

Memorandum

SUBJECT: CorHealth COVID-19 Stroke Memo #3 - **RECOMMENDATIONS FOR AN ONTARIO APPROACH TO ENGAGE & SUPPORT CAREGIVERS* FOR PERSONS WITH STROKE DURING COVID-19**

TO: Healthcare professionals and administrators providing services for persons with stroke
FROM: Office of the CEO, CorHealth Ontario
DATE: June 11, 2020
TIME: 10:00 AM
VERSION: #1

DISCLAIMER: The information in this document represents general guidance based on current practice and available evidence. The document was developed by provincial clinical experts, reflecting best knowledge and evidence at the time of writing, and is subject to revision based on changing conditions and new evidence. This information is *intended to be* “guidance rather than directive,” and is *not meant to replace clinical judgment, regulatory body requirements, organizational, or hospital visitation policies*. Reference to any Infection Prevention and Control (IPAC) or Personal Protective Equipment (PPE) in this document should not replace or supersede the IPAC and PPE protocols or directives in place at your organization.

**Caregiver includes all individuals involved in providing unpaid care to the person with stroke. This can include family members, friends and substitute decision maker(s).*

Recommendations for an Ontario Approach to Engage & Support Caregivers for Persons with Stroke during COVID-19

PREAMBLE

Engaging caregivers for people with stroke remains an incredibly important focus for our healthcare community. The COVID-19 public health emergency has significantly changed how we work and provide care. This new environment has made the engagement process with caregivers even more complex creating greater likelihood that they may experience feelings of frustration, isolation and inability to cope. The stroke healthcare community is committed to engaging and collaborating with patients and caregivers to adapt to this new reality, finding innovative ways to engage and support them as part of the team, and to ensure the best possible care for people living with stroke, whether they are at home, at a healthcare facility, or transitioning back to home after a hospital stay.

RECOMMENDATIONS

To support caregivers of persons with stroke during this unprecedented time, we have developed these guidelines and advice for healthcare professionals. For ease of use, we’ve divided this into three key stages of the care journey:

1. Inpatient Stay (Acute and/or Rehabilitation)
2. Discharge Planning and Transition
3. Community and Home-based Care

1. INPATIENT STAY

- Designate a healthcare team member at time of admission to be the **point of contact for the caregiver**. Have regular, ongoing and consistent contact with the caregiver. Be responsive to the expectations of the caregiver and the communication plan (e.g. frequency and mode of contact).
 - a. Additional healthcare team members will be included in communications with the caregiver when specific education or expertise is required. This ongoing communication will provide an opportunity for caregivers to ask questions or raise concerns and team members should respond in a timely manner.
- **Arrange virtual visits**, via phone or video, between caregivers at home and their family member in hospital (Appendix A). Visitor restrictions are difficult for many caregivers but being able to hear the voice or see their family members is critical in maintaining that vital family connection and building the relationship between families and health care providers. If the patient has a communication impairment, consult a speech-language pathologist for the optimal mode to facilitate virtual communication. If a language barrier exists, coordinate with additional supports (e.g. translator).
- **Provide caregivers with education and training** required to support the person with stroke. Provide resources that caregivers can reference in the future (e.g. home exercise program, websites). Video platforms should be used when feasible to provide visual instruction and for teach-back. (Appendix A)
- **Ask caregivers about their own needs and capacity to provide support**. This includes the caregiver's own mental health. If needed, refer the caregiver to appropriate supports and services available through the hospital, as well as a list of virtual supports (Appendix B).
- **Consider compassionate exceptions to the visitation policy** in palliative, end-of-life, and other unique situations. Where possible involve the organization's Patient Relations Department (or similar) to facilitate the process.

2. DISCHARGE PLANNING AND TRANSITION

- **Discharge planning should begin shortly after admission** to ensure supports are in place before discharge. Confirm that the person with stroke has access to primary care and ask that they book a follow-up appointment, preferably 1-2 weeks post-discharge. Provide support in scheduling the appointment as required.
- **Include the patient, caregivers and the healthcare providers in discharge planning meetings**. Discuss the feasibility of virtual care, the need for in-person visits and other strategies to support the needs of the person with stroke and their caregiver. With restrictions to hospital visiting, arrange this meeting by phone or videoconference. Explore the potential for caregiver(s) to participate in an in-person visit prior to discharge if education/training needs are complex resulting in safety concerns.
- Ensure patient-specific service requirements are available in the community and **provide the caregiver with a point of contact** for Home and Community care or community service provider e.g., Community Stroke Navigator. If the patient will not receive community services, the hospital team should establish the caregiver's preference for mode of contact including exploration of access to virtual care and plan for a timely follow-up.

- **Explain to caregivers the importance of creating a contingency plan** in case they become ill or need to self-isolate. Caregivers can access information about what to consider in this plan at [The Ontario Caregiver Organization](#).
- **Identify supports that the caregiver may need** to make them successful in their caregiving role. Ensure there is understanding of the care expectations and equipment and/or supplies that will be required. Provide direct communication to the next phase of care prior to discharge regarding the needs/role of the caregiver.

3. COMMUNITY AND HOME-BASED CARE

- If receiving community-based services, **contact should be initiated within 48-72 hours of discharge** to ensure the person with stroke and the caregiver are managing in the community.
- **Consider how virtual supports can be used** to increase access to ongoing health and support services (Appendix A). Introducing new technology may be stressful for the caregiver and/or person with stroke. Consider what might work best for the situation.
- **Provide caregivers with virtual education and information** resources as well, in case there is a delay in securing in-home rehabilitation and/or care. This could include [Your Stroke Journey, Taking Action for Optimal Community and Long Term Stroke Care](#) and links to other educational resources. (Appendix B).
- **Consider the caregiver's ability to care for the person with stroke**, including:
 - a. Current health status, employment and other responsibilities and how those will be managed in providing stroke care
 - b. Capabilities and experience in providing care to the person with stroke
 - c. Resource issues such as financial situation, housing, transportation, insurance, healthcare benefits, medication cost coverage
 - d. Available support from family members, relatives and social networks given social distancing guidelines.
 - e. Caregiver's mental health status and ability to cope and manage the added stress of caring for a person with stroke. Reinforce the importance of self-care. Caregivers can access information and tools to support them at www.ontariocaregiver.ca.
- **Provide caregivers with customized information to support them in navigating care** for the person with stroke during social isolation. (Appendix B)

ACKNOWLEDGEMENTS

CorHealth Ontario would like to greatly acknowledge the contributions of the Ontario Regional Stroke Networks' Provincial Community & Long Term Care Coordinators group, Ontario Caregiver Organization (OCO), Heart and Stroke Foundation, The Change Foundation, and Dr. Jill Cameron, PhD, FAHA Associate Professor, Vice Chair Research, Department of Occupational Science and Occupational Therapy, Rehabilitation Sciences Institute, Faculty of Medicine, University of Toronto and the Caregiver Advisors for providing their valuable thoughts and insight into developing this document.

APPENDIX A

CONSIDERATIONS FOR USE OF VIRTUAL PLATFORMS

In addition to consulting professional regulatory college guidelines, clinicians should:

1. Consider if a virtual interaction is a feasible means to deliver caregiver education and skills training.
2. Consider caregiver and healthcare providers' access to technology and internet etc., and other practical limitations.
3. Ensure and document consent considering that any electronic means cannot be 100% secure.
4. Ensure an environment that considers privacy for both the clinician and the caregiver(s) (e.g., are there others around in the office, does the caregiver have a private space at their home/workplace).
5. Ensure an alternate way of contact (e.g. phone number) in case of technology failure (e.g., Wi-Fi failure).
6. Be aware of the limitations of using a virtual platform to deliver education and training to a non-healthcare provider (i.e. caregiver). Assess each situation to determine if in-person training and teach-back is required.
7. Any organization providing virtual care should ensure that the healthcare team has access to the supports required to deliver it effectively (e.g. technology, training etc.).
8. Explain potential privacy/security risks associated with virtual care to the caregiver and person with stroke. Obtain verbal consent to use virtual care electronic communications and document consent in patient's chart.

APPENDIX B

RESOURCES TO ASSIST THE HEALTHCARE TEAM IN SUPPORTING CAREGIVERS FOR PERSONS WITH STROKE

- CorHealth COVID-19 Resources -Listing of virtual/on-line resources including caregiver and mental health supports. [Community Supports](#)
- Heart & Stroke Foundation - Various resources for caregivers including links to COVID-19 webinars. [Your Stroke Journey](#)
[Taking Action for Optimal Community and Long Term Stroke Care](#)
[Post Stroke Checklist](#)
[Your guide to Transitions and Community Participation](#)
[Your guide to Rehabilitation and Recovery](#)
- Healthline - On-line area-specific health and support service listings [The Healthline.ca](#)
- March of Dimes Canada After Stroke - Listing of supports and services for caregivers including virtual (online) sessions, workshops and programs. [March of Dimes Canada After Stroke](#)
- March of Dimes Canada Caregiver Guide - Booklet on caring for persons affected by stroke. [March of Dimes Caregiver Guide](#)
- March of Dimes Canada After Stroke Warmline - Toll free line offering caregiver support 1-888-540-6666
- [The Ontario Caregiver Organization](#) – offering caregiver education, 24/7 helpline and virtual peer support groups.
- [Stroke Engine](#)
- Toronto Stroke Networks [Guide for Stroke Recovery](#)
- Telehealth Ontario
Free, confidential phone service for health advice or information available 24/7.
1 866-797-0000
- Ontario 211 - Free helpline to connect to area-specific community and social services 24 hours a day, 365 days a year, in over 150 languages. Call 211