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## SUBMISSION IN RESPONSE TO THE AUSTRALIAN GOVERNMENT DEPARTMENT OF SOCIAL SERVICES CONSULTATION PAPER

### **National Disability Advocacy Program**

## Background to stroke in Australia

Before addressing the National Disability Advocacy Program (NDAP) consultation paper, the Stroke Foundation would bring to your attention a brief background on issues faced by stroke survivors and their carers.

This year alone, there will be over 50,000 strokes in Australia. Some of those strokes will lead to death, while others will be minor and not impact much on future quality of life. However, there will be many that will require individualised care for anywhere from a few months to the rest of their lives.

It is estimated there are over 450,000 stroke survivors living in Australia and that two-thirds of those live with a disability that requires them to receive daily care.

Stroke is a life changing event – for the stroke survivor and their carer. It is a complex and highly individual health condition. It happens suddenly, and is not well understood in the community. Many people will have little knowledge about stroke before it happens to them or to a loved one. Lack of knowledge increases the difficulties experienced after stroke and can leave people ill-equipped to participate in decisions about their treatment and care. Lack of knowledge in the general community also has a negative impact on the availability and quality of social support for stroke survivors and carers.

Many stroke survivors, carers, family members and friends rely on a range of services and supports to guide stroke recovery and the ability to self-advocate for access to these supports varies widely. The Stroke Foundation plays an important role in making information available to people impacted by stroke regarding stroke treatment, care, impact and recovery options. While we don't provide a formal advocacy service we do engage regularly with survivors and carers to provide information and advice. On occasion this service can extend to informal advocacy as required by individual cases. Our engagement is done primarily through an inbound telephone service called StrokeLine and through an outbound telephone-based patient follow-up and referral service. Due to resource constraints the outbound service is currently only servicing Queensland stroke patients however from 1 July 2016 the service will be extended to a proportion of Victorian and New South Wales patients. We also engage with survivors and carers through an online information service called enableme ([enableme.org.au](http://enableme.org.au)). The Stroke Foundation established this online community as a platform for stroke recovery and it serves to improve an individual's ability to self-advocate. It includes a wide-range of information and self-recovery support tools including template recovery plans and a growing peer support network.

Without information and support, many stroke survivors and their family are not always aware of what is required, let alone available, to maximise their chance for a full recovery. This can lead to feelings of being overwhelmed and even depression. By providing this information and support, the Stroke Foundation has helped many stroke survivors and their families regain control of their lives and to improve their ability to advocate for themselves. Despite this we know there is a level of demand from our community for advocacy support services.

## Response to the consultation paper questions

### Models of advocacy

**1.1** *How do people with disability, their families and carers benefit when agencies are funded to provide only one or two models of support?*

**1.2** *What are the drawbacks?*

### **1.3** *How do we value and support the various models of advocacy while ensuring equitable access to individualised, fit-for-purpose advocacy, regardless of location?*

The main benefits of agencies with only one or two models of support are the expertise that they provide in their area of specialisation. However, there are potential drawbacks with many of these being small organisations that may not be large enough to absorb the administrative burdens and reporting requirements when fulfilling their funding obligations.

Regarding equitable access to individualised advocacy, as noted earlier, the Stroke Foundation does not provide a formal advocacy service to stroke survivors and carers. Through our, often personalised, information and service referral programs, however, we do support development of self-advocacy skills and there are times when these services tend towards personal advocacy. Key support that we provide to those impacted by stroke includes the telephone services and online community (enableme) that are described elsewhere in our response. enableme ([www.enableme.org.au](http://www.enableme.org.au)) is a relatively new online resource having been launched last year and feedback from users has been positive.

The Stroke Foundation would recommend consideration of existing information and referral services when considering disability advocacy strategies.

## **Improving access to advocacy supports**

### **2.1** *How do we improve access for:*

- *people with disability from Aboriginal and Torres Strait Islander communities and their families?*
- *people with disability from culturally and linguistically diverse communities and their families?*
- *people with disability in rural, regional and remote locations?*
- *people who are very socially isolated including those with communication difficulties and those in institutional care?*

### **2.2** *What are the strategies or models that have worked? What are the strategies that do not work?*

Given the wide spectrum of stroke impact experienced by survivors and their families we have found that the best approach is to develop systems that enable access to information and support at the right time and in the right place. We also know that specialist knowledge and skills are needed to address the many and varied needs of stroke survivors. While mainstream supports provide some value there can be a lack of stroke specific knowledge that leaves stroke survivors short of the information and support they require.

The Stroke Foundation would encourage consideration of how existing services and information channels operated by non-government groups, especially disease specific groups, could be incorporated. This is an area of strong interest to the Stroke Foundation as we know stroke survivors and carers often don't receive the information and support they need for their recovery journey and this often leads to problems down the track which may result in the need for advocacy services.

Some stroke survivors have cognitive, vision, or speech issues, making it hard to communicate. This can be in addition to physical disability. It is estimated that two-thirds of stroke survivors live with a disability that requires them to receive daily support.

There are also other groups such as Aboriginal and Torres Strait Islander, those from culturally and linguistically diverse communities as well as vulnerable communities who we know find it harder to access information and support services. Access issues can also impact those in more remote areas where services are fewer.

Our view is that disease specific programs, such as those operated by the Stroke Foundation can have a positive impact. These programs can also help avoid the need for disability advocacy services in the future.

The Stroke Foundation's StrokeConnect program was developed to address a known gap in provision of information and support services to stroke patients and their carers. The program includes an in-hospital information resource called My Stroke Journey, an online resource called enableme ([enableme.org.au](http://enableme.org.au)) as well as an inbound (StrokeLine) and outbound telephone service.

In terms of raising awareness and providing information early in the stroke journey the Stroke Foundation has found liaison with patients and carers in the acute hospital setting to be of enormous value. To meet the early information needs of patients and carers we have developed an information pack called My Stroke Journey. The resource is designed to inform patients and carers about stroke and prompt them to ask questions before leaving hospital. It is also a longer term support tool for when they get home as they are able to refer to it as the post-hospital recovery journey begins. This is particularly important in more rural areas.

The enableme website is dedicated to stroke recovery and support. It acts as a gateway to information and resources for stroke survivors and their carers and is also a valuable peer support network. The site contains tips and tools that have been shared by other stroke survivors and their carers, as well as information provided by health professionals. The enableme community includes discussion forums, blogs, podcasts and a 'ask a health professional' section.

For those needing immediate assistance the Stroke Foundation's StrokeLine inbound call service operates during business hours to provide information and support to patients and carers. This includes advice on who to contact to manage and resolve issues or to access services. It is not uncommon for carers to call StrokeLine from hospital to get information about what they should be expecting from their care and how to prepare to go home.

The Stroke Foundation also provides an outbound follow up service called StrokeConnect Follow Up however due to resource constraints this does not currently reach all stroke patients in Australia. This service is delivered in partnership with hospitals whereby patients and their carers are contacted by phone in the period around 6-8 weeks following discharge from hospital for a needs assessment. Issues can then be discussed and information and advice about support services is given. Importantly patients and carers are then linked in to a longer term support network where they know they can return to for advice.

This pathway is designed to ensure that stroke patients and carers get the information and support they need to manage and recover from their stroke.

Providing stroke survivors and their carers with the above recovery support services provides them with the skills and the confidence to become better self-advocates and hopefully be less reliant on formal advocacy services throughout their recovery journey.

## Improving the advocacy evidence base and coordination on systemic issues

**3.1** *What mechanisms could be used to ensure information on systemic issues gets to the right people and organisations?*

**3.2** *How can we help disability advocacy organisations work with a wide range of other organisations with similar aims, such as:*

- *disabled people's organisations (DPOs)*
- *the Australian Human Rights Commission*
- *Ombudsman organisations*
- *aged care advocacy organisations*
- *state disability advocacy organisations*
- *peak bodies?*

The Stroke Foundation supports the use of data to inform service mapping and ongoing monitoring. We also support the concept of data transparency and of broad collaboration with other organisations with similar aims.

As a national organisation with a specific focus on stroke and supporting stroke survivors and their families we have built a body of knowledge about the needs of our community and the challenges they face when it comes to accessing supports and services. While we don't currently provide formal advocacy services to stroke survivors we would have an interest in engaging with organisations who do and with government agencies responsible for commissioning and monitoring these services. Our interest would be in understanding current levels of access as well as potential gaps in access from our community. We would welcome any opportunity to share relevant information about stroke survivor and carer needs and to discuss how the programs and services we currently deliver are of relevance and benefit to stroke survivors and their families.