

Advocacy Position Statement

Research

What we believe:

- Spinal Life Australia understands the importance of and supports the latest medical and social research aiming to improve the lives of people with spinal cord damage, their carers, and families.
- It is important to improve our understanding of barriers to full participation in society for those with spinal cord damage.
- Spinal Life Australia, while recognising there is no cure for spinal cord damage, supports research into enhanced treatments and future possible cures for spinal cord damage.
- The provision of high quality services that work with individuals now and every day to improve their lives can also be improved through research.

The current situation:

- There are many organisations undertaking research into people with spinal cord damage, their connections to the community and their lived experience.
- Spinal Life Australia supports research and treatment with strong ethical standards, proven through randomised controlled trials, and is undertaken in an environment that is tightly controlled and regulated to ensure accuracy of results and reporting.
- There are many organisations conducting research into the medical and societal aspects of people with spinal cord injury, and Spinal Life Australia will work closely with suitably qualified and experienced organisations for the benefits of our members and the wider spinal cord damage community.
- Stem cell therapy uses stem cells to treat and prevent conditions. For some conditions stem cell treatment has been used safely and successfully for years, while other treatments are experimental and the outcomes and effects unknown. Stem cell treatments currently available and promoted for spinal cord injury treatment lack evidence of effectiveness and safety.



Spinal Life Australia will:

- Work to identify opportunities for Spinal Life Australia, its members, and clients to participate in research will be considered in a holistic manner, to ensure that the research is:
 - Scientific – part of a reputable scientific organisation, well documented, well-resourced, and well structured, with the aims of being written for other scientists to learn from
 - Relevant – research will be aligned with topics, themes, and situations that people with spinal cord damage think are important and valuable, and will link directly to improving lives for people with spinal cord damage, rather than for purely scientific purposes.
 - Transferable – research findings will be shared, and will be able to be transferred to other areas, other cohorts, and other organisations to support people with spinal cord damage to live a more enjoyable, independent, and connected life.
 - Leading Edge/Best practice – research will not be re-iterating past research, and will be based on existing evidence where possible.
- Advocate to the Australian Government and private enterprise to encourage new research and continued promising research to be incentivised.
- Continue to apply for and partner with other organisations to apply for funding to enable the delivery of and/or participation in contemporary research opportunities for the benefit of our members and the wider community of people with spinal cord damage.