

6.7 Caregivers, Family and Friends

There are many considerations that are crucial to promoting safety and optimizing recovery when working with people who have had a stroke. The TACLS Quick Reference Guides were developed from the TACLS resource and can be used as quick reference to help *support healthcare providers* and informal caregivers who may not typically work with and care for people who have had a stroke.

We recommend reviewing the full **TACLS resource** for more complete information:
strokebestpractices.ca/resources/professional-resources/tacsl

Quick reference guide highlights

- **Always follow the current care plan for the person that you are working with.**
- A stroke affects the whole family as well as the person's community of supports. Each family is unique and family members may react differently, depending on their relationship with the person who has had a stroke and their own personalities and coping mechanisms.
- People with stroke, their families, and caregivers, should be screened for their level of coping, risk for depression, and other physical and psychological issues. Ideally screening should take place at each transition and additionally when indicated.
- In this document, caregiver can refer to a spouse, child, sibling, other relative, close friend or a neighbour. It excludes paid healthcare providers.
- Just like the person who had a stroke, caregivers may feel like they are on an emotional roller coaster. Caregivers may experience grief and different emotions which can be intense.

Denial

- A caregiver may initially be in shock that their loved one has had a stroke. They may have difficulty processing what has happened and thinking about what the future may hold.
- This can result in denial; the caregiver may feel that all the effects of stroke will go away quickly. A caregiver may need time to process what has happened.



How you can help

- Present a realistic sense of hope about the future – be honest, and do not give false hope.
- Remind the caregiver that most people who have had a stroke continue to improve for months or even years in some cases.
- Encourage the caregiver to talk with stroke care team members about recovery, available support and questions.

Anger

- It is natural for a caregiver to feel anger that a loved one has had a stroke.
- This anger may manifest as feeling resentful, making uncharacteristic and negative comments, expressing a lack of recognition and/or not feeling valued.



How you can help

- Listen and validate their emotions.
- Communicate clearly and consistently with them.
- Ask what can be done to decrease the demands placed on them. Avoid lecturing and passing judgement.

Stress, anxiety, worry, fear, guilt

- A caregiver may experience stress, anxiety, worry, fear as concerns arise regarding longevity of caregiving, financial stress, quality of care, judgement from others, fear of a worsening situation and/or social isolation.
- A caregiver may also express feelings of guilt, using statements such as “what if...” or “if only...”



How you can help

- Be aware that they may be uncomfortable discussing these feelings, as they may be concerned with judgement.
- Suggest talking with a member of the care team, such as a social worker, or someone in their faith community. Ask how they feel and take time to listen.
- Provide resources as able for support.

Despair, sadness and/or feeling overwhelmed

- A caregiver may feel some despair, sadness and/or feel overwhelmed. Weeping, anger, poor eye contact, and withdrawal from others are possible signs of sadness or a depressed mood.
- If you are concerned about the caregiver, share these observations with your team.



How you can help

- Listen to the caregiver; they may want to share their feelings.
- Suggest that they call someone who can help them cope with their emotions, such as a social worker, other member of the care team or someone in their faith community.

Relationships, intimacy, sexuality

- As a person who had a stroke and their partner readjust to life after stroke, they may become more aware of how stroke can impact intimacy, sexuality and their relationships. A person who has had a stroke and/or their partner may have concerns about safety with sexual activity, physical limitations and the emotional consequences of stroke.

- When indicated, a person and/or their partner should be supported and be offered an opportunity to discuss intimacy, relationships, sexuality and sexual function.
- Support could be in the form of counselling, individual education (verbal or written), and/or group education sessions to address frequently asked questions, e.g., changes in relationships, emotions, impact of medication and/or fears with sexual activity.
- Support for the person and partner should be considered prior to discharge from hospital and with transition back to community.



How you can help

- Be supportive with the person and/or their partner by listening to and validating their concerns about changes in relationships, intimacy, and sexuality.
- Ensure they are aware that you will bring their concerns/questions forward to an appropriate member of their care team such as a social worker and/or a medical practitioner who can then provide necessary education and support.

Caregiver fatigue

- Being a caregiver for a person who has had a stroke can be mentally and physically challenging and can result in extreme fatigue or exhaustion.
- It can also bring new financial challenges and changes in roles and responsibilities within the family.



How you can help

- Watch for signs of caregiver fatigue, stress, or changes in mood.
- Provide caregivers with information and support to help them feel confident in their abilities. Reassure them about the care that is being provided and demonstrate your ability to meet the person's needs.
- Learn about the caregiver's support system and encourage the person who had a stroke and their caregivers to accept help from others. Provide information about peer support.
- Encourage caregivers to take time for themselves to prevent extreme fatigue or exhaustion.
- Always encourage the caregiver to talk with the stroke care team members about recovery, available support and questions they may have.

When supporting a caregiver, encourage them to

- Share concerns with the healthcare team. The team is there to answer questions, identify and address the physical, social, emotional, mental and cognitive needs and provide education.
- Write about their achievements and progress, record information about medications or therapy, keep track of medical appointments, and write down questions to ask at future appointments.

- Use a checklist as it gives the person with stroke and the caregiver an ongoing record of progress, makes it easier for healthcare providers to understand how the caregiver is dealing with everyday challenges and to then recommend appropriate resources, support and services.
- Remember, it is a team effort. Care should involve collaborative goal setting, shared decision making and an individual recovery plan that is developed together, regularly reviewed and updated as progress is noted.
- Participate in community. Caregiver communities share experiences, quality information and tips, and offer social and emotional support in a safe, inclusive and respectful community.
- **If you feel a caregiver is not doing well and needs more support, talk to your case manager/ coordinator or suggest that the caregiver call the case manager/coordinator or social worker to discuss options.**

Note: This information represents some priorities of care related to Caregivers; consult with the stroke care team, such as the social worker, for any questions or concerns. For additional caregiver resources, refer to **full TACLS** and the **Heart and Stroke website for the Care Supporter's Community and the Community of Survivors**.

References:

1. Canadian Stroke Best Practice Recommendations: **Transitions and Community Participation Following Stroke**, 6th Edition, Sections 1 and 2
3. Taking Action for Optimal Community and Long-Term Stroke Care (TACLS) – **Caregivers, Family, and Friends**

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