

SHARED DECISION-MAKING GUIDE FOR STROKE SURVIVORS WITH MODERATE TO SEVERE DISABILITY

Purpose of the Shared Decision-Making Tree and Guide

This Shared Decision-Making (SDM) Guide is designed to accompany the **SDM Tree** to support clinicians through a process of SDM with stroke survivors and caregivers. The aim of this SDM process is to develop a personalised physical rehabilitation program via telehealth for stroke survivors with moderate to severe physical disability. For simplicity, physical rehabilitation via telehealth will be referred to as 'telerehabilitation'.

SDM is a process by which all parties (stroke survivors, caregivers and clinicians) make decisions using the best available evidence and informed preferences (1). It involves discussion and collaboration between all parties. It takes into account stroke survivor and caregiver's values, priorities and preferences as well as the benefits, risks and uncertainties of treatment. Using a structured SDM process, including decision aids, can increase knowledge; agreement between values and final decisions; and overall satisfaction with the decision-making process (2).

Intended users of this guide

This guide and the **SDM Tree** are designed to be used by clinicians to support stroke survivors and their caregivers to create and implement a personalised telerehabilitation plan. It was primarily developed to support shared decision-making with stroke survivors with moderate to severe physical disability, however, the process may be suitable for other groups.

When to use this guide

This guide and the **SDM Tree** should be used when it is first identified that telerehabilitation could be included in a stroke survivor's rehabilitation plan. This may be early during the acute phase of recovery while the stroke survivor is an inpatient. The rehabilitation plan should be reviewed at regular intervals during the stroke survivor's rehabilitation journey.

How to use this guide

As a clinician, your role is to assist the stroke survivor and their caregiver through the decision-making process. This includes:

- Assessing and addressing decision-making needs
- Providing information on available options
- Verifying understanding of available options
- Clarifying and discussing values and outcomes
- Teaching skills in communicating preferences
- Assessing decision quality and implementation needs

We have identified a range of resources which may assist you at each step. This list of resources is not exhaustive, and these are suggestions only; you are free to select the resources which best help you, the stroke survivor and caregiver.

The suggested language provided in the right-hand column of the guide may assist you to support the stroke survivor and caregiver through each step of the shared decision-making process. Ideally, your role during shared decision-making is to share information, rather than give advice. Tailor the suggested language to suit each person's communication style and needs including language ability, cultural background and information needs.

The following information will assist you to work through each step of the SDM Tree:

Key stages of SDM	Explanation of key actions at each step of SDM process	Suggested language
Consider the shared decisions	Before you begin: Consider the shared decisions you need to make together	
	<p>The shared decisions which need to be considered during this process are listed in the SDM Tree in the blue row.</p> <p>The decisions you need to make together are:</p> <p>How will rehabilitation be delivered?</p> <ul style="list-style-type: none"> ▪ Could telerehabilitation be included in the stroke survivor’s care plan? ▪ Is telerehabilitation being offered alone or in conjunction with in-person rehabilitation? <p>If telerehabilitation will be included in the stroke survivor’s care plan:</p> <p>What can be done safely and effectively in telerehabilitation vs in-person rehabilitation?</p> <ul style="list-style-type: none"> ▪ What can be done in-person before and during telerehabilitation? ▪ What can be done via telerehabilitation, and how will this be done? ▪ If restricted, when can in-person rehabilitation recommence? 	
Starting shared decision-making	Step 1 - Clarify the decision(s) to be made	
	Step 1 is about making sure the stroke survivor and caregiver know what decision(s) they are facing.	<i>You may be able to receive some of your rehabilitation via telehealth. Can we discuss this</i>

	<p>Gather background information to inform which options are available to the stroke survivor and caregiver</p> <p>Background information may include any restrictions or barriers to in-person rehabilitation. E.g. restrictions on healthcare visits due to the COVID-19 pandemic. This may limit the options available.</p> <p>If there are no restrictions or barriers to in-person rehabilitation, consider whether:</p> <ul style="list-style-type: none"> ▪ The stroke survivor and caregiver may prefer to include telerehabilitation in their plan ▪ There are potential advantages for incorporating telerehabilitation in their plan <p>Inform the stroke survivor and caregiver about available options.</p>	<p><i>to work out what best suits you?</i></p> <p><i>You are eligible to receive rehabilitation either at home via telehealth, [in clinic/ at home] with a therapist, or a combination. I would like for us to discuss these three options to work out what best suits you.</i></p> <p><i>In-person therapy is limited/ may be difficult due to [reason]. One way to continue your rehabilitation is via telehealth. What do you know about telehealth and rehabilitation?</i></p>
	<p>Give the stroke survivor and caregiver the Decision Aid ‘Telerehabilitation Information Sheet for Stroke Survivors and Caregivers’. The decision aid provides information about telerehabilitation to help the stroke survivor and caregiver make an informed decision. There is a Brief Version and a Complete Version.</p> <p>Talk through this information with the stroke survivors and caregivers and provide and relevant additional information that is specific to them.</p> <p>If you are providing inpatient care to the stroke survivor, consider consulting without patient rehabilitation team to determine if telerehabilitation is available. This will help to:</p> <ul style="list-style-type: none"> ▪ Inform discharge planning ▪ Include telerehabilitation in goal setting if appropriate ▪ Ensure you provide accurate information about the options available to the stroke survivor and caregiver 	

	Communication between all members of the stroke care team (inpatient and outpatient clinicians) will ensure that accurate and consistent information about telerehabilitation is provided to the stroke survivor and caregiver.	
	Check the stroke survivor and caregiver understand the options: Ask them to describe in their own words the decisions they are facing and available options	<i>Can you tell me in your own words about the options you have?</i>

Gathering information to inform shared decision-making	Step 2 – Explore the decision(s)	
	Step 2 is about exploring the options available to the stroke survivors and their caregiver. This involves you providing stroke survivors and caregivers with information about telerehabilitation as well as exploring the risks and benefits. Stroke survivors and caregivers also need to provide you with information to inform the rehabilitation program at this step.	
	<p>You can use the resources highlighted in the SDM Tree to assist this step.</p> <ul style="list-style-type: none"> ▪ The Risk Assessment Guide can help identify potential risks and strategies to reduce risks. ▪ Further telerehabilitation resources can be found here in Appendix 2 <p>In addition, clinicians will need to provide any relevant local information. For example: service policies relevant to the decision, current service capacity, other usual processes.</p>	
	<p>Assess understanding:</p> <ul style="list-style-type: none"> ▪ Check understanding of all considerations, including: <ul style="list-style-type: none"> ○ options, ○ benefits, ○ potential harms/risks, ○ costs, ○ probabilities of outcomes 	<p><i>What do you know about stroke rehabilitation?</i></p> <p><i>What do I need to know about you (stroke survivor and caregiver) to help you in your rehabilitation?</i></p>

	<ul style="list-style-type: none"> Clarify any points that are unclear or uncertain. 	<p><i>Tell me what you know about the reasons to choose telerehabilitation (benefits)?</i></p> <p><i>What do you think may be difficult with telerehabilitation?</i></p> <p><i>What do you think may be some of the risks of telerehabilitation?</i></p> <p><i>How comfortable are you with each of the risks we've identified?</i></p> <p><i>What support is your caregiver able to provide? Are they comfortable doing this?</i></p>
	<p>Provide further information:</p> <ul style="list-style-type: none"> Try to align everyone's expectations about how telerehabilitation might help Provide information about what might be the outcomes for the stroke survivor and caregiver of including telerehabilitation in their plan. 	<p><i>That's right; You've got it.</i></p> <p><i>Did you know...?</i></p> <p><i>The research shows...</i></p>

<p>Gathering information to inform shared decision-making continued</p>	<p>Step 3 – Understand values and priorities</p>	
	<p>Step 3 is to ensure you understand the values, priorities and concerns of the stroke survivor and/or their caregiver to further develop the rehabilitation plan.</p> <p>You may also give some examples of what other people with similar problems have identified as goals at this step.</p>	
	<p>Clarify the stroke survivor and caregiver's values:</p> <ul style="list-style-type: none"> Assess the perceived importance of outcomes related to each option 	<p><i>What do you want to achieve during rehabilitation?</i></p>

	<ul style="list-style-type: none"> ▪ Assess their personal values ▪ Assess how their personal values affect the stroke survivor and caregiver’s preferred benefits and the risks they most want to avoid 	<p><i>What are your goals, or what do you want to improve?</i></p> <p><i>Which benefits of telerehabilitation are most important to you?</i></p> <p><i>What appeals to you about telerehabilitation?</i></p> <p><i>What concerns do you have about telerehabilitation?</i></p>
	<p>Provide some examples of:</p> <ul style="list-style-type: none"> ▪ potential SMART* goals; ▪ what you think is important to include in the rehabilitation plan; ▪ progress / outcomes of other stroke survivors with similar needs. <p>*SMART goals: <u>S</u>pecific; <u>M</u>easurable; <u>A</u>chievable; <u>R</u>ealistic; <u>T</u>ime-based</p> <p>Ask the stroke survivor and caregiver what their preferred options are based on the information discussed so far.</p>	<p><i>Some of the goals of other stroke survivors I have worked with have included...</i></p> <p><i>At this point, what do you think you could do or would like to do/try via telerehabilitation?</i></p>

<p>CHECK POINT Identify decision-making needs</p>	<p>Assessing and discussing decision-making needs</p>	
	<p>This checkpoint allows you to assess and/or discuss the decision needs of the stroke survivor and/or caregiver.</p> <p>Sometimes there can be decisional conflict, where there is personal uncertainty about which course of action to take when the choices involve risk, loss, regret, or a challenge to personal life values (5). Also, people’s self-confidence with making decisions can vary.</p>	

	The SURE Test can help you to identify decisional conflict quickly and assess the stroke survivor's/ caregiver's decision-making self-efficacy (see Appendix 1).	
	Assess the involvement of others in the decision: <ul style="list-style-type: none"> Ask about who else is contributing to the decision (consider if others are offering opinions, support or pressure for or against available options) 	<i>Who else is/should be involved in the decision?</i> <i>Are you feeling pressure from anyone to choose a specific option?</i> <i>How could they support you?</i>
	Develop the skills and confidence of the stroke survivor and caregiver in decision-making: <ul style="list-style-type: none"> Assist the stroke survivor and caregiver to communicate their preferences Offer support to assist them with handling with any pressure from others 	<i>Whose opinion is most important to you?</i> <i>What role do you prefer in making the choice?</i>
	Continue to explore the decision-making needs of the stroke survivor and caregiver: <ul style="list-style-type: none"> Ask follow-up questions 	<i>Do you know the pros and cons of each option?</i> <i>Are you clear about which pros and cons matter most to you?</i> <i>Do you have enough support and advice to make a choice about your rehabilitation plan?</i> <i>Do you feel confident about the best choice for you?</i>

Making shared decisions about the inclusion of telerehabilitation in the plan	Confirm all shared decisions
	Confirm the shared decisions and agree on the telerehabilitation plan.
	In step 1, you decided on one of the three available options:

	<ol style="list-style-type: none"> 1) Combination of ‘telerehabilitation + in-person’; or 2) Telerehabilitation only; or 3) In-person rehabilitation only <p>Based on the option you agreed on at step 1, now confirm your shared decisions for the following questions:</p> <ul style="list-style-type: none"> ▪ What can be done in-person before and during telerehabilitation? ▪ What can be done via telerehabilitation, and how will this be done? ▪ If restricted, when can in-person rehabilitation recommence?
--	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Developing the telerehabilitation plan	Step 4 – Develop rehabilitation plan and review feasibility.	
	<p>Step 4 is to develop the rehabilitation plan with the stroke survivor and caregiver and review feasibility.</p> <p>The rehabilitation plan should include:</p> <ol style="list-style-type: none"> 1. Rehabilitation goals. 2. Frequency and duration of telerehabilitation, in-person sessions and home practice sessions. 3. Types of activities to be included in telerehabilitation and home practice sessions (If appropriate you may specify the types or activities which will not be included/ should not be attempted). 4. Level of assistance caregiver/s able and comfortable to provide. 5. Equipment/ resources required including technology and exercise equipment are set up and ready for safe use. 6. Plan for program review and monitoring including dates and/ or triggers for review. <p>Review supports required for the stroke survivor and caregiver, check if any concerns about safety remain, review what technology is required for</p>	

	<p>telerehabilitation sessions, and consider any further training the stroke survivor and/or caregiver may require.</p> <p>The Risk Assessment Guide will be helpful again in Step 4.</p>	
	<p>Check-in again about any unmitigated risks:</p> <ul style="list-style-type: none"> ▪ If there are any risks identified at step 2 which could not be mitigated, discuss with the stroke survivor and their caregiver. ▪ Decide if the plan needs to be changed or how else these risks may affect the plan. 	<p><i>Do you/your caregiver have any safety concerns that we haven't addressed?</i></p> <p>OR</p> <p><i>There were some risks which we were not able to change, let's discuss these further...</i></p>
	<p>Screen for implementation needs:</p> <ul style="list-style-type: none"> ▪ Consider if there are additional supports or resources which could address these issues. ▪ Whether further training is required to use the necessary equipment, including: <ol style="list-style-type: none"> 1. technological devices being used 2. physical rehabilitation equipment 3. caregiver handling during physical therapy and exercises 	<p><i>What do we need to do or to provide you with so that you can start and continue with telerehabilitation? (technology, rehabilitation equipment, handling)</i></p> <p><i>Do you have any other worries or concerns that we should address?</i></p> <p><i>What questions do you have for me about the telerehabilitation plan?</i></p>

<p>Confirming the telerehabilitation plan</p>	<p>Step 5 – Confirm the plan and check agreement</p>	
	<p>Step 5 is about confirming that the shared decisions are agreed upon by all.</p> <p>If everyone does not agree with the rehabilitation plan, identify which aspects of the rehabilitation plan are not satisfactory and revise the plan.</p>	

	Help the stroke survivor and caregiver develop skills and confidence with communicating their preferences to others and handling pressure.	<p><i>Whose opinion is most important to you?</i></p> <p><i>Are you confident to ignore opinions that aren't important to you?</i></p> <p><i>What role do you prefer in making choices about the rehabilitation plan?</i></p>
	Check that the stroke survivor and/or caregiver have the information and support they need to make an informed decision.	<p><i>Are you comfortable with the plan we have developed?</i></p> <p><i>What aspects of the plan are you unsure about?</i></p> <p><i>What do we need to change to have a program that you are comfortable with?</i></p>

Implementing the telerehabilitation plan	Step 6 – Implement, evaluate and monitor the rehabilitation plan	
	<p>Step 6 is the final step in the SDM process. You are now ready to start the rehabilitation plan. Ensure that you have a plan for ongoing evaluation of the program/progress <u>and</u> a plan for reviewing the shared decisions reached through this process.</p> <p>If any new issues arise, re-assess the stroke survivor and consider reviewing the plan from step 4 if required.</p>	
	<p>Evaluate the program:</p> <ul style="list-style-type: none"> ▪ Regularly assess/evaluate the stroke survivor's progress to determine the efficacy of the program. ▪ Agree on an interval for re-evaluation (E.g. weekly or monthly). 	<p><i>How often should we review the rehabilitation plan?</i></p>

	<p>Monitor satisfaction:</p> <ul style="list-style-type: none"> ▪ Monitor the stroke survivor’s and their caregiver’s satisfaction with the program and check if they are managing/coping with the program. ▪ Monitor satisfaction with the shared decisions informing the rehabilitation plan. 	<p><i>Is the program meeting the expectations you/your caregiver had?</i></p> <p><i>Are you comfortable/happy/satisfied with the current program/plan?</i></p> <p><i>What can we do to make the program better?</i></p>
--	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

<p>CHECKPOINT Reviewing the telerehabilitation plan</p>	<p>Review the rehabilitation plan</p>	
	<p>Review whether the rehabilitation plan is being implemented as agreed:</p> <ul style="list-style-type: none"> ▪ At regular, pre-determined intervals ▪ If there is a major change in the person’s circumstances. ▪ Major changes could include: <ul style="list-style-type: none"> ○ changes in performance during sessions, ○ coping or fatigue issues, ○ health status including medical instability, ○ changes in attendance rates or participation in program, ○ adverse events. 	

Further information

The 'suggested language' in this guide is based on the 'Decision Coaching using the Ottawa Personal Decision Guide' (4).

Further information about effective communication when providing decision support is available here (5): https://decisionaid.ohri.ca/docs/decision_coaching_communication.pdf

References:

1. Stacey D, Hill S, McCaffery K, Boland L, Lewis KB & Horvat L. Shared Decision-Making Interventions: Theoretical and Empirical Evidence with Implications for Health Literacy. IOS Press; 2017. vol. 240, pp. 263–283.
2. Stacey D, Kryworuchko J, Bennett C, Murray MA, Mullan S, Légaré F. Decision coaching to prepare patients for making health decisions: a systematic review of decision coaching in trials of patient decision aids. *Med Decis Making*. 2012; 32(3):E22-E33.
3. Carpenito LJ. *Nursing diagnosis: application to clinical practice*. 8th edition; 2000 Philadelphia, PA: Lippincott Williams and Wilkins.
4. The Ottawa Hospital Research Institute. Decision coaching using the Ottawa Personal Decision Guide (OPDG). 2015. Available from: https://decisionaid.ohri.ca/docs/decision_coaching_script.pdf
5. The Ottawa Hospital Research Institute. Communication skills when providing decision support; 2015. Available from: https://decisionaid.ohri.ca/docs/decision_coaching_communication.pdf

Appendix 1: SURE Test

SURE Test version for clinical practice

Yes equals 1 point

No equals 0 point

If the total score is less than 4, it indicates the probability that a patient experiences clinically significant decisional conflict.

		Yes [1]	No [0]
Sure of myself	Do you feel SURE about the best choice for you?		
Understand information	Do you know the benefits and risks of each option?		
Risk-benefit ratio	Are you clear about which benefits and risks matter most to you?		
Encouragement	Do you have enough support and advice to make a choice?		

The SURE Test © O'Connor and Légaré, 2008.

The SURE Test and further information about this test is available here:

Ottawa Hospital Research Institute (2020) Patient Decision Aids: Decisional Conflict. Available from https://decisionaid.ohri.ca/eval_dcs.html

Appendix 2: Additional Resources

This list is not exhaustive but includes a range of resources that may be useful.

Health professionals

Telerehabilitation

[Stroke Foundation InformMe: Telehealth resources in response to COVID-19](#). Resources collated to support delivery of telehealth to people with stroke.

[Australian Telehealth for Stroke Community of Practice](#). Forum for clinicians and researcher working in stroke rehabilitation, recovery and long term management.

[Canadian Stroke Best Practice Recommendations: Telestroke Implementation Toolkit 2020](#)

[Allied Health Professions Australia: Telehealth guide for allied health professionals](#).

[Laver KE, Adey-Wakeling Z, Crotty M, Lannin NA, George S, Sherrington C. Telerehabilitation services for stroke. Cochrane Database Syst Rev 2020;1\(1\):Cd010255](#). Systematic review of telerehabilitation services for stroke.

Home exercise

These resources may be used by health professionals to support delivery of a home based program. We suggest you review the resource to determine whether it is appropriate for individual stroke survivors.

[Andrew MK, Hoessly M, Hedges K. Your guide to exercise after stroke. A guide for people with stroke and their families. 2017](#). Book developed by physiotherapists which contains a range of home based exercises.

[A stroke of luck: Stroke specific exercise videos](#). Includes a range of videos suitable for people who have very limited mobility.

[FAME: Fitness and mobility exercise program](#). Exercise program developed for people with stroke who have some standing and walking ability. Does include some seated exercises which may be appropriate for people with limited mobility.

Stroke

[Stroke Foundation InformMe](#) Wide range of resources for health professional to improve stroke care.

Communication

[Centre for Research Excellence in Aphasia Recovery and Rehabilitation: Healthcare communication support resources](#) Range of resources to support communication for people with aphasia and other communication deficits.

Stroke Survivors

[Stroke Foundation EnableMe](#) Wide range of resources for stroke survivors and carers