

## Public consultation feedback and response Stroke Living Guidelines Updates

January 29 – March 13, 2024

Feedback from individual or group	Organisation	Topic	Feedback	Actions taken
Group 30.01.24	Canberra Health Services and ACT Health Directorate	Self-management	<p>Thank you for your email to provide Canberra Health Services with the opportunity to consider feedback to your public consultation process.</p> <p>This information has been shared with our clinical teams who have been advised to provide feedback through your suggested options.</p>	n/a
Individual 20.02.24	Living Stroke Guidelines Consumer Panel	Self-management	<p>Thank you for sharing. I think this is an excellent recommendation. Survivors may find themselves more motivated and invested when they have the ability to be part of the planning process rather than simply on the receiving end of advice and directives from health care professionals.</p>	n/a
Individual 23.02.24	Living Stroke Guidelines Consumer Panel	Self-management	<p>Within the guideline: Recommendation section:</p> <ul style="list-style-type: none"> <li>• Please define Self-Management – it may mean different things to different people and we need to be clear as to what exactly the Guideline is addressing. Once self-management has been defined, it will need to be decided as to whether there is adequate supporting evidence for this guideline as it stands.</li> <li>• The Primary objective involved the physical component of recovery, however self-determination involves much more than this, it involves autonomy and being self-directed, and it involves self-advocacy, and fighting against systems who view this as non-compliance. For the mid 70 year old age bracket in this study, who are likely retired and have less constraints on them systemically or structurally, perhaps the application of this RCT was adequate and focussed primarily around the physical component. However, from my experience, it is a lot more complicated than what was reported in the Taking Charge RCT paper; it is for this reason that I suggest defining Self-Management for the</li> </ul>	<p>Thank you for your feedback and questions. Within the guideline: Recommendation section</p> <ul style="list-style-type: none"> <li>•Self-management is defined in the introductory text ("management of tasks that individuals must undertake to live with one or more chronic conditions.") It may also be useful to know that the self-management topic of the guidelines also includes an existing recommendation which discusses other forms of self-management that may give context to this point.</li> <li>•We agree self-determination theory does involve more than physical recovery. We have added further discussion into the practical consideration regarding this.</li> <li>•While the study is titled "Taking</li> </ul>

		<p>purposes of this intervention so readers can ascertain whether it covers all aspects of self-determination of only a couple of aspects.</p> <ul style="list-style-type: none"> <li>• Just a typo correction – the intervention is called the ‘TakING Charge After Stroke’ intervention, not Take Charge.</li> </ul> <p>Benefits and harms section:</p> <ul style="list-style-type: none"> <li>• The guideline says that the ‘TakING Charge’ program involved a ‘talking therapy aiming to facilitate self-management of stroke recovery’.</li> </ul> <p>A hand book was handed out with pictures and topics suggested for discussion within the reported Taking Charge intervention. I don’t know if this can be called a therapy, or rather an information discussion session focussed on self-determination. I don’t know that 1-2 sessions of such discussion equate to a therapy.</p> <p>Certainty of evidence:</p> <ul style="list-style-type: none"> <li>• This was assessed as moderate. How did you get to moderate – there is really not much evidence collected here yet.</li> </ul> <p>Within the Taking Charge RCT paper:</p> <ul style="list-style-type: none"> <li>• At first glance this looks to be a very exciting paper, and I still believe that education sessions on self-determination would be most helpful to stroke survivors if geared to age/life stages and would likely assist them in achieving better outcomes, however as it stands this RCT needs more work, or needs further methods and data written up.</li> <li>• The intervention was developed and refined in line with Self-Determination Theory, which the RCT acknowledges proposes better outcomes for people with enhanced autonomy, competence, and relatedness. In an absence of a definition for self-determination as applied within the RCT, I can only assume that this provides the definition for self-determination. But I don’t know any of these were directly measured and yet it is they which would likely influence the improved outcomes experienced by participants.</li> <li>• The workbook offered to participants covered mobility, ADLs, communication, info needs, financial issues and emotional needs, along with supports and stroke prevention. So it is these that were discussed across 1-2 sessions. This is great and should be available to stroke survivors, and yet what was measured were physical outcomes and ADL’s, not autonomy over finances, or self-determination impacting changes in relationships after stroke, or workplace accommodations and</li> </ul>	<p>Charge After Stroke (TaCAS)” the intervention itself is called “Take Charge”.</p> <p>Benefits and harms section:</p> <ul style="list-style-type: none"> <li>•The working group noted your comments. In this instance therapy is a broad term reflecting intentional efforts to help the stroke survivor recover valuable life after stroke. The main focus of the intervention was the ‘talking therapy’ and the booklet was deemed to be a secondary component.</li> </ul> <p>Certainty of evidence:</p> <ul style="list-style-type: none"> <li>•We use the GRADE methodology to assess certainty of evidence. Several factors are considered including quality of study design. We have arrived at “moderate” strength as the evidence involved 5 trials overall but the main evidence was the “Take Charge” evidence which are relatively large trials (n=400 &amp; n=172) across 2 different populations, with consistent results and good study methods compared to other evidence previously reported.</li> </ul> <p>Within the Taking Charge RCT paper:</p> <p>It was the view of the working group that while not perfect this evidence is sound and the benefits clearly outweigh any risks. The intervention was geared to milder strokes within a common age range. Further evidence may highlight if certain patient groups will respond more</p>
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Group 28.02.24	NSW Health (Agency for clinical innovation)	Self- management	The NSW Agency for Clinical Innovation Stroke and Rehabilitation networks have reviewed the amendments and are supportive of the proposed new recommendation about patient led rehabilitation. Broader consultation with NSW clinicians will also be supported by the dissemination of your feedback request via the Agency for Clinical Innovation clinical networks.	n/a

Individual 13.03.24	Living Stroke Guidelines Consumer Panel	Self-management	My comment to the draft recommendations is “directed by stroke survivors who have been trained...” or “directed by trained stroke survivors”. Without training there is a lot of scope for well meaning stroke survivors to do damage without realising the negative impact. Training provides an opportunity to recognise different perspective on self-management.	Thank you for your comments. For this recommendation, the self-management intervention is facilitated by a trained clinician (nurses or physiotherapists), but the topics and conversations are directed by the stroke survivors. We have added details into the rationale to ensure readers understand this clearly (information is already in the practical information section).
Individual 25.03.24	Medical Research Institute of New Zealand	Self-management	Supportive without additional feedback	n/a
Individual 25.03.24	Hawke's Bay District Health Board	Self-management	Supportive without additional feedback	n/a
Individual 25.03.24	National Clinical Stroke Network	Self-management	Supportive without additional feedback	n/a
Group 10.04.24	Austroads	Self-management	We have reviewed the content, and we don't have any specific changes to the self-management section. However, for future reference we are interested to understand how the self-management approach and process might support people with a driving need after stroke. We continue to discuss the management of driving and stroke with our stakeholders and look forward to providing input on these aspects in the future.	n/a