

Stroke Recovery News

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Stroke in Australia: Long term survivors have fallen into a black hole

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People with long term disability after Stroke should have access to the services they need, when they require them.

Over recent years, the management of Stroke has undergone major changes in Australia, including the introduction of Stroke-equipped ambulances, improved delivery of thrombolysis, and the formation of acute Stroke units.¹ However, despite more people surviving, many people after Stroke are left with lifelong disability.² Furthermore, ongoing services and support are perceived to be inadequate by people after Stroke.³ This means that people living with ongoing disability after Stroke may not have the opportunity to achieve their preferred life goals. It is time to focus on the individual burden of disease and how we can best support people with Stroke in the long term.

Stroke is a chronic, lifelong health condition, but it is managed like an acute condition in Australia. Typically, a person after Stroke is admitted to an acute hospital for early management; they then receive inpatient rehabilitation if they meet the selection criteria, followed by outpatient rehabilitation.⁴ In reality, the amount of rehabilitation provided by the hospital sector is limited. Recent moves towards early discharge and rehabilitation in the home have been shown to be less effective in maximising function than inpatient rehabilitation,⁵ whereas functional gain is possible with investment in subacute and community rehabilitation (eg, Council of Australian Governments national partnership agreements).⁶ After hospitalisation, 64% of people after Stroke are referred for community rehabilitation; however, the actual amount of community rehabilitation that occurs is profoundly low.^{7,8}

People after Stroke are caught between the health, disability and ageing sectors. In the health sector, resources are prioritised in the acute phase of care, and once in the community, funding is via the general practitioner Chronic Disease Management Plan that is limited to five annual subsidised allied health sessions. Furthermore, it is hard for people after Stroke to access funding from the disability sector. People after Stroke report feeling forgotten and neglected once their allotted rehabilitation quota has finished.⁹

Stroke cost the Australian health and disability sectors an estimated \$1.3 billion in 2020.¹ Having a disjointed and inequitable system cannot ensure value for money. One of the costs is the National Disability Insurance Scheme (NDIS), Australia's disability funding model. In 2020, the NDIS supported 5,160 people who nominated Stroke as their primary disability - approximately 1% of people after Stroke living in Australia at that time.¹



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The NDIS does not readily accept people after Stroke for two reasons. First, you must be aged 65 years or younger when you acquire your disability. In Australia, 61% of people who had a stroke in 2020 were aged over 65 years.¹

Second, the disability must have a permanent and significant impact on function or participation in life roles (<https://www.ndis.gov.au/applying-access-ndis/am-i-eligible>). It can be incorrectly assumed that people after Stroke recover and therefore will not have ongoing disability, especially people with initial mild to moderate symptoms. While people typically have some recovery after Stroke, it is usually partial and plateaus after the first 6 months.¹⁰ A significant proportion of people also deteriorate over time, creating greater levels of disability.¹⁰ If not eligible for the NDIS, people after Stroke may need to wait until they are eligible for aged care services, which are currently not only inadequate but do not optimise participation and quality of life.¹¹

Other chronic health conditions such as heart disease receive ongoing support aimed at preventing recurrence.¹² After Stroke, exercise and the promotion of physical activity as secondary prevention strategies are also important but are rarely accessible. Further, participation in such programs can be limited by the complexity and severity of post-Stroke impairments, such as muscle weakness and cognitive/language deficits.¹ It is time for people with long term disability after Stroke to have access to the services they need, when they require them.

We suggest a new model of long term support for people after Stroke who experience ongoing disability. The cornerstone of the model is a deliberate move to the disability sector from the health sector. This article is a call for people with ongoing disability after Stroke to be able to access ongoing services regardless of age or disability. The current system is disjointed with multiple funding sources, leading to inequality in who receives which services and when. People after Stroke need the ability to have regular ongoing check-ups with services implemented where required, more support for ongoing lifestyle changes such as text reminders, person-centred tools such as self-management, habit-forming exercise, ongoing gym memberships, and strategies for meaningful social interactions.^{13, 14} These issues are applicable not only for people after Stroke, but also for many others with ongoing disability. We support the urgency for a national rehabilitation strategy to move the rehabilitation focus from the hospital to the community.¹⁵

References:

1. Deloitte Access Economics. The economic impact of stroke in Australia, 2020. Stroke Foundation, November 2020. <https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-dae-economic-impact-stroke-report-061120.pdf>
2. Sturm JW, Donnan GA, Dewey HM, et al. Determinants of handicap after stroke: the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke* 2004; **35**: 715- 720.
3. Walsh ME, Galvin R, Loughnane C, Macey C, et al. Factors associated with community reintegration in the first year after stroke: a qualitative meta-synthesis. *Disabil Rehabil* 2015; **37**: 1599- 1608.
4. Lynch EA, Luker JA, Cadilhac DA, Hillier SL. Inequities in access to rehabilitation: exploring how acute stroke unit clinicians decide who to refer to rehabilitation. *Disabil Rehabil* 2016; **38**: 1415- 1424.
5. Lynch EA, Labberton AS, Kim J, et al. Out of sight, out of mind: long-term outcomes for people discharged home, to inpatient rehabilitation and to residential aged care after stroke. *Disabil Rehabil* 2020; **44**: 2608- 2614.
6. Poulos CJ, Eagar K, Faux SG, et al. Subacute care funding in the firing line. *Med J Aust* 2013; **199**: 92- 93. <https://www.mja.com.au/journal/2013/199/2/subacute-care-funding-firing-line>
7. Grimley RS, Rosbergen IC, Gustafsson L, et al. Dose and setting of rehabilitation received after stroke in Queensland, Australia: a prospective cohort study. *Clin Rehabil* 2020; **34**: 812- 823.
8. Stroke Foundation. National Stroke Audit: rehabilitation services report. 2020. https://informme.org.au/media/drtlcbsp/rehab_strokeservicesreport_2020.pdf (viewed May 2020).
9. National Stroke Foundation, *Walk in our shoes: stroke survivors and carers report on support after stroke*. Melbourne: NSF, 2007.
10. Van De Port IG, Kwakkel G, Van Wijk I, Lindeman E. Susceptibility to deterioration of mobility long-term after stroke: a prospective cohort study. *Stroke* 2006; **37**: 167- 171.
11. Royal Commission into Aged Care Quality and Safety. Final report: Care, dignity and respect. Volume 2: The current system. Canberra: Commonwealth of Australia, 2021. https://agedcare.royalcommission.gov.au/sites/default/files/2021-03/final-report-volume-2_0.pdf
12. Dalal HM, Doherty P, Taylor RS. Cardiac rehabilitation. *BMJ* 2015; **351**: h5000.
13. Sakakibara BM, Kim AJ, Eng JJ. A systematic review and meta-analysis on self-management for improving risk factor control in stroke patients. *Int J Behav Med* 2017; **24**: 42- 53.
14. Morris JH, MacGillivray S, McFarlane S. Interventions to promote long-term participation in physical activity after stroke: a systematic review of the literature. *Arch Physical Med Rehabil* 2014; **95**: 956- 967.
15. Cameron ID, Crotty M, Kurrle SE. The future of rehabilitation for older Australians. *Med J Aust* 2021; **215**: 169- 170. <https://www.mja.com.au/journal/2021/215/4/future-rehabilitation-older-australians>

New tool to tackle debilitating post-Stroke fatigue

Newcastle researchers are one step closer to developing a new tool to help tens of thousands of survivors of Stroke who experience the debilitating impacts of post-Stroke fatigue. The team, led by Dr Dawn Simpson, will work with Stroke survivors, their caregivers and health professionals to co-design the tool that translates concepts from effective persistent pain education into post-Stroke fatigue. Three of the research team are Stroke survivors with lived experience of post-Stroke fatigue.



The 'Protectometer' is an educational package of resources that will assist survivors and health professionals to identify tasks or situations that exacerbate their fatigue and then supports problem solving through the development of personal strategies to improve recovery and quality of life.

The research project is one of five that have been announced as part of the 2023 Stroke Foundation Research Grants. Dr Dawn Simpson, from the University of Newcastle and Hunter Medical Research Institute, says the funding will be critical to co-designing the tool which will assist to reduce the impact of fatigue on Stroke survivors and their families.

"Post-Stroke fatigue is life-altering. Survivors I've been working with have described it as a complete turn of a switch where they just have to stop what they're doing and can't continue; they feel physically and emotionally wiped out and cannot concentrate or continue to function."

Fatigue affects more than half of Stroke survivors, but Dr Simpson says there is a gap in current Stroke practices with survivors telling her they receive limited information about fatigue from health professionals.

"Fatigue management is not a one-size-fits-all approach. This tool will give survivors of Stroke a better understanding of their fatigue and, by working closely with their health practitioner, will provide a tailored approach to fatigue management. As a result, we expect the patient to have greater participation, confidence, and quality of life." Dr Simpson said.

The study will happen in two stages, and the team will be recruiting Stroke survivors, their caregivers and a range of health professionals at each stage. The first stage will involve online workshops to allow participants to provide input into, and feedback about the tool. The second stage will test how effective the tool is and get further information about how 'user-friendly' it is in clinical practice. The study will be advertised on the Hunter Medical Research Institute website and publicised on social media, hopefully in mid-March.



Article by Dr Dawn Simpson - Lecturer in Physiotherapy, College of Health, Medicine and Wellbeing, School of Health Sciences, Newcastle University.

You can watch Dr Dawn Simpson's presentation "*Living with fatigue after Stroke*", which she presented at the 2022 Creating Connections Stroke Conference, by visiting: <https://youtu.be/KLf9R4JGqjl> or scanning the QR code on this page.

The number of people losing money as a result of scammers is on the increase in Australia. It is important to be vigilant and ensure you protect yourself as much as possible.

Scammers are now operating through; telephone, texting, emails, and all forms of social media. They are becoming very sophisticated and are now impersonating banks, government agencies, your family members and even police.

Common scams in 2023

In the latest scams to be aware of, there are several tricks being used by fraudsters to steal your money and personal information. These include:

1. **The 'Hi mum' Scam** - this is when you may receive a text message or WhatsApp from an unknown number pretending to be your child or grandchild. They will ask you for money to replace their phone. Do not send any funds, but call your family member directly to verify the message.
2. **The Suspicious Transaction Scam** - fraudsters may call you and pretend to be from your bank. They will claim that there has been a suspicious transaction on your account and ask you to confirm your personal details. To protect yourself, it's important to hang up and call your bank directly using their official number to verify the status of your account.
3. **The Toll Road Scam** - where you may receive a text message from what appears to be a toll company requesting payment for an unpaid toll. However, it's important to note that toll companies will never text you for payment or ask for personal details. Instead, these notices will always come in the mail.
4. **The Online Job Scam** - this scam usually occurs through social media or WhatsApp. Scammers may pose as recruitment officers offering a promising job opportunity. They will often ask you to create a cryptocurrency wallet and deposit money into it as a way to secure the job, but this is a red flag to watch out for.

Scams work by deception. Scammers often pretend to be from trusted organisations, including from us. They may pretend to be from any of the following:

- MyGov
- Services Australia
- Centrelink
- Medicare
- Child Support
- Other government agencies, like the Australian Taxation Office (ATO).

Scammers may want your personal information, including your:

- Centrelink Customer Reference Number (CRN)
- Name
- Address
- Date of birth
- MyGov sign in details
- Bank details
- Passwords
- Identity details, such as your Medicare card details
- Credit card details.

Scams and identity theft

They may also tell you to:

- Pay fees or transfer money to get a payment or benefit, or repay a debt.
- Upload copies of your identity documents
- Buy gift cards or vouchers, such as an iTunes gift card
- Give them remote access to your computer.

Additional resources from Services Australia:

- **How to spot if it's a scam** - <https://www.servicesaustralia.gov.au/how-to-know-if-its-scam>
- **How to protect against scams** - <https://www.servicesaustralia.gov.au/how-to-protect-against-scams>
- What to do if a scam has affected you - <https://www.servicesaustralia.gov.au/what-to-do-if-scam-has-affected-you>
- **If you think that your identity has been stolen** - call idcare on 1800 595 170.
- **If you are worried about a scam**, you can call the Scams and Identity Theft Helpdesk on 1800 941 126 or email reportascam@servicesaustralia.gov.au for information, help and advice.

REMEMBER: DO NOT GIVE OUT YOUR PERSONAL INFORMATION TO ANYONE. ALWAYS CALL THE ORGANISATION INVOLVED DIRECTLY AND ASK IF THEY HAVE ATTEMPTED TO CONTACT YOU.

Cost of living support - Energy Rebates and finding unclaimed money in NSW

The NSW Government is helping reduce the cost of living with more than 70 rebates and vouchers. To find out what you may be eligible for go to the Service NSW website: <https://www.service.nsw.gov.au/> and complete a very simple questionnaire and a list of rebates suitable for you will be displayed.

What rebates are available in NSW?

- *NSW Family Energy Rebate*
- *Low Income Household Rebate*
- *NSW Gas Rebate*
- *Life Support Rebate*
- *Medical Energy Rebate*
- *Seniors Energy Rebate.*

How to search for unclaimed money in NSW

Sometimes, you don't receive money owed to you because you have moved address, changed your name, lost the paperwork or forgotten about it. It's our job to make this information available, so the money can be found and given to the right person.

To find out more information and to see if you may be eligible, contact revenue NSW on their website: <https://www.revenue.nsw.gov.au/unclaimed-money>.

About eBility

eBility is a one-stop accessible marketplace for all disability equipment and products. Established in 1998, eBility is owned by IDEAS, the knowledge experts in fact-checked verified disability information and connection.



What is IDEAS?

IDEAS stands for Information on Disability, Education and Awareness Services. They are a not-for-profit organisation that specialises in disability information.

eBility's purpose is:

1. To make it easier and quicker for people with disability to find relevant new and used products in an accessible format, so you can power up your life.
2. To offer value by connecting sellers and buyers and free access for those wishing to donate items to new homes and users.
3. To support and promote web accessibility with tips, tricks and hacks written by subject experts.

How do I post an ad to sell my used disability equipment and products?

1. Visit <https://ebility.com.au/en/>
2. Click on the 'Post an ad' button at the top of their homepage on the website. You will need to create an account and sign in before posting an ad.
3. Once you are signed in, click the 'Post an ad' button found on the main menu and fill out the form.
4. Watch the short tutorial video that they have created that takes you through the simple listing process (<https://youtu.be/V3L2bgo0q8k>).

How much does it cost to list an item on eBility?

For more details on the pricing of selling on eBility, visit <https://ebility.com.au/en/help/pricing.html>.

The prices below are GST-inclusive and apply to private/individual sellers for 1 item per listing:

- Selling your item for under \$150 = free to list the item.
- Selling your item for \$150 - \$1,499 = \$14.95 to list the item.
- Selling your item for \$1,500 - \$3,000 = \$24.95 to list the item.
- Selling the item for over \$3,000 = \$29.95 to list the item.
- Selling an accessible vehicle = \$74.95 to list the item.
- Selling a modified property = \$149 to list the item.

How do I contact an advertiser?

In some instances, advertisers will post their phone number or email address in the contact field. To view these details, you will need to be logged in to the site. Otherwise, you can use the contact form on the right-hand side of the ad.

How do I get an item that I would like to purchase?

You must contact the advertiser to arrange to pick up or drop off any advertised equipment. eBility is a classifieds site only and do not handle the exchange of items or delivery.

'The Pool' Short Film Premiere



The Association recently partnered with young film writer and director, Erica Long, from Waiting Room Productions and her army of volunteers to make a short film on recovery from Stroke. "The Pool" which premiered in November 2022 at the Palace Cinema in Darlinghurst, is intended to raise community awareness of Stroke and Stroke rehabilitation through visual storytelling.

The story is told from the perspective of a suburban pool as it reminisces about its life and those of the humans who were part of that life over many years. The film centres around the lives of Ari and Connell, and the

tragedies that occurred in their lives and how that was influenced and witnessed by the pool. The writer was inspired by her personal experience with her partner's dad (a Stroke survivor) and stepmother (a carer) and the film captures the devotion and connection between carer/family and Stroke survivor.

"The Pool" also depicts various forms of rehabilitation exercises that Stroke survivors undertake and the important role of their carers to assist in their rehabilitation journey. The filmmaker worked with the therapists at Mt Wilga Rehabilitation Hospital Sydney to ensure that Stroke rehabilitation was accurately portrayed. The end of the film includes facts about Strokes.

The filmmakers intend to enter 'The Pool' in film festivals across the world to raise awareness of Stroke. Once the film is available for general viewing, the Association will be showing the film at a future Creating Connections Stroke Conference.

Life membership awarded

Ray and Judith Thornley from the Hornsby/Ku-ring-gai Stroke Recovery Club were awarded a life membership from the Stroke Recovery Association NSW at the 2022 Annual General Meeting.

Judith and Ray Thornley joined the Stroke Recovery Association after Ray's Stroke in 2009. Since this time, they have been involved in the Hornsby/Ku-ring-gai Stroke Recovery Club, were founding members of Aphasia NSW and have been active members of the Hunter Stroke Olympics Committee. Judith has also been a member of the Board of the Association since 2015 and is the current Vice President and Secretary of the Stroke Recovery Association.



Judith, with Ray's constant support, is the President and Coordinator of the Hornsby/Ku-ring-gai Stroke Recovery Club and is responsible for the organisation of all the events, meetings and outings. Judith and Ray are passionate about members attending events held by the Association as it enables members to connect with other Stroke survivors, carers and families within the Stroke community.

Since Ray's Stroke in 2009, Ray and Judith have dedicated their lives to the improvement of services for Stroke survivors, not only at the local level, but also at the state and national levels.

Building Capacity Training Conference



Sydney Stroke Olympics



Creating Connections Stroke Conference

Stroke Awareness Week Launch



2022 in pictures

Combined Clubs Morning Tea



Combined Clubs Picnic



Hunter Stroke Olympics



Online Stroke Support Groups





PRESIDENT'S HIGHLIGHTS

Mr John Garbutt

To begin, I will congratulate the staff, our wonderful Stroke Recovery Club/group/choir volunteers, and my fellow Board members, for their initiative and ongoing commitment to the Association over the past year. It has taken an enormous amount of energy to maintain our services with the ups and downs of the ongoing health crisis, which appears to be here to stay with us for the foreseeable future.

The latter part of 2021 was again plagued with lockdowns and cancellations of events. Stroke Recovery Clubs/groups/choirs were just starting to rejuvenate prior to the second major lockdown, which occurred from July to November, when COVID-19 raised its ugly head yet again. The usual events of the Association and the activities of our Stroke Recovery Clubs/groups/choirs were once again cancelled. While the organised events scheduled for the latter half of 2021 were cancelled, we were able to host the Creating Connections Stroke Conference entirely online in September 2021.

2022 began with great optimism. We were notified that the funding received from the NSW Government Department of Community and Justice would not only be restored but doubled to \$150,000 per annum. A great achievement for Michelle and the team.

The first half of 2022 saw everything re-opening, and as back to normal as possible, with the Association holding events, including the 45th Anniversary cocktail party, the Building Capacity Stroke Conference, and the Sydney Stroke Olympic Games day.

The Association's services in review:

I know I begin with this every year but never has this been more apt than the past 12 months. The staff have exceeded expectations through the challenges of COVID-19 to ensure the services of the Association remain relevant for members. The performance of the Association continues to be a source of pride for all involved. The Association's statistics indicate that the services and programmes are performing well and there has also been an enormous shift and expansion in our online and live streaming capabilities, expanding our services to rural and remote areas of the state and allowing more members than ever to access Association events.

Support and Information

The information, counselling and support telephone line continues to be the frontline connection for those seeking the support of the Stroke Recovery Association. Survivors and carers regularly contact the Association for information and are more often than not linked to a whole network of support through our Stroke Recovery Club/group/choir communities. The statistics on pages 14 and 15 will give you an idea of the number of telephone calls taken by staff each year. A friendly voice on the end of the telephone is often the first point of contact for new members and anyone wanting to connect or learn more about Stroke.

Cont... President's Highlights 2022



Staff continue to respond to feedback on the website. In addition to the new look, we have now uploaded all our Stroke information sheets in a format that can utilise the text to speech function and be translated into over 10 different languages. We are still finessing the members only section of the website, which enables members to access to all the guest presentations from our conferences and Topical Thursday guest speaker recordings.

Support of Stroke Recovery Clubs/groups/choirs

This is the area of the Association's objectives which has seen the greatest change over the past 12 months.

The Stroke Connectivity Project has continued during 2022. The Stroke Project Officer has completed the first round of training to all Clubs/groups/choir, with all Clubs/groups/choirs having either already undertaken the training, or having their training session scheduled for the remaining half of 2022.

As COVID-19 caused an enormous interruption to the implementation of this project, we are confident that this funding will be continued for a further two-year period, concluding in June 2024. The continuation of this project will enable the Stroke Project Officer to revisit the Clubs/groups/choirs and provide further training to develop members' skills and confidence in accessing and utilising technology and online platforms even further.

The funding that the Association receives from the Department of Communities and Justice is now solid until June 2024. As a result, we have employed the Community Liaison Officer whose role involves forging closer ties with our health and disability colleagues and working with member Clubs/group/choirs to expand and strengthen the Stroke support network in the community.

The 2021 October Club video conferences were able to proceed using the online meeting platform 'Zoom'. It is amazing to see how members have embraced the new technology so readily. Who would have thought, prior to COVID-19, that we would all become so comfortable with using technology to communicate.

The Building Capacity Training Conference was held in May 2022 and incorporated a 45th anniversary cocktail party for the Association. Eighty percent (80%) of our Stroke Recovery Clubs/groups/choirs were represented at the two-day conference. It was again successfully livestreamed to all our members who were unable to attend in person.

Following the feedback received by members at the Building Capacity and October video conferences, the Stroke Project Officer and Community Liaison Officer have initiated monthly online governance training for Stroke Recovery Club/group/choir executives.

The online Stroke support groups have continued to expand, with many Stroke Recovery Clubs/groups/choirs experimenting with opening their groups to both online and face to face attendees. Online groups which continue to be successful (and popular with our members) are the Gardening Club, Sips and Nibbles Working Age Group, the Topical Thursday Guest Speaker and Trivia Tuesday. The staff work closely with many of our lovely volunteers to enable them to use their skills to facilitate the online groups. These groups are now entrenched as part of the services of the Association and have forged many a friendship between members located far and wide.

Stroke Awareness and Education

Stroke awareness and education is an area that has been greatly reduced due to the impact of the lockdowns this year. Most Clubs/groups/choirs were unable to participate in NSW Stroke Awareness Week 2021 due to the second COVID-19 lockdown. The Annual NSW Stroke Awareness Week launch and the Stroke Choir Recital were both cancelled. Community talks and education opportunities have also been very much reduced.

Advocacy

The Chief Executive Officer continues to be very active in advocating for services through all levels of government. All of these have continued to meet during 2021/2022 using online platforms. Areas where the Association has had significant input has been through the Agency for Clinical Innovation (ACI) Stroke Network and Ability Transport Access Committee (ATAC) through NSW Transport in the roll out of the new fleets and other related transport. This is a vital aspect of the Association's mandate. We will continue to be involved with NSW Health and Transport NSW, with the provision of consumer representatives. As your President, I will continue to provide a vital voice within Health Consumers NSW, serving as their Chairperson again in 2021/2022.

Moving Forward

One major achievement over the past year has been the continuation of funding for the development of the Stroke Recovery Clubs/groups/choirs through the Department of Communities and Justice. Not only was the funding reinstated, the amount received annually has doubled. This, along with the expected continuation of the Stroke Connectivity Project funded through the Information and Linkages and Capacity programme, will mean that the Association has three secure sources of funding until June 2024. It is anticipated that these increased resources will have a flow on effect to support the development of both the Association's face-to-face Clubs/groups/choirs and also our online presence.

Advocacy remains a key strategy of the Association. We are committed, along with our partner organisation, the Physical Disability Council of NSW (PCDN) who have been funded to coordinate the Disability Advocacy Network, to ensuring that the needs of people with disability are at the forefront of decision making in 2023.



Cont... President's Highlights 2022



Members can be assured that your staff and Board of Management will continue working with Stroke survivors and their carers to ensure that the interests and the voice of Stroke survivors will be heard within the decision-making processes of NSW. Whether that be directly, through the work of our CEO, or through our connection with key strategic partners, PDCN and Health Consumers NSW.

The use of technology is now an essential tool to deliver some of the Association's services. The online Stroke support groups are now embedded in the yearly programme for staff. It is imperative that these continue, as they have ensured that members, wherever you are located, can still enjoy more access to the services and events made available by the Association.

The ongoing success of the Association's education conferences will ensure that they are part of our support to members in 2023. The capacity to livestream to those unable to attend events face-to-face will also continue to grow in popularity as members become more familiar and comfortable using online platforms.

Members can be assured that the Board will continue to evaluate the programmes of the Association and ensure that they evolve to meet the changing needs of our members and the Stroke community. The Association will also continue to work on our governance procedures to ensure compliance with all relevant authorities.

As we move into 2022/2023, we can look back on the past 12 months yet again with enormous pride in the achievements of this Association during another very difficult year of lockdown, Club/group/choir closures and event cancellations. The Association has risen to the challenge of the ever-changing and trying conditions of COVID-19, and we have also found new and improved ways to engage with and provide services to our members.

Thank you

I always conclude my report by acknowledging the individuals and organisations who have contributed to the success of the Association over the past 12 months. That contribution might be through volunteering their skills to a Club/group/choir, or as a member of staff, led by our CEO, Michelle Sharkey, who celebrates 25 years with the Association in 2022.

We are a very solid and strong organisation led and directed very capably by my fellow Board members who contribute their time freely. This past 12 months has seen a significant change of Board membership, however, I am sure you agree that the quality of the support provided through the Association is first class and continues to develop under the stewardship of the Board and the very capable staff. I thank you all for your contribution to the work of the Association and look forward to a very successful year ahead.


John Garbutt
 President

FINANCIAL REPORT

At the conclusion of the 2021/2022 financial year, the Association is in the best financial position it has ever been as a result of further bequests and increased government grant monies. The financial overview on the following page gives you a compact picture of how monies have been received and expended over the past year and a comparison with the previous financial year.

The income and expenditure report indicate that there has been a decrease in monies received from most areas over the past year, an indication of how we have been impacted by COVID-19. The Association received \$249,088 in bequests over the past financial year, an enormous increase over that received in the previous financial year. Due to the current low interest rates in the 2021/2022 period, our investment returns have decreased in relation to previous years. It is anticipated that this performance will improve next year.

The overall annual expenditure in 2021/2022 has again increased due to higher staffing levels. Staff have worked diligently to source alternative sources of funding and this is reflected in the extension of the grants received from NSW Health, NSW Department of Communities and Justice and a further grant from NDIS (ILC Programme) for the 2022/2024 period.

Our funding agreement with NSW Health is secured until June 2023. We were also successful in a tender submitted to the NSW Department of Communities and Justice under the Disability Advocacy Futures Programme (DAFP). This replaced and doubled the grant monies we were receiving from them previously under the Transitional Advocacy Futures Programme (TAFP). This funding is a guaranteed annual amount of \$150,000, secure until 30 June 2024.

A further two-year extension of the NDIS grant to rollout the Stroke Connectivity Training Project to members at the Stroke Recovery Club/groups was also granted in early July 2022 and this funding is also now secure until 30 June 2024. This means the Association now receives core government funding of approximately \$497,000. This increase is being utilised to increase the staffing level at the Association in order to provide more support services to members, particularly those who attend the Stroke Recovery Clubs/groups/choirs.

Staff have again been successful in working with Clubs/groups/choirs to source monies from the ClubsGrants programme.

The Association is also very appreciative of the bequests that were received from the Estates of Ann Whetton, Shenay Yusuf and Jane Frolich. The combined amount received from these estates was just under \$250,000. A major boost to our retained earnings.

The amounts noted in the auditor's report for Clubs/groups/choirs is the overall revenue received by all the Clubs/groups/choirs of \$71,784 and their overall expenses of \$60,876 for the 2021/2022 financial year. These figures continue to be incorporated into our audited statement, as required by the Australian Not-for-Profit and Charities Commission, however, they no longer greatly impact on the Association's bottom line figure as they did last year when they were first included.

As we move into the 2022/2023 financial year, we are in a very strong and viable financial position with a total cash reserve of \$1,689,629, an increase of \$178,291 or 12% on last year's position.

Our retained revenue will be managed carefully to enable the Association to continue to grow and move forward. Some of this cash reserve has been used to employ administrative support for the Association's office. This is an expense we will continue to incur in future years.

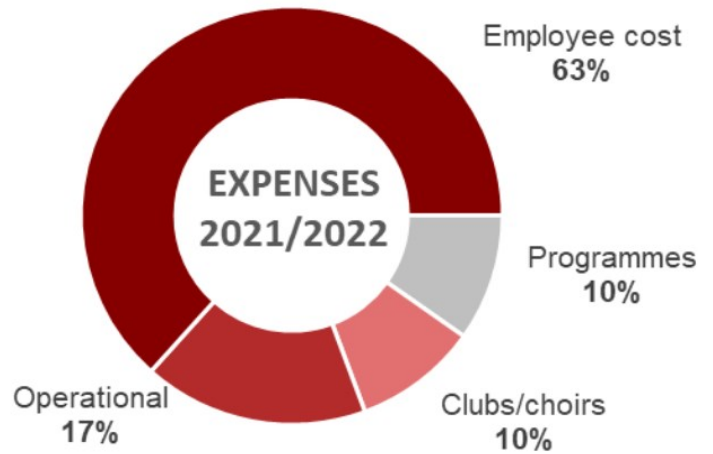
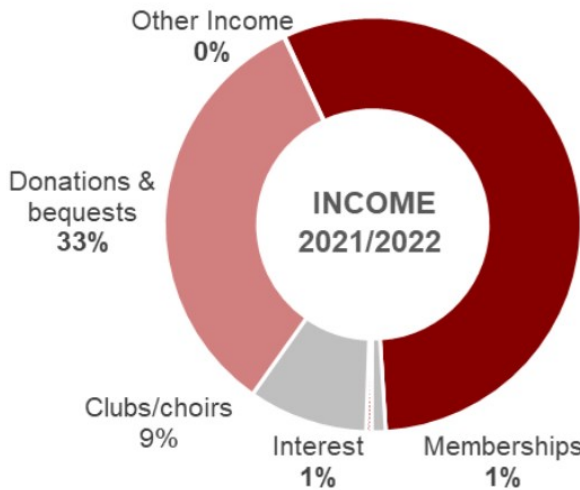
The Board is acutely aware of the ever-increasing legislative burden on the Association and our Clubs/groups/choirs, particularly the volunteers. It is imperative that the Board monitors the spending of monies diligently to ensure that our legal obligations are fulfilled. It is vital that we maintain our status as a charity and strictly comply with the new processes of the Australian Not-for-Profit and Charities Commission. Financial diligence remains a primary concern of the Board.

The Board would like to acknowledge the extra work undertaken by the financial manager, Cheryl Smith, and the treasurers of the Clubs and choirs who have worked diligently to ensure we comply with the requirements of the Australian Not-for-Profit Charities Commission.

The staff and Board express our appreciation for the outstanding work of our honorary auditor Vishal Modi from Nexia. A copy of the independent Auditor's Report is included on page 21 of this report.

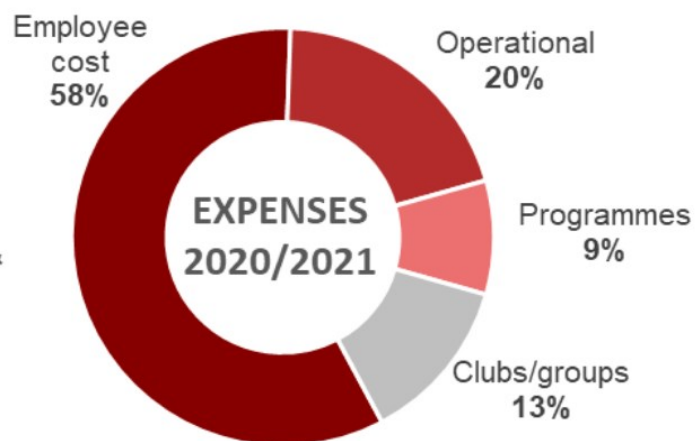
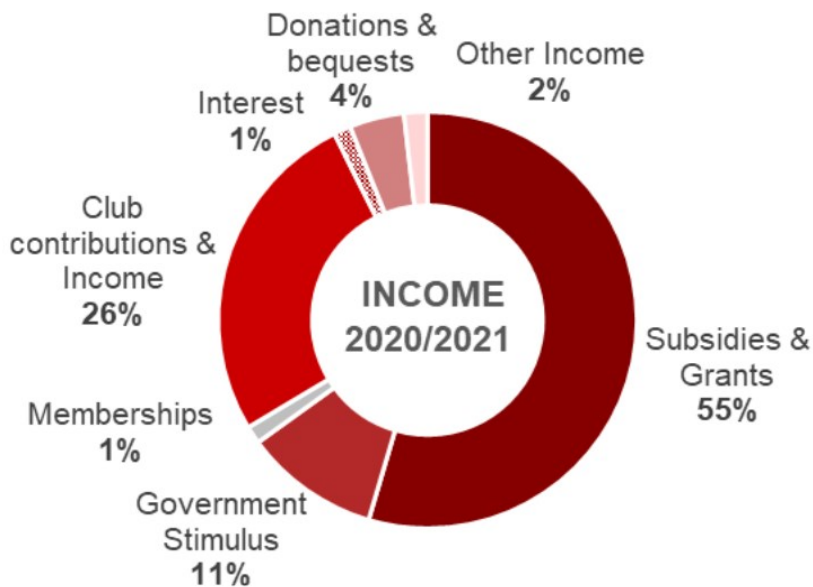
Financial position

This financial year - 2021/2022



Net position 2021/2022
+ \$ 152,829

Last financial year - 2020/2021



Net position 2020/2021
+ \$ 250,076



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MEMORIAL DONATIONS

The passing of a family member, friend or loved one is a very sad and stressful time. Sometimes, symbolic gestures and actions provide great comfort to those who are grieving.

It is with gratitude that the Stroke Recovery Association receives donations in memoriam. These donations, which assist us to continue our valuable work, are a wonderful remembrance of the person who has passed away. All donations received by the Association are tax deductible and can be forwarded to our postal address above. Acknowledgement will be sent to the family of the deceased.

The Association is happy to provide memorial donation pamphlets, which can be made available at a funeral service, with pre-paid addressed envelopes. Thank you for your support.

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