportunities of happiness and security extending to play and adventure. In Australia, we would consider this our birthright. But an accident happened to Jackson when he was three-months-old that denied him the nurture and love of living with his parents and brothers, Matthew and David.

In my illustration the red section demonstrates the most unusual and unexpected journey. We have moved through these stressful and unknown areas, often on a daily basis and sometimes in very unacceptable ways. However, within even the most traumatic situations, we have forged caring partnerships. Partnerships with family, friends, Jackson’s attendant carers, rehabilitation, medical and research experts. Also successful relationships and friendships have been found with our State and Federal politicians. Indeed some most inspirational people you meet by chance along life’s journey. Say “hi” to the person beside you, this could be your chance!

CARE, FAMILY CARE-GIVERS & ATTENDANT CARERS

Let us start with the family care-givers. Our family, friends and Jackson’s attendant carers all love and hold a place for Jackson in their hearts. Jackson is our teacher. We give him the love and care he needs while we await the cure. This isn’t a promise but I have faith in medical science and indeed, that is why so many of us are here at this Forum.

Peter Stephens, Jackson’s maternal grandfather is his best buddy. They attend scouts weekly and Poppy Stephens comes to stay with Jackson often. Jackson awaits his daily phone calls, which are a real highlight in Jackson’s life.

My closest school friend, Foxie, tragically died of cancer. Foxie had promised that she would help me bring up Jackson. My long-time friend, Christine Bull, gently guides me, believes in me and

supports me when I am in troubled waters. They have both shown me the immeasurable value of friendship.

When Jackson was barely two, his attendant carer, Cathy Murphy came into our lives. She is a Registered Nurse. Cathy is part of our extended family and most valuable in Jackson's life. She bridges the gap between our attendant carers and Jackson.

Then the 'Caring People' company came into our lives. When Jackson was one-year-old, I could not find the right care company. So I spoke to a friend of mine Sandra Chiles who owns an employment agency. I said, "Can you help me?" Sandra said, "We will work together to provide Jackson with quality carers". Sandra and Cathy have worked consistently and effectively to provide Jackson with a dedicated attendant care team. The team have been with us from one to seven years. Jackson's day-to-day care is successful and it is because of the caring partnerships between the 'Caring People' Company, our attendant caring team, Jackson and myself.

REHABILITATION, MEDICAL & RESEARCH

Jackson came home from hospital with me when he was three-months-old on Friday 13 May 1994 with no plans and no future. I simply had a belief that this terrible injury would disappear. In spite of Jackson's catastrophic injuries, I visualize Jackson healed, complete, and lacking in nothing. I realise it is a long rehabilitation process to complete this vision. Jackson came home as a lovely baby and grew into a most beautiful child who needs nurture, love and acceptance. We focus on what he can do.

The first caring medical partnership was Dr Ric Dunstan, Jackson's Specialist Pediatrician. Over nine-years of meetings, research and debate, Dr Dunstan has delivered, allowing me to hold my dreams for Jackson and supporting him with best medical practice. Jackson has had five shunt operations, one hip operation and he is medicated for epilepsy. With this aside, Jackson is a most healthy, strong and happy little individual.

LEGAL : JACKSON'S COURT CASE

Jackson's Compensation Court Case in the Supreme Court will commence in March this year. This is a challenge that I am very concerned about. I dread going to Court. When Jackson was two, I collapsed and Jackson needed continuing twenty-four care in our home. It was Jackson's barrister, Paul Jones who listened and supported us in our lobby on television. 'A Current Affair' with Mike Munro assisted others and encouraged the Motor Accidents Authority to provide professional attendant care for people badly injured like Jackson. This became a reality, thanks to David Bowen the General Manager of NSW Motor Accidents Authority, in 1998 legislation. People now who are catastrophically injured will have adequate professional care paid by the Defendant or Insurer until their Court Case is heard. A court settlement may take up to a decade from the time of accident. This caring partnership with David Bowen then moved onto a new challenge, with the Structured Settlement Group. Our law reform lobby was for Structured Settlements and Structured Orders. This law reform advocacy has been very close to my heart.

STRUCTURED SETTLEMENTS & STRUCTURED ORDERS

Can you imagine someone who has been catastrophically injured receiving a lump sum and being expected to manage it competently for the rest of their lives? Indeed, some people are totally capable but others are extremely vulnerable and need to be protected. Thanks to our Federal Parliament a solution has evolved in the form of Structured Settlements and Structured Orders.

Structured Settlements are available when a Plaintiff and Defendant both agree on settlement. However on occasions when a Plaintiff and Defendant cannot agree on settlement or a Structured Settlement in Court then a Judge may make a Structured Order. These Structures are in the form of an indexed life-time annuity to pay for care, rehabilitation and medical needs. So as a result we have an extremely secure and viable solution for our compensable injured people who wish to have life-long security.

What did our Government achieve? They removed taxation on Structured Settlements and Structured Orders. This is a great initiative and encourages injured people to look at their long-term security. Indeed, a win for Plaintiff, a win for Defendant and a win for Australian taxpayers who now don't have to support our compensable victims with health and social security benefits.

A few years later, I started looking beyond the day-to-day care and wondering how people like Jackson, who would receive compensation, could manage their affairs for the rest of their lives. After all, I am now fifty-eight and Jackson is only nine. The big issue really is – what happens when I am no longer here? That's the enormous concern facing so many people who manage the affairs of those who are differently abled.

So I looked at the alternatives that are available both in NSW and other States and, quite frankly, was far from impressed. In fact, I began to see how big this whole issue is, particularly when I started becoming aware of what was happening all around us. You only need to look at the case of Jon Blake and you may recall millions of dollars wasted on litigation to remove the Office of the Protective Commissioner. His Mum's terrible plight with the Office of Protective Commissioner took years to come to the satisfactory judgement when the Supreme Court Order allowed Mrs Blake to find an appropriate Trustee of her choice. Regularly the media relates sad stories of mismanaged, lost or stolen compensation; injured people and their families subsequently being stripped of their dignity. It's a major issue, so scary for so many.

Our situation has been similarly caught up in this type of challenge, a challenge which produced continuing aggravation and unnecessary hardship. Let me explain. In September 1997, the Office of the Protective Commissioner NSW was appointed as Jackson's Financial Manager. I had visited the Protective Commissioner and was told that they would manage Jackson's parents' estate in conjunction with me. But I was completely duped. Since their appointment, it would appear to me they do not have Jackson's care and financial needs at heart, as their promises have not been fulfilled. Considering our predicament, I gave time to research solutions. Something had to change. And my great discovery was that Structured Settlements are available in the UK, Canada and USA. So the journey to make the changes began...

There were many visits and consultations with the Structured Settlement Group and meetings with my friend Danna Vale MP, Minister for Veterans' Affairs and Rod Kemp, then Assistant Treasurer. There were informal discussions with Peter Costello, Treasurer. I also met with the Prime Minister's Department and worked closely with the Assistant Treasurer's Office over the years. The current medical and public liability crisis has helped the passage of Structured Settlements and Structured Orders.

You may like to look at our evolving community website www.daretodo.asn.au where we share our story of Jackson's rehabilitation and legal journey in the hope that it will assist others. The legal feature illustrates our law reform advocacy for Structured Settlements.

From a Plaintiff's perspective, Structured Settlements and Structured Orders make great sense. The Defendant Insurer knows that the settlement money is focussed on the injured person's needs. The Judge no longer has the terrible task of having to put a 'use-by' date onto the Plaintiff's life.

It was great news on 6 June 2002 when our Assistant Treasurer, Helen Coonan introduced the Structured Settlements and Structured Orders Bill in Parliament. We know that our Government is very focussed on helping those injured and vulnerable in our society. Helen listened with great compassion and understanding when we met in Canberra. On Tuesday 10 December 2002, legislation reached its final stage and passed through the Federal House of Representatives. On Thursday 19 December 2002, Structured Settlements and Structured Orders legislation was given Royal Assent. The Federal legislation is complete. It is now vital that each State and Territory amends their Common Law legislation to ensure that Structured Settlements and Structured Orders are available to injured people as soon as possible. In 2003, my professional focus will be to ensure this happens quickly. Our NSW Premier Mr Bob Carr is to be complimented for his vision and he has ensured that Structured Settlements are available in the NSW Motor Accidents Act.

Thanks to Premier Bob Carr for his ongoing support. Also David Bowen of the Motor Accidents Authority in Sydney who has already made provisions for Structured Settlements in NSW. However, Structured Orders have yet to receive the NSW Parliamentary seal and this should happen as soon as the State election is completed in March 2003.

To summarise, what do Structured Settlements and Structured Orders mean for people like us:

- They mean that our years of being under scrutiny, of living in a goldfish bowl, have come to an end and we can now get on with the business of living.
- They mean that Jackson's financial future is now assured, and that his financial wellbeing will no longer depend on the vagaries, abilities, knowledge, motives, lifespan or integrity of anyone. This year, Jackson will receive a Structured Settlement or Structured Order when his compensation court case is heard.
- They mean certainty and security, elements that will allow us to concentrate solely on improving Jackson's potential for recovery and continually improving his quality of life, education, rehabilitation and medical needs.
- They mean transparency. We now know what we are dealing with; we will be able to budget for all Jackson's future needs and indeed move forward.
- And all of that adds up to focus, hope, and the ability to celebrate life and what it has to offer.

It is people like Jackson who give us inspiration to move boundaries to dare to make a difference. So now I am asking you to consider: Do you know someone who will benefit from a Structured Settlement or Structured Order? We certainly do! Indeed, another "Caring Connection".

With all the good things that have happened, it is thanks to the support of our caring partnerships. Many of us here have sustained injuries or health problems that have caused great challenge. We need to hold our dream and always consider the importance of caring partnerships along our journey.

Judie Stephens
Sydney, January 2003

Dare to Do Australia website ... www.daretodo.asn.au