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

DESIGNING THE NEW INTEGRATED CARER SUPPORT SERVICE

Background to stroke in Australia

Before addressing the discussion paper, the Stroke Foundation would bring to your attention a brief background on issues faced by carers of stroke survivors.

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 leaves 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.

This year alone, there will be over 50,000 strokes. 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.

Stroke survivors, carers, family members and friends therefore rely on the Stroke Foundation for information on stroke treatment, care, impact and recovery. The Stroke Foundation begins providing people with information and support immediately after their stroke and continues for as long as required.

Partners of stroke survivors are often left without a clear understanding of what the future holds, and it can take a while for people to identify as carers. The Stroke Foundation's telephone support service, StrokeLine, often receives calls from partners months after discharge, when the reality of their 'new normal' starts to hit home. They approach the Stroke Foundation as they can see the changes in their life and the challenges they face as directly related to the stroke. These initial conversations often involve discussion of the transition from partner to carer, and education about the services and supports that can help. **Disease-specific helplines are often a first point of call, and are vital in raising awareness of carer supports and services.** Partners often need to be supported to see themselves as carers in order to see that carer services are relevant to them. Once this is done, easily accessible single access points greatly assists helplines such as ours in ensuring that taking the next step is as easy for people as possible.

StrokeLine also receives many calls from partners who have decided that they do not want to make the transition to carer. Health and community services often operate from the assumption that those closest to the stroke survivor will make the transition to carer and partners often feel they have little choice. Calls to StrokeLine from partners considering leaving their relationship are common, and people are seeking two things – a safe place to discuss how they are feeling, and advice on how they might relinquish care safely and well. It will be important for any integrated carer support service to consider how they will help partners in this situation, and how they will raise awareness of the support they can provide to these consumers.

The Stroke Foundation conducted a carer survey in 2011 and found that prior to taking on a carer role 40% reported a moderate to extreme reduction in the amount of work or study that they were able to perform. Of the carers that participated in leisure activities prior to taking on a carer role, almost half (47%) reported a moderate to severe reduction in the number or type of leisure activities that they were able to participate in. Of carers that were the partner or spouse of the stroke survivor, almost one in three (31%) reported moderate to extreme changes in their relationship. Many carers also reported moderate to extreme changes in their relationships with other family members (20%) and with other people outside the family such as friends (32%). Despite these large impacts, only one in four (23%) reported attending a carer support group. However, of those that did not attend a support group (13%) reported that they would have liked to have attended and 21% were not aware of any support groups.

These are but some of the issues that carers of stroke survivors bring to our attention on a daily basis. The design of the new integrated carer support service provides the opportunity to ensure that the necessary supports are put in place and that these carers are not forgotten.

Response to the proposed services

Awareness, information and intake

In terms of design considerations for the integrated carer support service 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.

A good example is the Stroke Foundation's StrokeConnect program, which 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) as well as an inbound (StrokeLine) and outbound (StrokeConnect Follow Up) telephone service.

The Stroke Foundation agrees that 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, let alone the more specific information relevant to the stroke survivor's individual needs. Because stroke occurs suddenly, many carers are required to immediately change their lifestyle. This can include dramatic reduction or cessation of work and social activities, to ensure they can provide the care needed. This often leads to the carer becoming overwhelmed with everything they need to do when the recovery journey starts at home.

In terms of raising awareness and providing information early in the caring 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. Where resourcing allows we work directly with hospitals to support the dissemination of these packs to stroke patients and their families/carers before discharge from hospital. My Stroke Journey includes information about what to expect in hospital, how to prepare for recovery at home and includes a separate section on carers. The resource is designed to inform patients and carers 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.

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. While ideally all elements should be in place, we know that each element on its own has a positive impact. As the integrated carer support service is further developed we would encourage consideration of these sorts of existing services to meet the needs of specific carers within the broader caring community.

Education and Peer Support

Education is important for carers of stroke survivors as the individual experience of stroke can be unique. From speech issues, to cognitive issues to physical limitations, stroke survivors present a complex set of issues that carers are often required to address on a daily basis.

Carers of stroke survivors should be able to expect a formal needs assessment as well as carer training. Both are recommended within the Clinical Guidelines for Stroke Management 2010 and the Acute Stroke Clinical Care Standard developed by the Australian Commission for Safety and Quality in Health Care.

Quality Statement 6 in the Standard:

A carer of a patient with stroke is given practical training and support to enable them to provide care, support, and assistance to a person with stroke¹

Data from the National Stroke Audit 2015 unfortunately shows that many are still missing out on this important element of the care pathway. The proportion of stroke patients whose carer received a documented formal needs assessment was only 59%. When it came to training this figure was only 48%. While these figures are an improvement on the results from 2013 they show a significant gap in carer support and reinforce why the Stroke Foundation has focused efforts on developing information and support materials as well as practical strategies to see this information disseminated.

Of course, dissemination of information is one of our biggest challenges and further to our comments in the previous section we would encourage consideration of how the new integrated carer support service can assist in promoting existing services and information channels so that more carers are aware of them.

Regarding peer support, many people find support groups and services essential and rewarding, while others do not like meeting in big groups. Online communities have the potential to be important sources of support for people who don't like the idea of attending a support group, or who do not have access because there is not one in their area or because it is impractical for them to attend. Our previously mentioned website, enableme is designed to meet this need. Online communities can take the benefits of peer support, remove the barriers and make them more broadly available. What is imperative, however, is that everyone is made aware of these services and the best way to discover and connect

¹ Australian Commission on Safety and Quality in Health Care. Acute Stroke Clinical Care Standard. Sydney: ACSQHC, 2015.

with disease specific support groups is through disease specific websites. Therefore, it is advisable to stipulate this on the Carers Gateway and carer organisations' websites and provide links where possible.

Multi component intervention

The Stroke Foundation supports the multi component intervention, particularly as it addresses the three areas of highest need faced by carers of stroke survivors:

- Financial support
- Carer mentoring
- Respite support

As discussed above, carers of stroke survivors are placed in a carers role overnight and can sometimes struggle with basic requirements such as the opportunity to organise finances, and other requirements to best take care of the stroke survivor. The Stroke Foundation conducted a survey of survivors and carers in 2012. Of the stroke survivors that were working prior to their stroke, 71% reported a change in their work activities since their stroke. Over half of these reported that the change was moderate to extreme. About 60% of survivors that needed help returning to work did not receive any or enough help returning to work. While some of those at working age may be fortunate enough to initially rely on sick leave and annual leave, this doesn't last forever and many do find themselves applying for carer support payments. Additional expenses are often incurred for home modifications and frequent trips to therapy sessions. Over 36% of those surveyed by the Stroke Foundation reported a loss in income since having their stroke, while 60% reported an increase in expenses. Almost half (42%) reported needing some form of financial assistance or advice.

Multi component intervention is an important design concept that fits in well with the needs of our carers at the beginning of their carer journey. It affords them the opportunity to deal with the initial traumatic stages of getting home and being overwhelmed with access to respite support until they are confident in their ability to provide the carer function. It also provides the opportunity for carer mentoring, in concert with respite support, to help them deal with the many issues faced by carers. It also provides the financial assistance to help them travel to appointments, both with the stroke survivor and by themselves.

Stroke survivor carers are in a unique position, in that the hardest days for caring are often just after a stroke has occurred. In many cases stroke survivors will improve to some degree and require less intensive caring after a period of time, depending on the severity of the stroke. Sometimes carers can stop caring after a few months. However, carers aren't always aware of what is to be expected and can quickly become overwhelmed – even if the expected period of care is short.

Multi component intervention at the earliest opportunity for stroke survivor carers will be of benefit and could help to avoid situations where carers need more serious assistance to help them cope with conditions, some of which (like depression) can last long after the carer function ceases.

Needs identification and planning

The Stroke Foundation advocates for carer needs to be addressed as part of the stroke care pathway especially within the hospital setting. This is in line with stroke clinical guidelines which recommend that carers of stroke patients receive a formal needs assessment. 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.

Following discharge from hospital we advocate for follow up of patients and carers to ensure they have the information and support they need. At this point carers can be referred to appropriate community

services or other avenues including online support (enableme), peer support groups or health professional support. Just as every stroke survivor's journey after their stroke is unique, so too is that of their carer.

In summary, 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. Carers provide one of society's most important functions and there needs to be service structures in place to provide support that we know can make their jobs easier.

The Stroke Foundation reiterates its view that disease specific groups and organisations already play an important role in supporting and advocating for carers and that there should be consideration for how existing services and infrastructure can be incorporated and supported within any integrated carer support service. We would welcome further discussions about how to enhance linkages to further improve the ability of carers to receive the information and support they need, when they need it.