

Stroke and Carer Optimal Health Program (SCOHP)

A guide to using STROKE SURVIVOR-specific material in SCOHP

Each person's experience is going to be different. The following guide is a series of prompts to get you thinking and help facilitate your conversations in the sessions. Some carers and stroke survivors both sign up to participate and some do it as an individual.

While these notes have been grouped in sessions it is worth reading the document as a whole as these issues may well arise in a different order.

Session 1: OHP

Stroke Survivor Resources

It's ok at the start to ask them what interested them in being part of the Optimal Health Program and what they hope to get out of the program.

This session focuses on a broader perception of health. It is an opportunity to look at the stroke survivor's health in general. Many participants have other health challenges too, for example, diabetes or kidney disease, etc. When recruiting for this program if a participant is eligible for several arms of the OHP research we give them the choice to select the area that is most dominant or relevant for them.

Find out what they understand about what it means to have a stroke and life after stroke. If appropriate direct them to information from:

- National Stroke Foundation's 'My Stroke Journey' pack and *enableme* website
- Stroke Association of Victoria brochure

We have copies of these available for Program Assistants.

People take in information at different stages and relate to a health crisis and/or change in different ways. They may have recently had a stroke or had the stroke a number of years ago. They can vary in age and some may live on their own, some with a spouse or partner, and some in Residential Aged Care.

How do they best understand their stroke? How do they cope?

If they have someone doing the program with them do they use the terms carer or caregiver? Find out what they feel most comfortable using. What does the carer role mean to them?

What are the changes in their health since their stroke? Do they accept their condition or are they angry or resentful? How does their stroke affect each aspect of the health wheel?

It may also be useful to discuss barriers to attending sessions, such as their caring role, other ongoing issues, and how sessions would be postponed or cancelled if necessary. The mode of communication such as appropriate times to call the participant or boundaries can

also be discussed. Sessions are often less frequent than weekly e.g. fortnightly or three weekly.

Session 2: I Can Do Model Part 1, Health Plan 1

Implications of stroke for the stroke survivor

Some people may find it hard to discuss their strengths and vulnerabilities. They may find it easier to think of 'faults' than strengths. Gently encourage them. Creatively rephrasing can be helpful as different people relate to different language.

Be aware of making assumptions about what the stroke survivor is dealing with, for example, if their stroke was a long time ago there may be other more pressing issues, health or other for them – be aware of the complexities of people's lives.

If prompts are needed, you can ask if they have any health challenges? What was valued in their family in terms of health and coping with ill health?

The 70-90s age cohort can tend to feel more comfortable talking about physical complaints versus their mental health. Starting with physical conditions can be a gateway to discuss other topics. There's a tendency not to want to be a 'bother'. The prevalence of depression and anxiety can be very high with both stroke survivors and carers.

Session 3: I Can Do Model Part 2, Health Plan 2

Stressors and strengths for the stroke survivor

Participants are generally ok discussing what they get stressed by and you have had a couple of sessions to build rapport. The workbook may be more detailed about stress than is relevant for some stroke survivors as there's a lot to unpack. Some may need the facilitator to fill in the book for them if they cannot write.

Session 4: Medication

Relationships between health conditions and medication

Some participants love the practicality of this session that looks at medication and metabolic monitoring.

For the section on metabolic monitoring it is helpful to know the basic definitions, meanings of terms and why it is useful to monitor it before going into the session.

For participants living in Residential Aged Care this is going to be very different to those living at home. In aged care all their medications are managed by staff.

Session 5: Collaborative Partners & Strategies

Support networks

Is their main support person a spouse or partner? How has that changed their relationship? Do they feel dependent? Is their main support person an adult child or friend? How has that changed their relationship?

Reinforce that there are support networks around, including both stroke survivor and carer groups. Isolation can be a factor in depression developing.

Session 6: Change Enhancement

Transitions between acute care and rehabilitation post discharge

This session provides opportunity to explore the stroke survivor experiences of changes in care e.g. from acute to rehabilitation and any related goals or wishes for these transitions. If a participant is elderly and feeling at the end of their life, it is ok to develop short term achievable goals.

Session 7: Visioning & Goal Setting

Journaling personal story

This session offers stroke survivors opportunity to journal their personal wishes and expectations for the future in the OHP booklet activities. Some participants who are older may not think goal setting is relevant to them as think that “I’m of an age now...” It’s important to find a language that they can relate to. There may also be assumptions about what a goal must look like e.g. large and long-term. It may be a simple task they have put off.

Session 8: Building Health Plans

Advanced Care Planning

Look for what are the key issues or themes identified and explored. This session offers a more in-depth focus on planning for serious health challenges which may include advance care planning. Stroke survivors may reflect on their personal preferences and where applicable, their carer’s preferences for health care in the future.

Booster

3 months later a review of what they have learnt and where they are at NOW. Support session. Answering any questions they may have.

Couples or Families doing OHP

Generally if working with a couple you will do the session with one person privately and then the other afterwards. One person may have a preference as to who goes first. You may experience some fatigue having 2 sessions back to back.

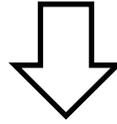
It is normal for a couple of to have a style of interacting, which may include banter or even a 'tiff'. Just allow it or be with it, there is nothing to fix or change. A partner may be nosey or curious about the other and what is said. Gently remind them that what is said is confidential, they may want to ask their partner but you need to keep it confidential. Don't let things shared 'leak' into the session. Some people may have false perceptions of how the other partner thinks or feels, you may gently question their thinking but don't reveal how their partner thinks or feels.

Questionnaires

All participants fill out 4 questionnaires. The first one is before they start the OHP, then after 3, 6 and 12 months. These questionnaires are managed by the Program Manager. Participants may ask you about these and you may want to talk to the Program Manager about it if anything comes up.

One participant had a lot of trouble with the rating the scales, so the Program Assistant would tell their participant that '5' represented okay, and would ask them if they were less or more/better than okay with the situation to help them decide. I often say to people filling out questionnaires that there's no right answer, so don't spend too much time thinking about your response. Just go with whatever comes to mind

Stroke Carer Optimal Health Program



Session 1



Session 2



Session 3



Session 4



Session 5



Session 6



Session 7



Session 8

Optimal Health – Health Wheel: Six domains of health

Stroke Survivor Resources

I Can Do Model Part 1 – Strengths and Vulnerabilities (Understanding the balance)

Implications of stroke for the stroke survivor

I Can Do Model Part 2 – Strategies and Stressors (Understanding and monitoring impact)

Stressors and strengths for the stroke survivor

Medication – Medication and Physical Health (Metabolic Monitoring)

Relationships between health conditions and medication

Collaborative Partners & Strategies – Identification of key partnerships (Connecting with key people)

Support networks

Change Enhancement – Understanding past events and defining change

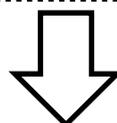
Transitions between acute care and rehabilitation post discharge

Visioning and Goal Setting – Creative problem solving and planning (Developing, setting and celebrating goals)

Journaling personal story

Building Health Plans – Health Plan I, II &, III (Maintaining Well-being)

Advanced Care Planning



Booster