

# Shared Decision-Making Guide

## Purpose of guide:

This Shared-decision making (SDM) guide is designed to supplement the SDM flowchart to support therapists through a SDM process with stroke survivors and their caregiver(s). The aim is to devise a personalized physical activity (PA) program.

SDM is the process whereby an informed health decision is made by the individual, caregiver and therapist using the best available evidence and the patient's informed preferences (1). It involves discussion around the available options, treatment benefits and risks, values and preferences of the stroke survivor and caregiver (1).

## How to use this guide:

Follow the 6 stages of SDM presented in the SDM flowchart and the SDM guide, to assist the stroke survivor and caregiver through the SDM process of developing their PA program.

Additional resources have been developed to support each stage. Use of these resources is entirely optional; select those which will best help you and the stroke survivor and caregiver devise a PA program.

The right-hand column of this guide provides examples of suggested language to facilitate discussion throughout the SDM process. Language should be tailored to the individual's communication ability and information needs.

## Key shared decisions to make:

- Is a PA program necessary for the stroke survivor?
- What will this PA program involve?
- How will this PA program be implemented safely and effectively?

| Stage of SDM                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            | Suggested language                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
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| <b>Stage 1: Start of SDM</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                            |                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Ensure the stroke survivor (and caregiver) understand what the decision(s) to be made is.<br>Clarify the role of the therapist, stroke survivor (and caregiver) in the decision-making process and during the implementation of the PA program.<br><br><b>RESOURCES:</b><br>Provide the decision aid ' <b>Physical Activity Infographic for Stroke Survivors &amp; Caregivers</b> ' before or at the start of the consultation. This decision aid provides brief information about the benefits of PA following stroke.<br><br>For further information about PA following stroke (including benefits, risks, safety), see the written and video formats of ' <b>Physical Activity Information for Stroke Survivors &amp; Caregivers</b> '.<br><br>You may talk through this information and provide further information as appropriate. | Regular participation in physical activity would be beneficial in your long-term stroke recovery. Together, we can work out what best suits you.<br><br>We know that increasing physical activity levels promotes health benefits. Can we have a discussion about including physical activity in your routine?<br><br>Do you have a clear understanding of your and/or my role in this decision-making process? Would you like me to explain how this process will work? |

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| <p>If you are unsure about the stroke survivor's readiness to participate in this program, have a look at the 'Readiness to Change Resource'.</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <b>Stage 2: Information exchange</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <p>Gather background information to inform which options are available to the stroke survivor. This may include:</p> <ul style="list-style-type: none"> <li>• Medical History: including mobility, communication ability</li> <li>• Social History: including house set-up, family/caregiver(s), level of assistance provided by caregiver(s)</li> <li>• Local information: such as availability and accessibility to community programs, services and facilities in the stroke survivor's local area.</li> <li>• Other information that may be relevant to the decision</li> </ul> <p>Provide Stroke survivor and caregiver with information and evidence about participation in PA following stroke.</p> <p>You may discuss the preferred method of delivering this information:</p> <ul style="list-style-type: none"> <li>• Verbal discussion during consultation</li> <li>• Visual e.g. videos</li> <li>• Written materials to take home</li> </ul> <p>Check understanding of:</p> <ul style="list-style-type: none"> <li>• Benefits and/or outcomes</li> <li>• Potential risks or disadvantages</li> <li>• Costs</li> </ul> <p>Clarify any points that are unclear.</p> | <p>Is there anything else I should know about you (stroke survivor and/or caregiver) that might have an effect on your ability to engage in physical activity?</p> <p>What do you know about physical activity after stroke?</p> <p>Can you tell me what you know about the benefits/reasons to be physically active?</p> <p>What do you think may be potential risks of physical activity after stroke?</p> <p>What do you think may be challenging/difficult with physical activity after stroke?</p>                                   |
| <b>Stage 3: Explore values &amp; set goals</b>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| <p>Explore the values, priorities and concerns of the stroke survivor and/or caregiver regarding PA.</p> <ul style="list-style-type: none"> <li>• Prior experiences with PA before stroke</li> <li>• Personal values or health beliefs</li> <li>• Which benefits/outcomes of PA are perceived to be important to them?</li> <li>• Any concerns regarding PA following stroke?</li> <li>• Perceived barriers to PA participation</li> <li>• Perceived facilitators &amp; confidence to PA participation and strategies to overcome barriers</li> </ul> <p>Establish SMART* goals.</p> <p>You may provide some examples of:</p> <ul style="list-style-type: none"> <li>• Potential SMART goals</li> <li>• What you think is important to include in the PA program</li> <li>• Goals/outcomes of other stroke survivors with similar needs</li> </ul> <p>*SMART: Specific, Measurable, Achievable, Realistic, Time-based</p> <p><b>RESOURCES:</b></p> <p>Use the <b>Goal-setting resource</b> to help establish goals and develop the PA program in stage 4.</p>                                                                                                                 | <p>Can you tell me about your experiences with physical activity prior to your stroke?</p> <p>How much physical activity did you do prior to your stroke?</p> <p>What kind of activities did you enjoy before your stroke?</p> <p>What benefits/outcomes of physical activity are most important to you?</p> <p>What do you want to achieve during this physical activity program?</p> <p>What are your goals or what do you want to improve?</p> <p>Some goals that other stroke survivors I've worked with have come up with are...</p> |

#### Stage 4: Develop PA plan and assess preferences

The PA program plan should include:

1. SMART goals
2. Type of PA
3. Setting (who, where)
4. Frequency and duration (if possible, specify days and times)
5. Level of assistance that caregiver is able to and comfortable to provide
6. Equipment/resources required:
  - a. technology, exercise equipment, facilities
  - b. Safe set-up at home
7. Plan for monitoring progress and reviewing the program

Explore preferences for PA.

- **WHAT** activities could be included in the program?
  - What type of activity do they find enjoyable?
  - Consider interests/hobbies/sports
  - Do they prefer low-intensity, moderate-intensity or vigorous intensity activities?
- **HOW** do they prefer PA to be delivered?
  - Individual/group setting (e.g. exercise class)
  - With/without supervision by a health professional / personal trainer and/or carer
  - In-person/online (e.g. pre-recorded or live video)
- **WHERE** do they prefer to perform PA?
  - Indoors/outdoors
  - Home/Gym/Community (e.g. park, shops)
- **WHO** do they prefer to perform PA with?
  - Alone/ with family or friends
  - Others: stroke survivors or non-stroke survivors
- **WHEN** do they prefer to perform PA?
  - Do they prefer a fixed routine or variability in their PA program?
  - Preferred times (e.g. morning, afternoon, evening) and days of the week
  - Duration of each session
- How should feedback and monitoring be provided?
  - Feedback type: e.g. from physiotherapist, devices (phone apps, fitbit)
  - Feedback mode of delivery: e.g. messaging, phone call, video-conferencing, face-to-face
  - Feedback frequency: e.g. each session, weekly, monthly
  - Self-monitoring (consider technology or low-tech options): e.g. phone apps, activity diary/log
- What timepoints/intervals to review the PA program with the therapist?
  - Will there be ongoing evaluation by the therapist?
  - Include dates and/or criteria for evaluation/review with physiotherapist
  - Agree on delivery method: face-to-face, videoconferencing

What support is your caregiver able to provide?

Are they comfortable doing this?

Do you feel confident to do this at home?

Do you feel like you need additional supports?

How can we support you?

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| <p><b>RESOURCES:</b></p> <p>The <b>‘Physical Activity Options Infographic’</b> is a handout for stroke survivors.</p> <p>A more extensive <b>‘Physical Activity Options Resource’</b> is available for therapists.</p> <p>Consider the <b>‘Feedback and Monitoring Options’</b> list, which includes technological and analogue methods of monitoring progress.</p> <p>Consider <b>‘Behaviour Change Techniques Options’</b> list for additional ways to support the stroke survivor to adopt health behaviour change. (e.g. Social support, rewards)</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <p><b>Stage 5: Check feasibility and Confirm plan</b></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <p>Check implementation requirements:</p> <ul style="list-style-type: none"> <li>• Review supports required for the stroke survivor and caregiver</li> <li>• Equipment or technological devices to be used</li> <li>• Consider any further training the stroke survivor and/or caregiver may require <ul style="list-style-type: none"> <li>○ Technology set-up &amp; use</li> <li>○ Exercise equipment set-up &amp; use</li> <li>○ Caregiver handling during PA/exercises</li> </ul> </li> <li>• Check for remaining concerns about safety, any risks <ul style="list-style-type: none"> <li>○ Discuss how these may be mitigated</li> <li>○ Decide how these risks may affect the plan, if the plan needs to be changed</li> </ul> </li> </ul> <p>Check that the stroke survivor and caregiver have the information and support they need to make an informed decision.</p> <p>Confirm that the shared decisions and PA program plan are agreed upon by all parties (therapist, stroke survivor, caregiver).</p> <p>If everyone does not agree with the plan, identify which parts of the plan are unsatisfactory and revise accordingly.</p> | <p>Do you think you have enough support for this plan?</p> <p>What do we need to do or provide you with so you can continue this program?</p> <p>Are you confident to set-up and use this technology/equipment at home?</p> <p>Are you (the caregiver) confident in providing assistance during this PA program? Is further training required?</p> <p>Do you (stroke survivor and caregiver) have any other safety concerns that we haven’t addressed?</p> <p>Is there anything else you would like to know more about?</p> <p>Are you happy with the plan we have created? What parts of the plan are you uncertain about? How can we change this to make this plan better for you?</p> |
| <p><b>Stage 6: Implementation &amp; Monitoring</b></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <p>Ensure the stroke survivor and caregiver are prepared to implement the PA program.</p> <p>Evaluate the program:</p> <ul style="list-style-type: none"> <li>• Regularly evaluate the stroke survivor’s progress to determine effectiveness of program.</li> <li>• Review the program and update/revise as needed</li> <li>• Evaluate how the stroke survivor and caregiver are managing/coping with the program</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | <p>How are you finding/managing the program so far?</p> <p>Are you happy/satisfied with the current program?</p> <p>What can we do to make the program better?</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |

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| <ul style="list-style-type: none"> <li>• Have there been any changes in personal circumstances that may affect the program? <ul style="list-style-type: none"> <li>○ Changes in performance (does the activity need to be regressed/progressed?)</li> <li>○ Issues with adherence to intensity / duration / frequency</li> <li>○ Issues with coping, fatigue, mental health</li> <li>○ Medical health status</li> <li>○ Adverse events</li> </ul> </li> </ul> |  |
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## 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. *Studies in health technology and informatics*. 2017;240:263-83.

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