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# BRAIN INJURY AUSTRALIA

## Position Paper:
## YOUNG STROKE

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# R E C O M M E N D A T I O N S

**While the median age for stroke in Australia is around 75 years, one in every four occurs in a person aged less than 65 years. Compared to older people, young strokes take longer to seek medical attention, are less likely to receive rehabilitation, and have more unmet needs in relation to psychosocial functioning and return to work. Though there is a lack of solid local trend evidence, rates of young stroke are increasing worldwide due to an increase in modifiable risk factors such as obesity, hypertension and diabetes.**

1. Brain Injury Australia recommends a national level overhaul of health services and disability-funded supports to meet the age-appropriate needs of young stroke – for example; in the provision of specialist physiotherapy, occupational therapy and counselling of sufficient frequency, intensity and duration to effect optimum family/ relationship functioning, community reintegration and return to work.

2. Brain Injury Australia recommends that such an overhaul needs to be matched by a national level stroke awareness, as well as primary and secondary stroke prevention, campaigning to target the potential resistance of young stroke given the disease's association with old age. Such campaigning also needs to be highly geared to meet the health information needs of population subgroups at greater risk of stroke – those from areas of social-locational disadvantage, Aboriginal and Torres Strait Islander and culturally and linguistically diverse (CALD) communities.

3. While Brain Injury Australia welcomes the significant local, and international, research efforts in stroke prevention, treatment and rehabilitation it also notes the gaps in evidence-based, age-adapted interventions in young stroke. Brain Injury Australia recommends that a national level collaborative research effort be dedicated to investigating and implementing age-specific best practice standards in service and support delivery to young strokes.

## *BACKGROUND:*

Globally, stroke is the third most common cause of death after heart disease and cancer.[1] Stroke has been the second most common cause of death among women and the third among men in Australia over the past three decades.[2] In 2010, there were 8,300 deaths in Australia due to stroke, comprising six per cent of all deaths.[3] However, since 1977 the death rate for stroke has been decreasing by an average of four per cent per annum for both men and women[4] due to, for example, reductions in smoking rates, improved treatments for high blood pressure and enhancements in the acute care of stroke.[5]

## definitions

- The most recent Australian Institute of Health and Welfare (AIHW) *National Community Services Data Dictionary* **defines acquired brain injury (ABI) as the "multiple disabilities arising from damage to the brain acquired after birth. It results in deterioration in cognitive, physical, emotional or independent functioning. It can be as a result of accidents, stroke, brain tumours, infection, poisoning, lack of oxygen, degenerative neurological disease etc.**"[6]

- The AIHW defines stroke as occurring **"when an artery supplying blood to the brain either suddenly becomes blocked (ischaemic stroke) or ruptures and begins to bleed (haemorrhagic stroke). Either might result in part of the brain dying and lead to sudden impairment, including paralysis of one or more parts of the body, or difficulties with swallowing, speech, vision and cognition. In many but not all cases, stroke is preventable, as many of its risk factors are modifiable.**"[7]

- Many people who sustain a stroke, and many stroke advocates, do not think of stroke as a brain injury. Even though stroke comprises the largest subgroup of people with an ABI, Brain Injury Australia has engaged little in *active* stroke advocacy. Instead, its advocacy has largely *responded* to "young strokes" who often find their needs unmet by traditional stroke recovery supports, which ordinarily cater to older Australians.

## incidence, prevalence

"There are no national data on the incidence of stroke [number of new 'events'] in Australia," according to the AIHW.[8] Nevertheless the National Stroke Foundation estimates "there are 50,000 strokes a year."[9] A Deloitte Access Economics report commissioned by the National Stroke Foundation estimated that in 2012 **"there were over 420,000 people [nearly 2 per cent of the Australian population] living with the effects of stroke... there were nearly 130,000 or 30 per cent of stroke survivors under the age of 65 in the community. By 2032 there will be around 709,000 Australians living with stroke, or 2.4 per cent of the population."**[10]

## "young stroke"

- **The median age for the 4,000 stroke patients who received acute services in the 112 participating Australian hospitals in a 2015 National Stroke Foundation audit was 76 years,**[11] similar to the "mean age for acute stroke…in industrialized countries," 75 years.[12]

- According to unpublished data provided to Brain Injury Australia by the Australian Stroke Clinical Registry, **of the 21,340 stroke events recorded by 40 participating Australian hospitals between January 2010 to December 2014, 5,296 (24.8 per cent) were in adults aged less than 65 years.**[13]

- While an agreed definition of "young stroke" is lacking, Brain Injury Australia uses that of both National Stroke Foundation and YoungStroke (a "Stroke Support Organization of the World Stroke Organisation"); "young stroke" is a "first-time stroke event occurring between the ages of 18 and 64,"[14] in people of "working age". While this Position Statement does not specifically address the unmet needs of paediatric stroke (stroke in children and adolescents) Brain Injury Australia believes that its overarching recommendation – that health and disability-funded services and supports be age-appropriate – applies equally to this patient group.

- According to same unpublished data provided to Brain Injury Australia by the Australian Stroke Clinical Registry, referred to above, **compared to patients aged over 65 years, young strokes "take longer to arrive at hospital after the onset of their symptoms (median minutes 234 versus 157)".[15] This means that younger stroke patients are at greater risk of not receiving thrombolysis - the administration of intravenous recombinant tissue plasminogen activator (rt-PA), which breaks down blood clots the cause of the most common type (in around 85 per cent of cases) of stroke, ischaemic stroke – within the optimum 4.5 hours of symptom onset recommended by the National Stroke Foundation.[16]** Moreover, "only 26 percent of ischemic stroke patients in Australia receive disability reducing thrombolysis treatment within 60 minutes of hospital arrival, compared with 43 percent of American patients and 56 percent of stroke patients in the United Kingdom."[17] Young strokes are also more likely to be male (63 per cent versus 51 per cent)."[18]

## trend?

- While there appears to be no conclusive evidence for *local* trends in the *incidence* of young stroke, a 2013 editorial in the *Journal of the American Medical Association* argued that "the number of Australians in this younger group [young strokes, aged less than 65 years] alone is expected to have risen to 18,500 by 2017 as the decline in stroke incidence seen in older age groups has not been seen in those under 65 years of age in Perth [Community Stroke Study] and Auckland [Regional Community Stroke (ARCOS) Study Group]."[19]

- **The Global Burden of Diseases Stroke Experts Group "noted a 25 per cent significant increase in stroke incidence in people aged 20–64 years [between 1990 and 2010]**, mostly attributable to an 18 per cent significant increase in low-income and middle-income countries."[20]

- A "Nationwide Inpatient Sample" of over 5 million hospitalisations in the United States for ischaemic stroke between 2000 and 2010[21] found the **age-specific rates for ischaemic stroke decreased for individuals aged 65 years and over but increased for individuals aged 25 to 44 years by 44 per cent and by 5 per cent for those aged 45 to 64 years.**[22]

- "Stroke was traditionally thought of as a disease of elderly people; however, our data show that the proportion of stroke burden is greater overall in individuals younger than 75 years than in those who are older, especially in low-income and middle-income regions. Although in the past two decades there was a trend towards occurrence of incident stroke later in

life, probably because of an ageing population, the proportion of young people (aged less than 20 years) and young and middle-aged adults (20 to 64 years) affected by stroke increased…**A worrisome trend towards increasing stroke incidence in young adults has been reported for some countries. In view of the worldwide epidemic of diabetes and increasing prevalence of other cardiovascular risk factors in young adults and overall, especially in low-income and middle-income countries, the shift in stroke burden toward younger populations is likely to continue globally unless effective preventive strategies are urgently implemented."**[23]

- **"Around 30 per cent of Australia's more than 420,000 stroke survivors are of working age. Sadly, the rates of stroke in young people are on the increase largely due to poor control of lifestyle factors and its impact will continue to grow unless action is taken to stem the tide and improve outcomes. Health and community care/welfare systems are not well set up to manage young stroke survivors, particularly those with high dependency.** Younger stroke survivors in Australia are more likely to have health needs related to falls, pain, concentration and vision that are not being met limiting their return to quality life."[24]

## rehabilitation

- **"Compared to those aged over 65 years, young strokes are less likely to be referred to rehabilitation - potentially going home without follow-up therapy, supports to resume everyday life - such as work, friendships, community life, leisure and sexual relationships."**[25]

- "A major difference in the rehabilitation of young stroke patients is that, on average, they will have longer to live with residual disability. Without appropriate rehabilitation, this longer period of time with the disability can result in large dependency costs."[26] **A 2009 prospective study of 105,000 stroke patients in Sweden found the 17,500 young strokes received greater relative benefits from stroke care than older stroke patients.[27] A 2011 study looked at the economic benefits of stroke rehabilitation for working aged adults and found that it would require 21 weeks of inpatient rehabilitation in order for the rehabilitation to offset the cost of dependency.**[28] **The National Stroke Foundation's 2014 audit of stroke rehabilitation in 111 Australian hospitals found the median length of stay for the 3,000 patients was 22 days.**[29]

## awareness

- Brain Injury Australia believes one explanation for the longer time taken for young strokes to seek medical attention is their lower level of stroke awareness compared to older Australians. **Given stroke's association with old age, young strokes may not readily recognise its signs**; for example, familiarity with **FAST**, the mnemonic developed in the United Kingdom in 1998 to expedite administration of TPA. **Face**; has the person's mouth drooped? **Arms**, can they lift both arms above their head? **Speech**; is their speech slurred, can they understand you? And **Time**; if you see any of these signs, call 000.

- Brain Injury Australia has been unable to identify research examining differential stroke awareness based on age. **A survey of stroke awareness in 250 people from Adelaide conducted before, immediately following, and three months after the National Stroke Foundation's National Stroke Week in 2009 found only 22 per cent had heard of FAST beforehand. This increased to 40 per cent immediately after, and stayed at 39 per cent after three months. "However, only 30 per cent of people who had heard of FAST were able to describe what it meant, and only seven per cent could accurately describe all four components of the acronym at three months after National Stroke Week."**[30]

- **One perverse potential counterpart to a possible lower level of awareness among young strokes is their higher rates of misdiagnosis. A 2011 review of 57 young strokes found patients aged less than 35 years were more likely to be misdiagnosed. The review "demonstrates the increasing need for 'young stroke awareness' among emergency department personnel."**[31] "Physician-reported errors and closed malpractice claims indicate that stroke is among the most common dangerous missed diagnoses."[32] A 1998 review of 182 deaths in 12 United States hospitals found preventable deaths from stroke were attributable to diagnostic error over 30 times more often than deaths from heart attack.[33]

- Stroke, like other brain injuries, tracks social-locational disadvantage. This may present specific challenges to both stroke awareness and primary prevention campaigning, in making health information accessible and relevant to people with low literacy and low levels of educational attainment as well as Aboriginal and Torres Strait Islanders and those from culturally and linguistically diverse (CALD) backgrounds. **A 2011 analysis of over 3,000 patients from Perth, Melbourne, and Auckland, New Zealand found those from disadvantaged areas were 70 per cent more likely to experience stroke than those from more affluent neighbourhoods. This is likely due to the higher prevalence of risk factors such as hypertension, diabetes and smoking in more deprived areas. As a result, "age and deprivation were inversely related, with patients in the most deprived areas having strokes at an average age of 68 years, compared with 77 years in the least deprived areas."**[34]

- **Racial and ethnic differences in stroke risk are well-studied, and these can be even greater in younger populations. In the Northern Territory, where one-third of the population is Aboriginal and Torres Strait Islander, the incidence of first-ever stroke between 1999 and 2011 was four times higher in Aboriginal and Torres Strait Islanders than in the rest of the population, similar to differential stroke incidence rates found in Aboriginal and Torres Strait Islanders in Western Australia between 1997 and 2002.** The "excess stroke incidence" among Aboriginal and Torres Strait Islanders in the Northern Territory aged 15 to 39 was five times that of the rest of the population of the same age, compared to one and a half times for Aboriginal and Torres Strait Islanders aged 65 years and over.[35] "In contrast to the national trends of decreasing stroke incidence, there is no evidence for falling incidence…but an increase for the Northern Territory's younger population."[36] A paper delivered at the recent Asia Pacific Stroke Conference reported that Aboriginal and Torres Strait Islander people in South Australia are 70 per cent more likely to be hospitalised for stroke than the rest of the population, "with substantial burden in young people."[37]

## unmet need

- A 2013 National Stroke Foundation survey of 765 survivors of stroke found 96 per cent "reported having needs after their stroke. This equates to 403,000 Australians. Of those that reported having needs, 84 per cent had needs that were not fully met. This equates to 339,000 Australian stroke survivors who were living with unmet needs in the community."[38] The Survey also found **"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."**[39]

- A 2013 study into 704 respondents to the Australian Stroke Survivor and Carer Needs Survey found the 2 in every 5 who were aged less than 65 years had "greater levels of unmet needs than older survivors especially related to health, emotional support, social participation and finances. **Targeted services and strategies to improve the quality of life of younger stroke survivors should be a priority."**[40]

- A 2015 qualitative study, based on in-depth interviews with 5 survivors of young stroke, concluded their "obvious physical impairment [was] given attention, but frequently invisible psychosocial and cognitive impairment, also requiring neurorehabilitation, [was] less well recognized in survivors of mild to moderate stroke."[41] Moreover, the study "found an almost total lack of attention to participants' psychosocial rehabilitation needs, yet they spoke explicitly of their psychosocial needs with regard to relationships, physical and social wellbeing, miscarriage, returning to employment, and navigating the health and income support systems."[42]

## unmet need - mental health

- **A 2005 meta-analysis of 51 observational studies of 19,000 stroke patients found one-third of all stroke survivors experience depression.**[43] A 2014 follow-up of 61 studies involving 25,500 stroke patients found 31 per cent experience depression and concluded "there is a pressing need for increased clinical uptake of evidenced-based strategies to screen for, prevent, and treat depression after stroke."[44]

- **A 2014 National Stroke Foundation audit of stroke rehabilitation services found fewer than 2 in every 5 of patients "with identified mood impairment on admission were assessed by psychology and less than one-third of patients with stroke were provided formal counselling before their return home.**[45]

## unmet need - return to work

- A 2009 systematic review of seventy studies - involving almost 9,000 patients working before their stroke and assessed up to 27 years later - **found a mean return-to-work rate of 44 per cent, a rate roughly comparable to those for people living with moderate to severe traumatic brain injury**.[46]

- A 2013 systematic review of rehabilitation of young strokes found "problems including headache, cognitive and memory problems, fatigue, anxiety, and irritation have accounted for reasons that individuals have not resumed a regular work schedule...Several factors have been identified as significant predictors of return-to-work for stroke survivors such as age, sex, functional status, absence of psychiatric illness, and education level…**stroke survivors were more likely to return to work if they had limited residual muscle weakness, no apraxia [the inability to execute a voluntary motor movement, despite normal muscle function, due to damage to the brain] and white collar occupations."**[47]

- Of 140 young strokes in 2012 Finnish study, forty-one per cent had returned to work within six months. **The presence of any cognitive deficit (including impairment of the executive functions of the brain – in insight, judgment, planning and initiative – psychomotor and visual processing speed, episodic and working memory) doubled a patient's risk of subsequent inability to return to work. The authors concluded that, when compared with other demographic, occupational and clinical predictors, cognitive deficits were the primary determinant of occupational outcome.**[48]

- **A 2013 National Stroke Foundation survey of 765 survivors of stroke found "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."**[49]

- **A 2014 National Stroke Foundation audit of stroke rehabilitation services found nearly one in every three patients were *not* "offered assistance to return to work if [they] wanted to return to work."**[50]

## unmet need - social supports

- In a 2003 Swedish qualitative, in-depth, study 5 young strokes "expressed a need for communication with other stroke patients *their age* [italics added] that had been affected by similar experiences".[51]

- The National Stroke Foundation's 2014 audit of stroke rehabilitation services found "**only one-third of patients were given information about peer support groups or self-management programs. This is despite national guideline recommendations stating all stroke survivors and family/cares should be given information about the availability and benefits of local support groups.** This remains a consistent pattern with previous audit reviews and continues to be an area for service development."[52]

## burden of disease

- "**Worldwide in 2010, roughly 10 per cent of...deaths and about 4 per cent of DALYs [Disability Adjusted Life Years - a measurement unit that quantifies the impacts of morbidity and premature death associated with various diseases and injuries] were due to stroke.** Our findings show that although stroke mortality rates and mortality-to-incidence ratios have decreased in the past two decades, the global burden of stroke in terms of the absolute number of people affected every year, stroke survivors, related deaths, and DALYs lost are great and increasing, with most of the burden in low income and middle-income countries. **If these trends in stroke incidence, mortality, and DALYs continue, by 2030 there will be almost 12 million stroke deaths, 70 million stroke survivors, and more than 200 million DALYs lost globally."**[53]

- The Stroke Panel Experts Group of the Global Burden of Disease Study found that, in 2013, **"the burden of stroke in adults aged 20–64 years was high, with almost 11 million living with stroke and almost 1.5 million deaths from stroke, contributing to over 51 million DALYs."**[54]

- A Deloitte Access Economics study commissioned by NATIONAL STROKE FOUNDATION estimated stroke "caused 285,158 DALYs [in Australia] in 2012. This equates to a cost of $49.3 billion in 2012."[55]

## costs

- A Deloitte Access Economics study commissioned by the National Stroke Foundation estimated **the cost of lost earnings due to reduced employment due to stroke in people of working age was $975 million in 2012.**[56] And the "cost of absenteeism and lost home production due to stroke was estimated as $1.14 billion in 2012 for people of a working age. This includes around $1.05 billion due to absenteeism for people in paid work and around $0.09 billion in lost household productivity for those in unpaid work."[57]

- **The total cost of stroke in those aged less than 65 years in Australia in the year 2000 was estimated at $228 million. Around 10 per cent ($23 million) of that overall cost was caused by reduced productivity because of stroke-related sick leave, early retirement and premature death.**[58]

## risk factors/ primary prevention

- According to the 2010 Global Burden of Disease study, young adults aged 20 to 64 years constituted 31 per cent of incident strokes globally, and "**evidence suggests that changes in unfavourable lifestyle factors such as unhealthy diets high in sugar, salt and**

**processed foods, smoking, alcohol intake, drug use and reduced levels of physical activity have led to the increased exposure to stroke risk factors in the young.** A population-based study in the United States found an increase in the number of young people aged 18 to 54 years with stroke, and that over half of these were current smokers and 1 in 5 abused illegal drugs."[59]

- **Stroke is "highly preventable. Reducing the high prevalence of the modifiable risk factors could prevent many strokes".[60] While these risk factors are the same for both younger and older age groups, their "prevalence…is not the same in the two age groups.** Hypertension, heart disease (including atrial fibrillation [the most common abnormal heart rhythm]), and diabetes mellitus [a condition in which the pancreas no longer produces enough insulin or cells stop responding to the insulin that is produced, so that glucose in the blood cannot be absorbed into the cells of the body] are the most common risk factors among the elderly. In contrast, among 1,000 young stroke patients in Finland, the most common vascular risk factors were dyslipidaemia (60 per cent) [abnormality in, or abnormal amounts of, fats (lipids) in the blood], smoking (44 per cent), and hypertension [high blood pressure] (39 per cent)…Another study investigated the distribution of vascular risk factors in 3,944 young stroke patients from three distinct geographic regions in Europe. The three most frequent risk factors were current smoking (49 per cent), dyslipidaemia (46 per cent), and hypertension (36 per cent)."[61]

- A 2013 systematic review of rehabilitation of young strokes identified the following modifiable risk factors: **"smoking, alcohol, drug use, cocaine, use of oral contraceptives, hyperlipidaemia [too high a level of fats (lipids) in the blood], plasma homocysteine level [an amino acid, elevated levels of which are associated with heart attack, stroke, and blood clots], migraine, diabetes mellitus, chlamydia pneumoniae [a bacteria that causes respiratory illness] and hypertension [high blood pressure]."**[62]

## secondary prevention

- **Between 3 and 4 per cent of all patients who experience a stroke will sustain a second. A 2010 Finnish study of 800 first-ever ischaemic stroke patients found 10 per cent recurrence within 5 years.**[63] Secondary stroke prevention - aimed at reducing the risk of subsequent stroke – includes treatment of hypertension, hyperlipidaemia, diabetes mellitus as well as encouraging lifestyle changes (physical activity, diet lows in salt and saturated fat and high in fruit and vegetables, smoking cessation etc.)

- **The National Stroke Foundation's 2015 audit of acute stroke services in 112 Australian hospitals found one-third of ischaemic stroke patients and one-quarter of haemorrhagic stroke patients did not receive recommended secondary prevention medications.** "Given the high rates of recurrent stroke and the proven effects of secondary prevention strategies in reducing recurrent stroke risk, these gaps in care have significant implications for both the individual and the health system. Review of systems and processes (including the role of a stroke coordinator in providing education before discharge) is warranted."[64]

- "…The Australian National Stroke Foundation guidelines for Rehabilitation and Recovery rely entirely on the review of the very limited studies mentioned previously and recognise that 'there is no evidence for interventions specifically to assist in returning to work'". [65]

- A 2014 National Stroke Foundation audit of stroke rehabilitation services found "forty-one of the 54 hospitals reportedly conducting stroke research had a focus on rehabilitation-specific studies. A total of 132 research studies was being undertaken, of which 74 were rehabilitation specific."[66]

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