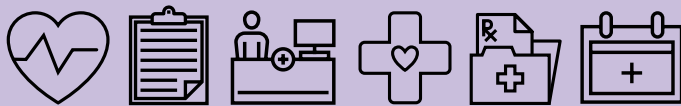


HEALTHCARE JOURNEY BINDER



Introduction



THE ONTARIO

caregiver

ORGANIZATION



Consent, Privacy & Confidentiality Reminder

As a caregiver, this *Healthcare Journey Binder* provides worksheets that ask for information related to your care recipient's personal health information. The Ontario Caregiver Organization recognizes that you can receive and record this important information based on a couple of scenarios:

- (1) The capable care recipient [patient] has authorized their healthcare provider to share their personal health information with you¹
- (2) The care recipient [patient] has been found incapable under the *Health Care Consent Act* to consent to treatment (or admission to long-term care/personal assistance services) or under the *Personal Health Information Protection Act, 2004* (PHIPA); and you are, or another person is, the highest-ranked substitute decision-maker. The substitute decision-maker gives or refuses consent for the collection, use or disclosure of personal health information of the care recipient [patient].² If you are not the substitute decision-maker, the person who has that role takes over any information decision-making.

If there is a decision to be made about collection, use or disclosure of personal health information (e.g., release of a test result to a third party such as an insurance company), and the care recipient [patient] is capable, they decide whether to share it; or if incapable, the substitute decision-maker decides.

The Ontario Caregiver Organization encourages you to ask your care recipient's healthcare providers for a copy of their written consent/release of information form or [Consent to Disclose Personal Health Information](#) form for your care recipient to sign; or ask the healthcare providers to ask the care recipient [patient] verbally for their consent and document the care recipient's [patient's] consent in their health record. It is also important to make sure that healthcare providers are aware of the documented consent.

Even when the care recipient [patient] has consented that their information can be shared with their caregiver, some caregivers still struggle to get timely information from health care providers. Sometimes healthcare providers need reminders that they are permitted to share certain information with caregivers based on the consent of the care recipient [patient] or substitute decision-maker, or that in some cases, no consent is needed because PHIPA or another Act permits the information to be shared.³

Caregivers should keep what is recorded within the *Healthcare Journey Binder* confidential and secure. Written records within the *Healthcare Journey Binder* should not be shared with another party without the consent of the care recipient [patient] (unless you have either their or their substitute-decision maker's consent – if you are the substitute decision-maker, you have authority to share).

¹ Making Privacy and Consent Rules Work for Family Caregivers. 2017. The Change Foundation. Retrieved from: https://www.homecareontario.ca/docs/default-source/publications-mo/privacy-and-consent-report_final-2107.pdf?sfvrsn=4

² Ibid 1

³ Ibid 1



Contents of this binder include:



Personal Information



Medications, Therapies & Allergies



Medical History, Vital Signs & ADL/IADLs



Consent & Legal Matters



Healthcare Team & Notes



Care Templates



What is the Purpose of the Healthcare Journey Binder?

The Healthcare Journey Binder was created by caregivers and healthcare providers to help improve the overall healthcare experience for people with an illness, disease, or medical condition. It can be used by anyone, including caregivers, to manage important healthcare information by:

- Having a place where documents and information can be kept in one place
- Making it easy to organize and find health information
- Allowing you to easily share any information with the healthcare team
- Helping to give you a sense of control

How Does the Binder Work?

Every healthcare journey is different! The Healthcare Journey Binder contains templates created by caregivers and other healthcare organizations.

“Make the Healthcare Journey Binder work for you, the person you provide care for and others involved. These needs may change as this healthcare journey progresses. Freely modify the contents as you go to make them work best for you.” - Caregiver

You can modify your binder by:

- Moving the binder sections into an order that you find helpful
- Adding or removing sections and templates
- Storing documents and papers in the binder or envelope provided

The Caregiver Role

A caregiver is defined as a family member, friend and/or neighbour who provides personal, social, psychological and physical support, assistance and care, for family members and friends in need. This support can be provided for any length of time.

Caregiving can include coordinating medical appointments, managing medications, arranging in-home healthcare services, and many other tasks.

“Often, being a caregiver can seem like an overwhelming and all-consuming experience. The Healthcare Journey Binder can become one of your most useful tools and resources, helping you and the person you are providing care for reduce stress and enhance your journey together.”
- Caregiver



A Word of Thanks

Connecting the Dots for Caregivers was a partnership of six health care organizations in Huron Perth, funded by the Change Foundation. Together, with caregivers, they worked to improve the caregiver experience by co-designing solutions, programs and resources that will ensure caregivers feel valued, respected, engaged and supported in their important role.

The **Healthcare Journey Binder** is just one of many resources created through a co-design process involving equal participation of caregivers and healthcare providers. A special thanks to all of those who participated. Thanks to the caregivers from the Ontario Caregiver Organization's Mental Health Working Group **for their help in updating this second edition** to ensure continued value as a support to all caregivers. For additional caregiver resources, please go to www.ontariocaregiver.ca

Contact for Binder Support:

Name/Organization:

Position:

Phone Number:

E-mail address:



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Province-Wide Support		
Resource	Description	Contact Information
Ontario Caregiver Organization - Helpline	The Helpline is available 24/7 and aims to provide a one-stop resource for information and support. Whether you are looking for respite care in your area, a support group, information about financial supports available to caregivers, as well as help navigating the health and social service systems, the helpline is here to connect you to the resources you need.	1-833-416-2273 (CARE)
Local Health Integration Network (LHIN) - Home and Community Care	<p>The Local Health Integration Network (LHIN) is spread across Ontario to ensure you can receive local resources that fit your needs.</p> <p>The LHIN can help if you, or someone you care about, needs health care services at home, at school or in the community, or if you are considering supported living programs or long-term care options, home and community care.</p> <p>They can also link you to providers in your community for specific information and local support.</p>	<p>Find your LHIN - Home and Community Care by entering your postal code: http://healthcareathome.ca/</p> <p>Depending on your region, each LHIN will have a specific number you can call.</p>
Financial Resources		
Government of Canada - Tax credits for family caregivers	If you have a dependent with a physical or mental impairment, you may be eligible for the Family Caregiver Amount tax credit.	https://www.canada.ca/en/financial-consumer-agency/services/caring-someone-ill/tax-credit-caregiver.html
Government of Canada - Basic Personal and Dependent Tax credits	If you have a dependent with a physical or mental impairment, you may be eligible for the Family Caregiver Amount tax credit.	https://www.canada.ca/en/revenue-agency/services/tax/technical-information/income-tax/income-tax-folios-index/series-1-individuals/series-1-individuals-1/income-tax-folio-s1-f4-c1-basic-personal-dependant-tax-credits.html
Government of Canada - EI Caregiver Benefits and Leave	Through Employment Insurance, you could receive financial assistance of up to 55% of your earnings, to a maximum of \$573 a week. These benefits will help you take time away from work to provide care or support to a critically ill or injured person or someone needing end-of-life care.	https://www.canada.ca/en/services/benefits/ei/caregiving.html



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<p>Veterans Affairs Canada - Caregiver Recognition Benefit</p>	<p>Having a disability sometimes means you need ongoing care to remain in your home. The Caregiver Recognition Benefit recognizes the important role a caregiver delivers on a day-to-day basis by providing them \$1,000 per month, tax free.</p>	<p>https://www.veterans.gc.ca/eng/housing-and-home-life/help-at-home/caregiver-recognition-benefit</p>
<p>Legal Support, Privacy and Consent</p>		
<p>Government of Ontario - Consent to Disclose Personal Health Information</p>	<p>It is reasonable for you to ask the patient you are caring for to consent to their healthcare provider sharing personal health information with you. Print this form for the patient to sign or ask the provider to document the patient's consent in their health record and make sure that the provider's staff is aware of the documented consent.</p>	<p>http://www.health.gov.on.ca/english/providers/project/priv_legislation/consent/consent_disclose_form.pdf</p>
<p>Ministry of Attorney General - Capacity Assessment</p>	<p>Capacity Assessment is the formal assessment of a person's mental capacity to make decisions about property and personal care. Many situations require capacity assessments to be conducted by specially qualified assessors who must follow specific guidelines.</p>	<p>https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/capacity_assessment.php</p>
<p>Ontario Ministry of the Attorney General - Power of Attorney</p>	<p>A Power of Attorney is a legal document in which you give someone you trust (called your "attorney") the right to make decisions for you if something happens and you are no longer able to look after matters on your own.</p>	<p>https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php</p>