

Stroke and Carer Optimal Health Program (SCOHP)

A guide to using CARER-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 individuals. In terms of our research, carers may be a spouse, a partner, an adult child or a friend who does a minimum of ten hours unpaid care per week.

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 Carer resources

It's ok at the start to ask participants 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's an opportunity to look at the carer's own health. Often the focus is on the stroke survivors' health and the carer may start with the other person and you can gently encourage carers to look at their own health. This will happen when they feel comfortable (this may or may not be in session 1).

Find out what the carer understands of 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 resources available for Program Assistants.

Some carers like doing their own research, by reading and understanding science as opposed to just what they have been told.

People take in information at different stages and relate to a health crisis and/or change in different ways. The person they support and care for may have recently had a stroke or had the stroke a number of years ago.

Different carers respond differently to their situation. How do they best understand stroke? How do they cope? How can they help their family member, partner or friend?

Many people do not use the terms carer or caregiver, so find out what they feel most comfortable using. What does the role mean to them?

Do they accept their role or are they angry or resentful? How do they view their role for example, is it another thing to cope with on top of other things in life?

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 may be less frequent than weekly e.g. fortnightly or three weekly if needed.

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

Implications of stroke for the carer

Some people may find it hard to discuss their strengths and vulnerabilities. They may find it easier to think of 'faults' than strengths. Carers may find it easier to focus on the person who's had a stroke.

Issues with completing homework may also come up. The carer may put the needs of the stroke survivor before their own needs. Gently reminding participants that the program is to help focus on their health, which can have benefits in their caring role, may be useful.

Be aware of making assumptions about what the carer is dealing with. For example, it might not be coping strategies, it might be their own physical illness – 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? Have they had other experiences of being responsible for someone else's care?

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

Self-care strategies

Participants may be feeling more familiar with discussing their experiences and you have had a couple of sessions to build rapport.

It can be good to be prepared to discuss self-care strategies for stress e.g., breathing exercises, relaxation techniques, meditation. If participants are interested, we have further information available for Program Assistants on these topics.

Session 4: Medication

Exploring the relationships between carer health conditions and medications

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 certain indicators before going into the session. Not all items listed will be relevant to everyone.

Carers may well have just as many physical health concerns as the stroke survivor. Some carers may have a lot of insight into their own health.

Session 5: Collaborative Partners & Strategies

Support networks

It can be useful to explore the shift in the carer's relationship with the stroke survivor, for example, the degree of collaboration with each other or is support just going one way.

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

It can be useful to again reinforce that it is equally important to care for yourself and lean on the collaborative relationships as it is for the person they are caring for.

Carers Victoria has a good website with lots of resources: www.carersvictoria.org.au

Some of our carers attend a Stroke Support Group and for some it is just as important a support as for the stroke survivor.

Session 6: Change Enhancement

Transitions between acute care and rehabilitation post-discharge

Explore the key issues or themes identified around change using the tools provided in the booklet. For carers and stroke survivors that are transitioning through care (e.g., from acute to rehabilitation post-discharge), this session offers opportunities to explore carer's views about these changes.

Session 7: Visioning & Goal Setting

Journaling personal story

Participants who are older may not think goal setting is relevant to them as “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, for example large and long-term. Goals or desires may be simpler tasks they have put off for various reasons. This session offers carers opportunity to journal their personal wishes and expectations for the future in the OHP booklet activities.

Session 8: Building Health Plans

Advanced Care Planning

Explore and identify key issues or themes around each Health Plan, with particular focus on developing Health Plan 3 for episodes of illness. This session offers a more in-depth focus on planning for serious health challenges which may include advance care planning. Carers may reflect on their personal preferences and their perceptions of the stroke survivor’s preferences for health care in the future.

Booster

3 months after session 8, this is a review of what participants have learnt and where they are at NOW. Support session. Invite them to pose and explore any questions they may have.

Couples or Families participating in OHP

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

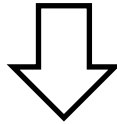
It is normal for a couple to have a style of interacting, which may include banter or even a 'tiff'. Just allow it or be with it, there is nothing to fix or change. A partner may be nosy or curious about the other and what is said. Gently remind them that what is said is confidential, they may want to 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. If you are uncertain about the boundaries of working with couples and families please seek support from the research team.

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 trial Program Manager. Participants may ask you about these questionnaires and you may want to talk to the Program Manager about it if anything comes up.

Sometimes participants have trouble with rating the scales. It is important to try and get a sense of why this is the case. Are they having problems seeing and/or reading the material? Are they concerned about representing themselves in the 'right' way? Depending on what the concern is, speak to the research team about a strategy for coping with these situations. 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 first.

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 Carer Resources

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

Implications of stroke for the carer

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

Self-care strategies

Medication – Medication and Physical Health (Metabolic Monitoring)

Relationships between carer 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

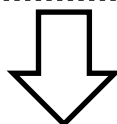
Transitions between acute care and rehabilitation post discharge

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