



strokefoundation

National Stroke Foundation

The needs of stroke
survivors in Australia

Stop stroke. Save lives. End suffering.
www.strokefoundation.com.au



About the National Stroke Foundation

The National Stroke Foundation is a national not-for-profit organisation that works with stroke survivors, carers, health professionals, government and the public to reduce the impact of stroke on the Australian community. Our mission is to stop stroke, save lives and end suffering. We are the voice of stroke in Australia.

We will achieve this by:

- Raising awareness about the risk factors and signs of stroke and promoting healthy lifestyles.
- Improving treatment for stroke to save lives and reduce disability.
- Improving life after stroke for stroke survivors.
- Encouraging and facilitating stroke research.
- Advocating for improved stroke prevention, treatment and support.
- Raising funds from the community, corporate sector and government to continue our mission.

Visit www.strokefoundation.com.au for more information.

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The National Stroke Foundation commissioned a survey of Australian stroke survivors to better understand personal needs relating to their stroke and how well these needs are being met. This report summarises the survey findings.¹

The results show widespread and varied need amongst stroke survivors with alarming proportions of unmet need.

Stroke strips away from survivors the ability to do things that most Australians take for granted. Unfortunately the health and welfare system is not working as it should to bridge this gap.

The needs reported here are those experienced by the 420,000 Australians living with stroke. Almost all of these people have needs in the community and for many of them, the needs are not met.

One-in-three survivors that need help around the house are going without. One-in-five who need adaptations to their home go without.

Almost three quarters of those that worked before their stroke reported an impact on their work activity. Alarmingly six-in-ten who need help returning to work did not get enough help.

Stroke survivors report that their needs change over time and that services and programs designed to support them are fragmented and difficult to access.

Many of them struggle due to disability that was often acquired unnecessarily because prevention and treatment was inadequate.

The degree to which their need is met varies across the country and across needs. This is due to variability in access to best practice care and demonstrates a clear need for national leadership and coordination.

These findings demonstrate that much more must be done to support stroke survivors in their recovery. Like all Australians they deserve to have their needs met by our government system and this is not currently happening.

Stroke in Australia

Stroke is a chronic condition which often requires ongoing support and management. In Australia, there are 50,000 strokes a year² and approximately 420,000 Australians are living after having had a stroke.² Nearly 90% of Australian stroke survivors live at home.³ Stroke is a leading cause of long-term adult disability in Australia and about 65% of survivors depend on others to help them with activities of everyday living.²

The Survey

This report² considers the needs of stroke survivors in the Australian community and the areas of greatest need. It outlines the results of a survey of 765 stroke survivors across Australia who had been living in the community for at least a year after their stroke.

The Survey included questions on the following factors:

- Health information and needs such as help with mobility, prevention of falls, bladder or bowel problems, treatment of pain, fatigue, emotional and concentration problems and speaking.
- Everyday living needs such as personal care, home help, additional aids, adaptations to home, transport and travel, getting back to driving and travelling on public transport.
- Work and leisure needs such as changes in hours or type of work or study since stroke and changes in leisure activities post-stroke.
- Family, friends and support needs such as changes in relationships with partner/ spouse
- Financial needs such as loss of income, increases in expenses, and advice on how to manage financially after stroke.

Overview of the extent to which stroke survivors needs were being met

Ninety-six percent of all stroke survivors reported having needs after their stroke. This equates to 403,000 Australians.

Of those that reported having needs, 84% had needs that were not fully met. This equates to 339,000 Australian stroke survivors who were living with unmet needs in the community after their stroke.

Health needs were least likely to be fully met, followed by leisure needs and work needs. For those with needs the median number of needs not fully met was four.

Survivors with needs not fully met as a proportion of those with needs in that area (N=765)

	Total with needs (%)	Need was not fully met (%)
Health	708 (93)	593 (84)
Everyday living	521 (68)	175 (34)
Work	171 (22)	102 (60)
Leisure	368 (48)	237 (64)
Support	420 (55)	218 (52)
Finance	301 (39)	113 (38)
All needs	730 (96)	611(84)

Health needs

The most common health problems reported by stroke survivors were mobility problems (74%) and ‘hidden’ problems such as fatigue (67%), emotional (59%), memory (59%) and concentration problems (59%).

Survivors with needs not fully met as a proportion of those with needs in that area (N=765)

	Total with needs (n, %)	Need was not fully met (n, %)
Mobility	555 (74)	255 (46)
Falls	491 (66)	226 (46)
Incontinence	378 (51)	196 (52)
Pain	408 (55)	221 (54)
Swallowing	302 (40)	132 (44)
Fatigue	499 (67)	375 (75)
Emotions	435 (59)	317 (73)
Concentration	431 (59)	338 (78)
Memory	433 (59)	332 (77)
Speech	382 (52)	223 (58)
Cognition	410 (55)	306 (75)
Reading	284 (38)	197 (69)
Vision	335 (46)	216 (64)

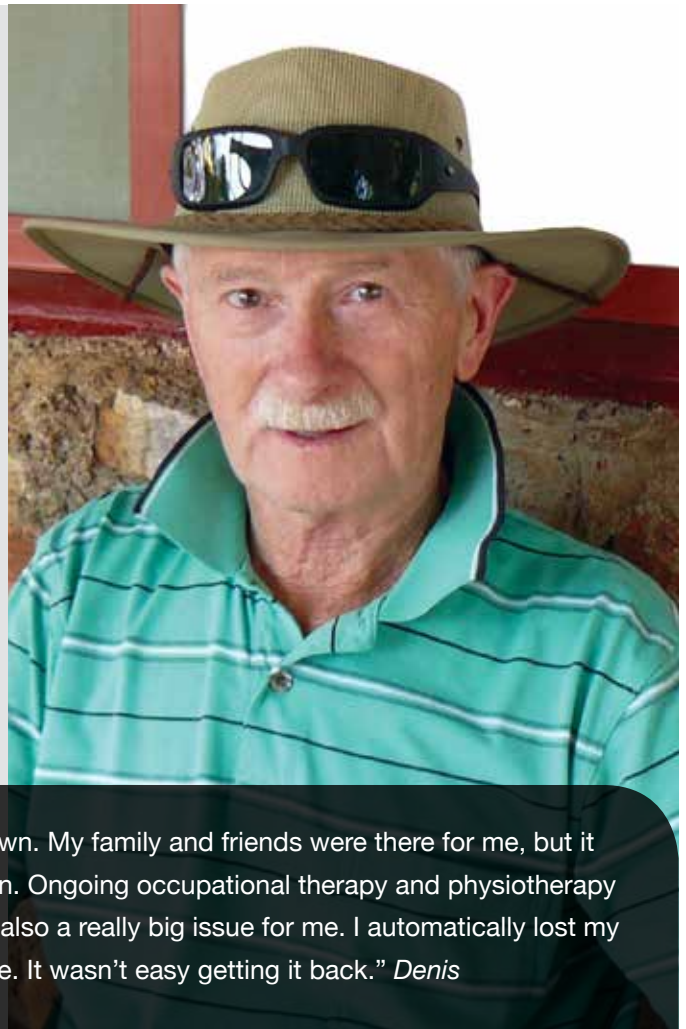


“As a result of my stroke I am often in a lot of pain and my brain is so overloaded I feel like I have narcolepsy. People often can’t tell that I have a disability caused by stroke. They have no idea how much energy and brain power it takes just to get through the day.” – Karen

Everyday living needs

About two thirds (68%) of survivors living in the community had needs associated with everyday living activities. Of these:

- 16% of those needing personal care reported that they were either not receiving enough or not receiving any help.
- 34% of the survivors that needed help around the house reported that they were either not receiving any help or not receiving enough help.
- 19% of those who needed adaptations around their home reported not having enough or any adaptations made.
- Transport use had changed for 60% of survivors with almost half (44%) reporting these are moderate to extreme. Of those that reported a change, the most common were physical reasons (57%), emotional reasons (11%), or physical and emotional reasons (24%).



“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.” *Denis*

Work and leisure

- Of the stroke survivors who were working prior to their stroke about three quarters (71%) reported a change in their work activities since their stroke. Over half (57%) reported that the change was moderate to extreme.
- Of those that needed help returning to work, 60% reported that they did not receive any or enough help returning to work.
- Almost 80% of survivors reported that their leisure activities had changed since their stroke. Over half (53%) reported that this change was moderate to extreme.
- Of the survivors that needed assistance returning to leisure activities, 64% reported that they did not receive enough help returning to leisure activities



“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*

Needs around support and relationships

- Over half (57%) of those survivors with a partner or a spouse reported that their stroke had a negative impact on their relationship.
- Almost half (43%) reported that their relationship with family members had changed since their stroke and 51% reported a change in relationships with people other than family.
- Almost two thirds (61%) of survivors felt that they needed “external” emotional support, outside of family and friends. Of these 52% reported that they were either not getting enough or not getting any external support.



“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*

Financial needs

- Over one third (36%) of respondents reported a loss in income since having their stroke.
- Almost two in three (60%) reported experiencing an increase in expenses.
- Less than half (48%) were receiving some form of benefit. Of those survivors who did not receive benefits, a third were not eligible or did not need benefits, one in ten were not receiving benefits but felt that they should be or didn’t know why they weren’t, and 3% were not receiving benefits because they found the system too difficult to negotiate.
- Almost half (42%) reported needing some form of financial assistance or advice.
- About a third of those who needed financial assistance reported that they either did not receive any or did not receive enough.



“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*

Variation in unmet needs across Australia

Level of unmet need varied between states.

- Survivors in Queensland (90%) and Western Australia (88%) reported the greatest levels of health needs that were not fully met.
- Survivors in Victoria (40%) and NSW (34%) reported the greatest levels of living needs that were not fully met.
- Leisure needs were most likely to be not fully met in NSW (68%) and Western Australia (67%).
- Work needs were most likely to be not fully met in Western Australia (83%) and Queensland (70%).
- Support needs were most likely to be not fully met in Queensland (58%) followed by Western Australia (56%) and NSW (56%).
- The financial needs were most likely to be not fully met in Queensland (42%) and NSW (43%).

Levels of need not fully met, reported by state

	n (%)	Health needs N=642 [†]	Living needs N=481 [†]	Work needs N=158 [¥]	Leisure needs N=344 [‡]	Support needs N=395 [‡]	Financial needs N=288 [‡]	All needs N=662
New South Wales N=207	With need	191 (93)	148 (73)	47 (24)	103 (51)	111 (54)	72 (36)	199 (96)
	Not fully met	159 (83)	50 (34)	24 (51)	70 (68)	62 (56)	31 (43)	165 (83)
Victoria N=158	With need	151 (96)	102 (65)	44 (29)	82 (53)	100 (64)	65 (42)	153 (97)
	Not fully met	125 (83)	41 (40)	25 (57)	53 (65)	47 (47)	23 (35)	132 (86)
Queensland N=100	With need	96 (96)	80 (80)	27 (29)	59 (60)	66 (67)	52 (53)	98 (98)
	Not fully met	86 (90)	26 (33)	19 (70)	38 (64)	38 (58)	22 (42)	87 (89)
South Australia N=78	With need	68 (87)	47 (61)	12 (16)	32 (43)	41 (55)	37 (49)	72 (92)
	Not fully met	54 (79)	15 (32)	6 (50)	18 (56)	16 (39)	11 (30)	56 (78)
Western Australia N=108	With need	101 (94)	78 (72)	18 (19)	52 (50)	61 (58)	52 (49)	103 (95)
	Not fully met	89 (88)	25 (32)	15 (83)	35 (67)	34 (56)	16 (31)	90 (87)
Tasmania N=35	With need	30 (86)	23 (66)	8 (26)	15 (45)	14 (42)	9 (26)	32 (91)
	Not fully met	21 (70)	4 (17)	4 (50)	7 (47)	6 (43)	2 (22)	21 (66)

N for domains: includes only those with a need in that area, [†] ≤1% missing data, [‡] ≤5%, [¥] ≤10% missing data. Not fully met = partially met + unmet. In this table only 686 of the 765 respondents were included. 74 were excluded due to missing postcodes and data from the Northern Territory was not included due to low numbers (n=5). New South Wales includes data from the Australian Capital Territory.

Level of health needs not fully met, reported by state

	n (%)	Mobility N=506‡	Incont- inence N=339‡	Pain N=368†	Fatigue N=454‡	Emotions N= 399‡	Concent- ration N= 401‡	Memory N=398‡	Speech* N=351‡	Cognition N=376†
New South Wales N=207	With need	149 (73)	99 (49)	113 (55)	122 (60)	113 (56)	109 (55)	114 (56)	92 (46)	112 (55)
	Not fully met	71 (48)	52 (53)	63 (56)	86 (70)	81 (72)	86 (79)	89 (78)	53 (58)	81 (72)
Victoria N=158	With need	116 (74)	74 (47)	73 (46)	104 (66)	86 (54)	99 (63)	100 (64)	84 (53)	91 (58)
	Not fully met	45 (39)	41 (55)	38 (52)	74 (71)	61 (71)	72 (73)	75 (75)	44 (52)	67 (74)
Queensland N=100	With need	82 (82)	55 (55)	67 (68)	79 (79)	72 (72)	72 (73)	70 (71)	61 (62)	63 (64)
	Not fully met	38 (46)	27 (49)	40 (60)	68 (86)	57 (79)	59 (82)	53 (76)	40 (66)	52 (83)
South Australia N=78	With need	53 (69)	39 (51)	34 (44)	45 (59)	40 (52)	35 (46)	32 (43)	38 (49)	35 (45)
	Not fully met	23 (43)	25 (64)	20 (59)	35 (78)	28 (70)	28 (80)	25 (78)	18 (47)	27 (77)
Western Australia N=108	With need	83 (78)	59 (56)	62 (57)	76 (70)	65 (60)	64 (59)	61 (56)	52 (48)	56 (52)
	Not fully met	44 (53)	26 (44)	27 (44)	58 (76)	49 (75)	53 (83)	50 (82)	37 (71)	41 (73)
Tasmania N=35	With need	20 (57)	12 (34)	17 (49)	26 (74)	20 (57)	19 (56)	18 (51)	21 (60)	17 (50)
	Not fully met	3 (15)	5 (42)	8 (47)	15 (58)	12 (60)	11 (58)	10 (56)	10 (48)	9 (53)

*Differences are statistically significant $p < 0.05$, N for domains: includes only those with a need in that area, † ≤1% missing data, ‡ ≤5% missing data.
Not fully met = partially met + unmet.

In this table only 686 of the 765 respondents were included. 74 were excluded due to missing postcodes and data from the Northern Territory was not included due to low numbers (n=5). New South Wales includes data from the Australian Capital Territory.

“ The degree to which need is met varies across the country and across needs. This is due to variability in access to best practice care and demonstrates a clear need for national leadership and coordination. ”

Levels of needs that are unmet reported by location according to remoteness

A greater proportion of survivors living in cities reported that their needs were not fully met in areas such as work, finances and everyday living. Stroke survivors residing in

inner regional areas were most likely to have their needs met in these areas. Health needs such as speech were also least likely to be met in those residing in major cities.

	n (%)	Health needs N=630 [†]	Living needs* N=470 [†]	Work needs* N=154 [‡]	Leisure needs N=366 [‡]	Support needs N=386 [‡]	Financial needs* N=281 [‡]	All needs N=648
Major city N=417	With need	383 (92)	283 (68)	97 (24)	203 (50)	238 (58)	177 (44)	400 (96)
	Not fully met	326 (85)	107 (38)	65 (67)	139 (68)	129 (54)	75 (42)	336 (84)
Inner regional N=173	With need	164 (95)	121 (70)	43 (27)	89 (53)	99 (58)	71 (41)	165 (95)
	Not fully met	135 (82)	26 (21)	18 (42)	50 (56)	51 (52)	18 (25)	138 (84)
Outer regional N=87	With need	83 (95)	66 (77)	14 (17)	44 (53)	49 (59)	33 (39)	83 (95)
	Not fully met	66 (80)	24 (36)	8 (57)	29 (66)	22 (45)	9 (27)	70 (84)

*Differences are statistically significant $p < 0.05$, N for domains: includes only those with a need in that area, [†] ≤1% missing data, [‡] ≤5% missing data, [‡] <10% missing data. Not fully met = partially met + unmet.

In this table only 677 of the 765 respondents provided sufficient information to be categorised according to their level of remoteness.

Levels of different health needs not fully met reported by location according to remoteness

	n (%)	Mobility N=495 [‡]	Swallowing N=268 [‡]	Fatigue N=446 [‡]	Emotions N= 392 [‡]	Concentration N= 394 [‡]	Memory N=398 [‡]	Speech* N=343 [‡]	Cognition N=371 [†]
Major city N=417	With need	311 (75)	160 (39)	270 (65)	242 (59)	231 (56)	230 (56)	212 (51)	230 (56)
	Not fully met	146 (47)	83 (52)	211 (78)	182 (75)	186 (81)	184 (80)	135 (64)	177 (77)
Inner regional N=173	With need	119 (70)	67 (39)	116 (68)	94 (55)	106 (62)	106 (62)	82 (48)	90 (53)
	Not fully met	50 (42)	21 (31)	82 (71)	66 (70)	84 (79)	76 (72)	46 (56)	64 (71)
Outer regional N=87	With need	65 (76)	41 (48)	60 (70)	56 (64)	57 (66)	56 (67)	49 (56)	51 (59)
	Not fully met	23 (35)	13 (32)	39 (65)	37 (66)	38 (67)	41 (73)	19 (39)	35 (69)

*Differences are statistically significant $p < 0.05$, N for domains: includes only those with a need in that area, [†] ≤1% missing data, [‡] ≤5% missing data. Not fully met = partially met + unmet.

In this table only 677 of the 765 survivor respondents provided sufficient information to be categorised according to their level of remoteness.

Needs of survivors of different ages, time since stroke and levels of disability

- Younger stroke survivors were more likely to report having more needs that were not fully met (median seven) compared to older stroke survivors (median four). Greater numbers of younger stroke survivors reported needs that were not fully met across the domains of health, everyday living, leisure activities, support and finance. Younger stroke survivors were more likely to have health needs related to falls, pain, concentration and vision that were not fully met.
- Survivors who were three or more years post-stroke reported significantly more needs that were not fully met (median 6) than those who were one to two years post-stroke (median 4). A greater proportion also reported that their needs were not being fully met. However, a significantly greater proportion of those who were one to two years post-stroke reported needs that were not fully met related to living needs, leisure needs and financial needs, compared to those who were three or more years post-stroke.
- Those with greater levels of disability as indicated by still needing assistance with activities of daily living (ADLs), reported significantly greater levels of needs that were not fully met across multiple categories compared to those that did not need assistance with ADLs. They also reported significantly more unmet needs (median 8) than those who did not need assistance with ADLs (median 3).
- In particular survivors with greater levels of disability were significantly more likely to report needs that were not fully met related to health, assistance with everyday living, returning to work, returning to leisure activities and emotional support.

	n (%)	Health needs [†] N=708 (93)	Living needs [‡] N=521 (68)	Work needs [§] N=171 (22)	Leisure needs [¶] N=368 (48)	Support needs [¶] N=395 (52)	Financial needs [¶] N=301 (39)	All needs [†] N=730 (95)
Age <65 [#] N=271	With need	255 (95)	167 (62)	125 (48)	153 (57)	183 (69)	126 (47)	261 (96)
	Not fully met	224 (88)*	78 (47)*	77 (62)	112 (73)*	116 (63)*	69 (55)*	229 (88)*
Age 65+ [#] N=433	With need	398 (92)	322 (75)	39 (10)	195 (47)	219 (52)	165 (39)	413 (95)
	Not fully met	325 (82)*	89 (28)*	21 (54)	114 (58)*	94 (43)*	40 (24)*	338 (82)*
1-2 years post-stroke [#] N=401	With need	359 (90)	259 (65)	79 (21)	182 (47)	215 (55)	155 (39)	376 (94)
	Not fully met	293 (82)	97 (37)*	53 (67)	127 (70)*	119 (55)	67 (43)*	306 (81)*
3+ years post-stroke [#] N=270	With need	262 (97)	207 (77)	76 (30)	154 (59)	170 (64)	125 (48)	265 (98)
	Not fully met	229 (87)	58 (28)*	40 (53)	90 (58)*	80 (47)	36 (29)*	233 (88)*
Independent with ADLs [#] N=423	With need	376 (89)	230 (55)	97 (26)	159 (38)	209 (50)	127 (31)	393 (93)
	Not fully met	290 (77)*	61 (27)*	44 (45)*	80 (50)*	88 (42)*	41 (32)	300 (76)*
Dependent with ADLs [#] N=280	With need	276 (99)	261 (94)	67 (26)	191 (71)	196 (73)	165 (61)	280 (100)
	Not fully met	258 (93)*	105 (40)*	53 (79)*	146 (76)*	123 (63)*	66 (40)	265 (95)*

*Differences are statistically significant $p < 0.005$, [†] $\leq 1\%$ missing data, [‡] $\leq 5\%$ missing data, [§] $\leq 10\%$ missing data. N for domains: includes only those with a need in that area, %: the percentage of total respondents with that need, ADL: activities of daily living, Not fully met = partially met + unmet. # proportions do not always add up due to missing data.

Conclusion

Nearly all of the 420,000 Australians who live with the effects of stroke have a need for support and the vast majority report a shortfall in help to meet that need.

The level of unmet need varies across the country and depending on how long the person has been living with stroke.

What doesn't vary is the widespread nature of the need.

The survey findings reported here reinforce the clear messages from stroke survivors and carers in their Call to Action, Fight Stroke document released in 2012.

Survivors are telling the National Stroke Foundation that there must be changes to the way they are supported after their stroke.

There must be changes to ensure that stroke survivors can access the care they need.

There must be changes so that survivors no longer fall through the cracks of a health and welfare system that is not geared to meet the specific needs of stroke.

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