Needs of Stroke Survivors

What do Services Need to Consider
Summary

• First time look in detail of unmet needs of Stroke Survivors in Australia
• Six areas of everyday life (domains)
  – Health
  – Everyday living
  – Work
  – Leisure
  – Support
  – Finance
Methodology

• National Survey
• Stroke Survivor & Carers Needs Assessment Survey
• Recruited through hospitals, Australian Stroke Clinical Registry (AuSCR), StrokeConnect group
• Cross sectional and non randomised
Demographics

- 1152 participants
  - 765 survivors
  - 387 carers
- Mean age 68 years
- 62% respondents were male
- 14% born in non-English speaking countries
- 2% ATSI identified
- 66% reside in capital cities
- Representative geographical spread
- 12 Months Post Stroke
Health Needs

“As a result of my stroke I am often in a lot of pain and my brain is so overloaded I feel like I have narcolepsy.

People often can’t tell that I have a disability caused by stroke.

They have no idea how much energy and brain power it takes just to get through the day.” – Karen
Health

• Help with:
  • Improving mobility
  • Preventing falls
  • Managing continence
  • Treatment for pain
  • Managing swallowing difficulties
  • Problems with fatigue
  • Memory problems
  • Speech difficulties
  • Cognitive problems
  • Overcoming reading difficulties
  • Vision difficulties
  • Concentration problems
  • Emotional problems

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<td>With Need</td>
<td>93%</td>
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<tr>
<td>Need Unmet</td>
<td>84%</td>
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“I had good care in hospital, but once I left I felt like I was on my own.

My family and friends were there for me, but it was really difficult for me to ask for help because I felt like a burden.

Ongoing occupational therapy and physiotherapy are very expensive, even if you have private health.

Transport was also a really big issue for me. I automatically lost my licence because of my stroke, which meant I lost my independence.

It wasn’t easy getting it back.” Dennis
Everyday Living

- Help with
  - Personal Care
  - Home Care (external agencies)
  - Transport/Travel
  - Home adaptions

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“I am not able to work after my stroke in September last year.

Before this I was a very busy CEO working in health. I’d be checking emails whenever I could! For the first six months after my stroke I couldn’t multi-task.

I was unable to talk while doing something as simple as buttering toast.

My fatigue is also really intense. I find that two hours is the longest I can dedicate to a task; after that I need to close my eyes and close down the stimuli to my brain.” Suzanne
Work

- Hours of work/study changed
- Enough Support returning to work/study

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Leisure

- Changes in the number and type of activities

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“I didn’t know that the medication I was given after my stroke would make me aggressive.

Ask my wife and kids – I was not a nice person to be around! The smallest thing, like my wife parking the car where I didn’t want her to, would set me off.

Eventually I found a psychologist who was a big help. It’s so frustrating that my wife wasn’t told what to expect. It really made it hard for her.”  Bill
Support

- Relationship changes
- Sufficient emotional/psychosocial support

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<tr>
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<td>52%</td>
<td>56%</td>
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Financial Needs

“I couldn’t keep working as a high school teacher after my stroke at the age of 42.

It meant there was no money to pay my mortgage and I had to sell my house and car.

I lived in a rental property for a while which was expensive. After a lot of hassle I was able to access my superannuation and buy a unit.

I’ll have to rely on the disability pension for the rest of my life. It isn’t much when you have to pay for things like podiatrist visits and $200 for specialty shoes.” Janet
Financial

- Sufficient assistance
- Changes

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<tr>
<td>Need Unmet</td>
<td>37%</td>
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Results

• Health
  – Major issues with mobility and psychosocial’
  – Provided with good information on stroke but insufficient information regarding long terms recovery implications
• Transport
  – Half reported extreme change – major cause psychosocial
• Leisure/Work
  – Reported change was extreme
• Family
  – 57% reported stroke had a negative affect on their relationships
  – Shift from partner to carer
• Financial
  – Decrease in income but increase in expenses
• Geography
  – Those in major metro more likely to have unmet need
Unmet Need in NSW

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<td>Not fully Met</td>
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<td>51%</td>
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So what can we do in NSW to support the long term implications for Stroke Survivors and their carers, family and friends?