


Ageing well? Lived experience perspectives of ageing with spinal cord injury

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Background



Spinal cord injury (SCI) is a catastrophic injury

People are living longer with SCI

More people are sustaining SCI later in life

= Number of people ageing with SCI is increasing¹

Ageing with SCI, or SCI with ageing?

How is the experience of ageing different for those who sustain their injury > 65 , compared to those that sustain their injury < 65 ?

Aim and Methods



Aim

To explore the lived experience of ageing with SCI, including challenges and supports required to age well, to guide policy, education, and resources for clinical practice



Methods

- National interview study (online) guided by Consumer Advisory Panel
- Recruitment
 - people with SCI + carers
 - snowballing (n=33)
- Data analysis
 - interviews analysed using thematic analysis

Results and Discussion - Participants

Participant	n	Gender (M)	Rural/ regional/ metro (n)
Person with SCI < 65	22	16/ 22	4/ 11/ 7
Person with SCI > 65	5	4/ 5	1/ 3/ 1
Carer* of person with SCI sustained < 65	3	0/ 3	0/ 1/ 2
Carer* of person with SCI sustained > 65	3	1/ 2	1/ 2/ 0

* Carers and people with lived experienced are not all dyads

Main Themes

SCI < 65

- Meaningful participation

SCI > 65

- Funding
- Residential aged care
- Carer role

Common themes:

- What does ageing look like?
- Challenges
- Supports

Case study 1: Jack aged 68 – sustained SCI at 19

- Incomplete quadriplegic
- Previously completely independent post-rehab
 - Working full-time
 - Participating in sport
 - Married
 - Self-funded
- Late 40's/early 50's functional decline
 - Requiring care and equipment
 - Early retirement
 - Currently uses power wheelchair, requires 12 hours of care/day
 - Government funding for disability
 - Maintained participation

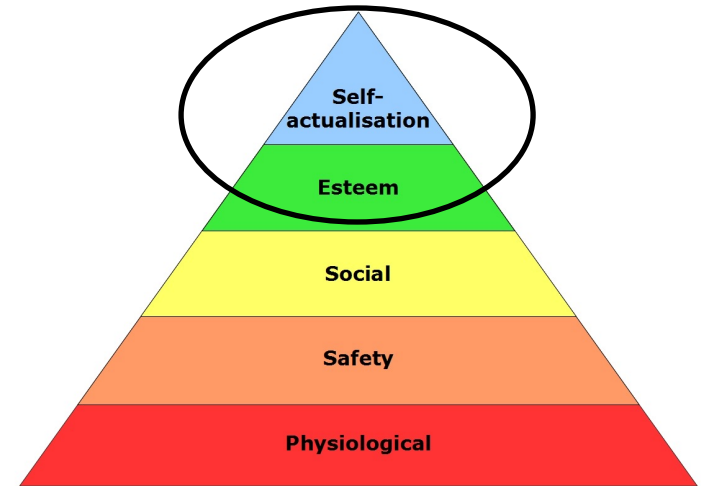


Image retrieved from: <https://lucidea.com/blog/understanding-and-applying-maslows-hierarchy-of-needs-in-special-libraries/>

Key theme - SCI sustained below 65

- **Participation in meaningful activity**

My life has been sport....I haven't stopped all competitive sport... I've just found Pickle Ball...

LEB12 – SCI <65

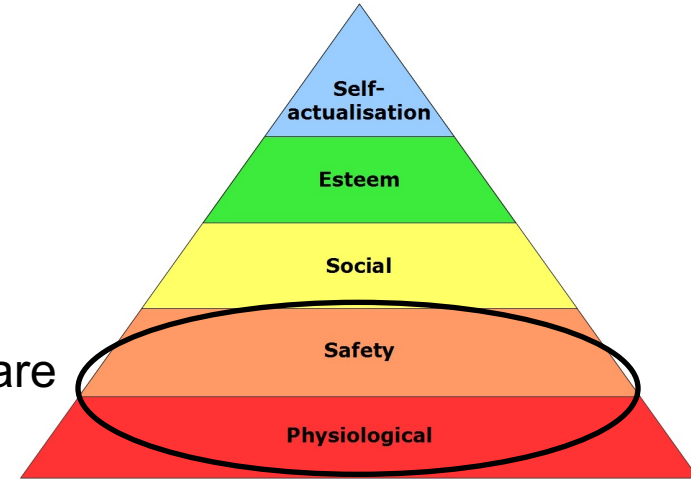
So I'm sort of moving from the doing lots and lots of service stuff to joy stuff.

CAP4 – SCI <65

....last year Jack climbed Australia's highest mountain to raise money to send athletes with a disability to the Paralympics

Case study 2: Mary aged 84 – sustained SCI at 71

- Incomplete quadriplegic
- Previously completely independent
 - Had run own business
 - Retired and was travelling the world
- Post-SCI
 - Fully dependent on care
 - Aged care funding, 12 hours/week of care
 - Supplements funding with retirement savings, but this will run out
 - Husband (86) provides extra care, but he is ageing too
 - Participation in community activities facilitated by husband



Key themes – SCI sustained above 65

I've had a real decline in my functionality... The fact that I'm unable to contribute a reasonable amount to my relationship. I don't want a carer. I want a wife.

CAP7 – SCI > 65

Carer role

Residential aged care

She was not eligible for the NDIS because she was over 65.... So we ended up with an Aged Care Package. The quality of care was horrible. I dropped from morning and evening, 7 days a week, to mornings only, 5 days a week, with one Sunday a month.

I'm getting tired, and particularly exercises to Mary... I'm giving the dinner... Then we eat dinner, then I massage Mary's hands... Then I pull her to bed, and it's just a bit of a drag... It's not easy.

LEA1 – SCI > 65

CAR5 – carer SCI > 65 CAR5 – carer SCI > 65

Inadequate funding Ageing carer

Common themes

What does ageing look like with SCI?

There's a lot of unintended cruelty
in the system..... I went to the
rehabilitation hospital... And they
when you (have) someone who has, you
just didn't want to know... they
know all about basic needs that
were all very into short-term
rehabilitation... Nobody had a
whole different years.....
clue about spinal...

LEEB12 - SCI < 65

LEA3 - SCI > 65

Supports to age well

Challenges to ageing well

Key recommendations – implications for practice

- More equitable funding for people who sustain their SCI >65
- Resources and information available on ageing with SCI
- Support for residential aged care and health professionals



Conclusions

- Compelling evidence that inequality exists for people ageing with SCI
- Occupational therapists should advocate and promote meaningful change to facilitate people with SCI to age well

Image retrieved from: <https://www.backuptrust.org.uk/news/busting-myths-about-ageing-with-a-spinal-cord-injury>



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