



Registered Charity  
ABN 42 006 173 379  
Level 7, 461 Bourke Street  
Melbourne VIC 3000  
Telephone 03 9670 1000  
StrokeLine 1800 STROKE (1800 787 653)  
strokefoundation.org.au

Australian Government  
Department of Social Services  
GPO Box 9820  
Canberra ACT 2601

15 December 2016

To whom it may concern,

Thank you for the opportunity to comment on the Australian Government Department of Social Services' (DSS) discussion paper on the draft service delivery model for a proposed new carer support service system. As a national not-for-profit organisation working across the stroke journey, the Stroke Foundation assists stroke survivors, carers, health professionals, governments and the public to reduce the impact of stroke on the Australian community.

As explained in our previous submission to the DSS, stroke is a life changing and sudden event for both the survivor and their carer. Poor understanding of stroke in our community increases the level of difficulty experienced after stroke and leaves people ill-equipped to participate in decisions about their treatment and care. This year alone, there will be over 50,000 strokes. Some of those strokes will lead to death, while others will be minor. Every stroke is a medical emergency, requiring rapid diagnosis and access to specialist stroke unit care to maximise the chance of a good recovery. For many stroke survivors and their carers, the impact is sudden and devastating. They face a recovery process which is long and challenging. There will be many that will require individualised care and support for activities of daily living for months and for some survivors until the end of life.

Stroke Foundation national audit data shows that stroke survivors and carers often do not receive the information and support they need for their recovery journey, despite the availability of specific resources to hospitals. The Stroke Foundation has developed StrokeConnect, a suite of resources designed to support stroke patients and their carers, ensuring they are better prepared for life after stroke. The StrokeConnect program includes:

- [My Stroke Journey](#) – delivering high quality information to stroke survivors, their family members and carers, and designed to support care planning and the transition from hospital to home;
- [Enableme](https://enableme.org.au/) – a website dedicated to stroke recovery and support aimed at survivors and their carers (<https://enableme.org.au/>);
- [StrokeLine](#) – a telephone service manned by health professionals providing information and advice on stroke prevention, treatment and recovery; and
- [StrokeConnect Follow Up service](#) – an outbound service where health professionals deliver information, advice and support to better manage health and stroke recovery following discharge from hospital.

Continued over

These services can make a huge difference to survivors and their carers after a stroke, but unfortunately, resource constraints limit their reach. We believe the StrokeConnect program should be available to all stroke survivors and their carers to ensure that they can receive access to appropriate community and social services to maximise their chance of a good recovery.

### **Encourage and normalise earlier uptake of services proven to help carers**

The Stroke Foundation supports the intention of the integrated carer support service proposal to encourage carers to seek support and services earlier in their caring journey. The Acute Stroke Clinical Care Standard (developed by the Australian Commission for Safety and Quality in Health Care) states that 'A carer of a patient with stroke is given practical training and support to enable them to provide care, support and assistance for a person with stroke<sup>1</sup>. As stated in our submission earlier this year<sup>2</sup>, National Stroke Audit Data (2015) found the proportion of stroke patients whose carer received a documented formal needs assessment was only 59 per cent, with only 48 per cent receiving carer training.

For the families of stroke survivors, hospital admission is often the point where the caring role begins. So whilst the objective to 'encourage and normalise earlier uptake of services proven to help carers in their caring journey' is positive, the Stroke Foundation is disappointed the acute health sector is not specifically identified in the proposed delivery mechanisms, with the focus instead on primary health, schools, community and cultural groups and organisations<sup>3</sup>. We believe that an awareness raising strategy specifically aimed at the acute health sector would help achieve the Department's objective to encourage earlier uptake of carer services, and would like to see a greater emphasis on this sector as a mechanism for change.

### **Regional Hub Program: provide high quality coaching and mentoring to carers, relevant to their circumstances and needs**

The draft service delivery model proposes providing carers with information and advice, tailored to their needs and circumstances, noting that this may also include helping carers link to services or supports that may not be directly funded by the integrated carer support service.<sup>4</sup> The Stroke Foundation is pleased the strategy recognises that many organisations outside the DSS provide support to carers. Information provision must be tailored to a carer's individual situation or it is of limited value. Carers of stroke survivors are often thrust into the role without sufficient information about stroke in general, and because stroke occurs suddenly, many carers are required to immediately change their lifestyle.

StrokeLine, the Stroke Foundation's telephone support service, often receives calls from family members of survivors in hospital in the days after a stroke has occurred. However, staff also regularly respond to calls from family members months after discharge, when the reality of their new 'normal' starts to hit home. The needs of people caring for stroke survivors are often complex and varied, and require a specialist knowledge of stroke. A clear framework for managing calls from carers of stroke survivors, including circumstances where calls are referred to the Stroke Foundation's StrokeLine, and vice versa, will provide a better experience for carers. The Stroke Foundation would like to confirm that these pathways are being developed as part of the implementation strategy, and that we will be consulted as part of this work.

---

<sup>1</sup> Australian Commission for Safety and Quality in Health Care – Acute Stroke Clinical Care Standard 2015  
<https://www.safetyandquality.gov.au/our-work/clinical-care-standards/acute-stroke-clinical-care-standard/>

<sup>2</sup> [https://engage.dss.gov.au/integrated\\_carer\\_support-submissions/1466058013/](https://engage.dss.gov.au/integrated_carer_support-submissions/1466058013/)

<sup>3</sup> <https://engage.dss.gov.au/a-new-integrated-carer-support-service-system/discussion-paper/> page 7

<sup>4</sup> <https://engage.dss.gov.au/a-new-integrated-carer-support-service-system/discussion-paper/> page 18

## **Essential components of a future quality framework**

In keeping with the Stroke Clinical Guidelines, the Stroke Foundation supports carer needs being addressed via a formal needs assessment as part of the stroke care pathway especially within the hospital setting. Where it is the wish of the stroke survivor, the guidelines recommend that carers should be actively involved in the recovery process by assisting with goal setting, therapy sessions, discharge planning and long-term activities.

The Stroke Foundation welcomes the move by the department to improve the care journey for all carers, who are often a forgotten part of our community. We encourage the DSS to deliver on a strategy that responds to the cultural diversity of our nation. All stroke survivors and their carers should have access to the services that make up the StrokeConnect program, including StrokeLine, My Stroke Journey and follow up support. Carer training prior to hospital discharge where it is needed should be made more readily available, and appropriate support, including respite is also essential. Carers provide one of society's most important functions and the Stroke Foundation supports strategies designed to improve services and support to carers.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Sharon McGowan', with a stylized flourish at the end.

**Sharon McGowan**  
**Chief Executive Officer**

