



Early Intervention Impossible for Spinal Cord Injured People in Remote and Regional Australia

Spinal Network Expert Meeting

April 7 2017

Billabong Room, Novotel Darwin CBD, 100 The Esplanade, Darwin NT 0800

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1. Abbreviations

ANZSCoS	Australian and New Zealand Spinal Cord Society
CARPA	Community, Ambulatory, Rehabilitation, Population and Allied Health - A Directorate of the SCHN
CoS	Continuity of Support
HCP	Health Care Professional
NDIS	National Disability Insurance Scheme
NT	Northern Territory
Qld	Queensland
SA	South Australia
SCI	Spinal cord injury

2. Summary

The Spinal Network Expert Meeting held in Darwin on 7 April 2017 was an initiative of the Spinal Network and partly funded by the Northern Territory Motor Accidents Compensation Commission and Keep Moving. Participants included clinicians from the spinal unit in Adelaide, representatives from the Department of Health in NT, community groups, paramedics and emergency, and remote medicine specialists.

The Expert Meeting was conceptualised as a strategic activity to facilitate discussions on early intervention for people suffering a SCI in remote and regional Australia and to continue the discussion on the difficulties encountered treating acute spinal cord injuries and providing subsequent follow up services in Central and Northern Australia.

The meeting was commenced by a foreword of Chris Bertinshaw, CEO of the Spinal Network. The introduction included an outline of the objectives of the Spinal Network and what the Spinal Network hoped to achieve with organising this meeting. To initiate discussions, the group was provided with two hypotheses:

- I. People who suffer a SCI in remote and regional Australia end up with the poorest functional outcomes due to the time it takes to get to a spinal cord unit.
- II. People living with a SCI in regional or remote Australia have less medical follow up and poorer health outcomes due to the difficulty in attending outpatient clinics.

The attendees were encouraged to identify issues, possible solutions and future actions points for both hypotheses. The following three hours, the group discussed numerous issues encountered by those involved in treating people with SCI in NT. Identified problems covered areas such as; staffing, community differences, the lack of a clear overall picture of the problem, outdated and incomplete guidelines and the rollout of the NDIS. While discussing the issues, the group also identified possible solutions and suggested areas of improvement.

3. Introduction

The Spinal Network was set up in 2008 and its whole objective is to coordinate everybody working in, caring for and researching for and trying to improve the lives of people with spinal cord injury (SCI) - to communicate, collaborate and connect the community. Our members are each of the spinal units around Australia and New Zealand, most of the universities that do research into SCI, clinicians, all sorts of people who get involved in supporting people with SCI. What we are trying to do is connect and make it possible for people to improve things. We presently have four clinical trials running, all of which are related to the acute setting, so doing something in the first number of hours that someone has a SCI, trying to reduce the secondary complications that may arise with SCI.

That's primarily because of two things:

1. We have some data relating to that period of time.
2. Because we have a patient in our hands and we do something with them.

After patients with acute SCI leave rehab, they tend to be 'lost' to the system. One of the things that the Spinal Network is trying to do is to establish a whole-of-life registry where we actually get data from everybody but SCI in Australia, throughout their lifetime, to see how people age and what might be happening to them and how we can improve their lives that way.

The Spinal Network aims to get a better insight of some of the issues faced by those affected by SCI and those involved in the care of people with SCI. This meeting was initiated to achieve this aim and used the principles of validated learning - listening to stakeholders in the system to hear what works for them and what does not.

4. Approaches

The Expert Meeting was advertised by the Spinal Network in their monthly newsletter, inviting anybody with an interest in the field to attend. The following people received a personal invite:

- ◆ Professor Ruth Marshall, Director, SA Spinal Cord Injury Service
- ◆ Peter Stewart, CEO, ParaQuad SA
- ◆ The Hon Greg Hunt, Australian Minister for Health
- ◆ The Hon Ken Wyatt AM, Australian Minister for Indigenous Health
- ◆ The Hon Nigel Scullion, Senator for NT, Minister for Indigenous Affairs
- ◆ The Hon Natasha Fyles, NT Minister for Health
- ◆ Aboriginal Medical Services Alliance NT

A total of 56 people registered to attend the meeting either face-to-face or by telecom. In the end the meeting was attended in person by 39 people (list of attendees section 7).

The meeting was commenced by a foreword of Chris Bertinshaw, CEO of the Spinal Network and lasted 2 ½ hours. The introduction included an outline of the objectives of the Spinal Network and what the Spinal Network hoped to achieve with organising this meeting. To initiate discussions, the group was provided with two hypotheses:

- I. People who suffer a SCI in remote and regional Australia end up with the poorest functional outcomes due to the time it takes to get to a spinal cord unit.
- II. People living with a SCI in regional or remote Australia have less medical follow up and poorer health outcomes due to the difficulty in attending outpatient clinics.

5. Outcomes

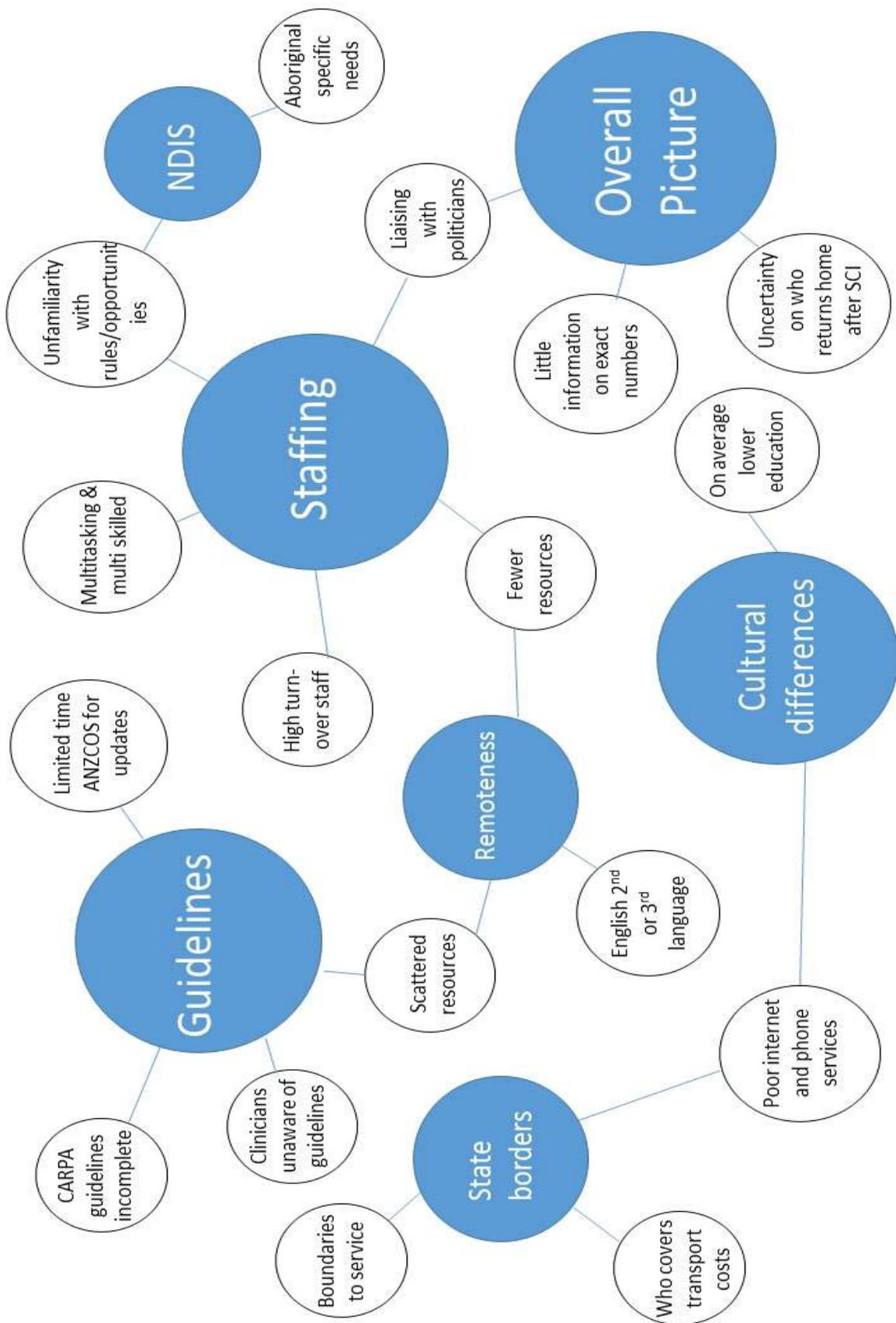
The attendees identified several issues when treating/caring for people with SCI in remote areas of Australia. The issues identified were placed under 1 of 7 main topics:

1. Lack of a clear overall picture
2. Issues surrounding staffing
3. Guidelines and information resources
4. Cultural differences
5. NDIS
6. Remoteness
7. State borders.

5.1 Lack of a clear overall picture

One of the first problems raised by the group was the lack of a clear overall picture. Without accurate data, those working in the field often have to work with assumptions. The knowledge of exactly how many people are affected each year by acute SCI in remote areas and how many with chronic SCI who are living in remote areas will give a better understanding of the size of the problem in caring for those affected by SCI. There is not only a need for accurate data recording, but also a more complete set of data. Data on where accidents happen, patient transport times, time to surgery, place of surgery, data on who returns to live in remote areas and what services are frequently used. Having a clearer picture will assist with identifying areas of need, point out areas where resources are best spent and help politicians understand the scope of the problem.

Prof Ruth Marshall offered to share some of the available data currently available with the other attendees. Kylie Wicks also offered to share some of the data she presented at last year's ANZSCoS meeting in Adelaide. Sharing of information and putting the data together can present a possible way of getting a clearer picture of treatment and care of acute and chronic SCI in remote NT.



5.2 Issues surrounding staffing

Staffing issues covered a wide range of issues, from staff shortages, to high turn-over of staff, to the need for multi-tasking of those working in remote areas.

One of the first problems identified was the fact that the Royal Darwin Hospital does not have a spinal surgeon and patients with acute SCI are transported to alternative hospitals to receive spinal surgery, most frequently the Spinal Unit at Royal Adelaide Hospital. Research has shown that early treatment has effects on the outcome. Attendees pointed out that as a result of not having a spinal surgeon in Darwin there is a significant delay in getting these patients operated on. Additionally, emergency physicians in Darwin were often focused on getting the patient stabilised and this further delayed the transporting of this patient to a hospital where spinal surgery could take place.

The care of a person with SCI in urban areas is performed by a team of carers, each would focus on their specialty. In remote areas carers are more likely to be expected to play a number of different roles within the care team. This places a lot of responsibility on the one person and also requires this person to be well informed and knowledgeable about several areas. Other issues regarding staffing included the lack of experts in remote areas.

The group offered some solutions, some of which were more feasible than others. Solutions included presenting a case to the NT government for the need for a spinal surgeon in Darwin. To be able to present a solid case, the report would need clear numbers on how many people are affected by SCI each year, what sort of delays these patients experience and how much delay could have been avoided by having a spinal surgeon in Darwin.

Looking at how other chronic diseases are approaching healthcare in remote areas can provide some answers regarding staffing. Some remote health care teams have been shown great progress in care for patients with chronic disease.

One attendee presented the need for engaging with the local people and businesses and getting them involved with some of the elements of care for people with SCI. Locals have not only a good understanding of the local community and are likely to be involved long-term, they can potentially benefit from being involved themselves. In reaction to this the attendee mentioned that it would be of great benefit to have HCPs of aboriginal origin.

5.3 Guidelines

A second issue raised during the meeting was the lack of good guidelines. Some attendees mentioned that there are guidelines available but they are very scattered. One commonly used set of guidelines is the CARPA Standard Practice Manual (involved in primary health care education, training and support of rural and remote health practitioners of various specialities and experience levels). A quick look at the guidelines during the meeting revealed the lack of any information on non-traumatic SCI. Another problem surrounding the CARPA guidelines is that clinicians are often unaware of their content or even existence. Large scientific meetings such as ANZSCoS often only dedicate a few hours to issues regarding care for acute and chronic SCI in remote areas. Scientific meetings can provide a great platform for making clinicians more aware of guidelines such as CARPA and update them on any changes and additions.

The group agreed that there was a need to review these guidelines for content and update if needed. However, an effort should be made that this document would subsequently be shared with relevant people, especially those working in the field of SCI. A positive example is the Machado Joseph Disease Foundation. This foundation is supporting project officers who are working with all HCPs in developing protocols and updating guidelines including the CARPA guidelines.

The CARPA guidelines were not the only source of information identified by the group as in need of updating. Patient information brochures, information on living with SCI and relevant organisations need updating and also stored centrally. A representative of the Australian Spinal Injury Alliance indicated they are keen to work with the Spinal Network on presenting and sharing information on treatment and care of SCI in remote areas.

Another solution offered by the group was the set-up of a centralised Helpline which people can call not only for questions related to care but also daily living questions. A central phone number can also provide support for those working with people living with SCI and can possibly be a solution for some of the staffing issues (described previously). Again, looking at other chronic disease models can give a great insight on how best to share information and distribute this among those interested.

5.4 Cultural differences

Cultural differences are a problem in treating and caring for people living with SCI both in remote areas and urban areas. A large proportion of those living in remote Australia have English as their second (or third) language. Additionally, those living in remote areas are more likely to come from lower socio-economic background with limited education. As a result they often struggle with medical jargon and understanding the health care system and what it has to offer. Because they are often economically disadvantaged they often do not have the means to pay for all services required in the care of someone living with SCI.

To better understand the issues and needs of certain communities in remote Australia, especially the NT, one of the attendees stated the need to give these communities a “voice”, make time and effort to listen to them and understand what they perceive as issues surrounding SCI in remote NT. They might also be able to provide possible solutions to some of the problems and might have a preference as to who should provide those solutions.

A great initiative in the NT is the community event Walking Wheel BBQ. Events bring together people living with SCI and allows people to share stories, advice and encouragement. Those who have lived for some time with SCI are often a great source of information for those newly affected by SCI.

One attendee discussed the importance of a book titled “The Story”. This book was a great source of information for indigenous people who recently suffered a SCI. However it is no longer in print due to sensitive information on some of the people featured in the book. It was agreed that it would be worth looking into possibly re-writing this book and publishing it again.

5.5 NDIS

NDIS is aiming to provide a better assistance to people living with SCI, however its roll out has provided a whole new range of issues for those working and living with SCI. As the NDIS has only been rolled out recently, a lot of elements are new and not often fully understood. Even HCPs working within the field are not always fully familiar with all rules and opportunities.

A person who coordinates supports under the NDIS falls under the NDIA's registration cluster of Support Coordination*. Ideally an individual would be identified in understanding and subsequently have information on the NDIS and what it means for those with SCI in NT and what it can offer. A support coordinator in the NT could take a leading role in identifying services for people with SCI in NT. One attendee argued that the NDIS and its implications are different again for Aboriginal people and that this would require special attention, ideally, there would also be an indigenous support coordinator in SCI requirements.

- * Not to be confused with CoS (continuity of Support), which relates to the transition into the NDIS of people over the age of 65 who are already receiving state funding.

5.6 Remoteness

An obvious problem faced by those living in NT is remoteness. This does not only mean long distances to travel (including health care services) and limited resources. Remoteness is often associated with other practical issues such as poor internet connections and limited availability of phone services.

Additionally, demographics of those living in remote areas are significantly different. Levels of education are different to those living in suburban areas and therefore the understanding of the Healthcare system and medical jargon is limited. Remoteness itself cannot be solved, the group offered ways of overcoming some of the issues. One possible solution offered by the group which has been receiving a lot of attention in Health Care is eHealth/Telehealth.

However, eHealth/TeleHealth can only be a solution if the correct infrastructure is in place. There is limited value for a centralised phone number if it cannot be reached from large parts of the NT. Discussions with those living with SCI in the NT can provide a clearer picture on what can be done and what would not work simply because of a lack of infrastructure.

Remoteness is obviously not only affecting those living with SCI. There are many people living with chronic disease in remote areas facing similar problems. For example, people living with chronic kidney disease who require frequent dialysis are likely to face similar problems with accessing health care facilities. Looking at some of the health care models used in chronic kidney disease and other chronic diseases can offer into possible solutions.

5.7 State borders

Problems associated with state borders were briefly mentioned during the meeting however this issue goes beyond the scope of this meeting. State border issues do possible affect possible solutions that were brought forward by some of the attendees. This highlights the need to investigate the situations in other states. Examples from remote areas in Queensland were mentioned on numerous occasions.

6. Way forward

Representatives from all areas covering the care and treatment of SCI in remote areas convened to discuss issues and possible solution surrounding SCI in NT. As a half day meeting, the discussion and recommendations are necessarily limited in scope, and should be seen as exploratory rather than definitive. Nevertheless, several important action points came out of it.

Those working in the field on SCI can possibly learn from working with representatives from other chronic disease who facing similar problems. HCPs assisting people with chronic kidney disease and heart failure had to develop care models which would allow them to maximise resources and provide optimal treatment. These models can possibly provide a platform for health care of SCI. Additionally, Prof James Middleton has recently published a description of the development of a new model of care for the management and support of children and adults with SCI in NSW. Engaging Prof Middleton in the discussion regarding treatment and care in remote areas can provide great new insights and possible solutions for some of the identified issues.

This meeting provided a great platform to discuss issues and possible solutions, however ideally similar meetings occur on a more frequent basis, allowing more issues to be discussed however more importantly it can allow for possible solutions to be explored. Having a quarterly meeting where either people attend or are able to dial in would be a great starting point. One attendee expressed the need for having a focus group like meeting with aboriginal people affected by SCI and allowing them to express their experiences with dealing with SCI. Another option for a meeting is having a similar meeting as this meeting but in remote Qld. This meeting would allow the identifications of similar problems but more importantly the identification of solutions. An example provided by one of the attendees was the way they handled the roll-out of the NDIS in Qld.

7. List of attendees

	Kylie Adams	
	Sam Bennett (b/- Michael Toomey)	Royal Flying Doctor Service
	Chris Bertinshaw	CEO, Spinal Network
	Kate Biven	
	Erica Bleakley	
	Robyne Burridge	Integrated Disability Action
	Brayden Callander	NT Motor Accidents Compensation Commission
	Leah Campbell	Spinal Network
APOLOGY	Ian Campbell	Office of Disability
	Professor Alan Cass	Director, Menzies School of Health Research
	Dr Gavin Chin	Director, Rehabilitation (Darwin and Alice Springs)
	Kim Clayworth	Office of Disability
	Andrew Congdon	Seating Equipment & Technical Service Darwin
	Jacqui Cornell	Jacqui Cornell
	Cameron Croker	Keep Moving
	Annie Davis	
	Marilou Dellow	
ABSENT	Dr Pooja Digra	
	Shelley Evans	
	Iain Evans	Spinal Network
	Dave Eves	Keep Moving
	Kim Faehse	Occupational Therapist
	Dr Vinay Gangathimmaiah	LifeFlight Australia
ABSENT	Paul Gerken	
	Vicki Gordon	Aboriginal Medical Services Alliance NT and Alice Springs
	Shiqin Guo	
ABSENT	Elisha Hamilton	
	Dr Sass Hayes	Queensland Health
	Felicity Head	
	Jan Hercus	SCI Nurse Top End
	Tegwen Howell	Emergency Medicine Foundation
	Eloise James	
	Anthony Liu	NT Motor Accidents Compensation Commission
	Heather Malcolm	Coordinator, Rehabilitation Network and Cancer Network
	Professor Ruth Marshall	Director, South Australia Spinal Cord Injury Service
	Anija Mathew	
	Juvy McPhee	
	Sharron Neeson,	ParaQuad South Australia
	Frances Porter	Spinal Life Australia
	Lorraine Sager	
APOLOGY	Katherine Saxton	Office of Disability
	Dr Iyngaranathan Selvaratnam	Danila Dilba Health Service (Aboriginal Medical Service Darwin)
ABSENT	Dr Sindhoora Shetty	
APOLOGY	Tony South	PBF Australia
	Denys Spencer	
	Peter Stewart	CEO, ParaQuad South Australia
	Julia Swenson	NT Therapy Solutions
ABSENT	Dr Karthik Thangaraj	
ABSENT	Patrick Tshuma	
	Kylie Wicks	ParaQuad Northern Territory
APOLOGY	Glen Woods	Office of Disability