



# Helping Caregivers Understand Consent and How to Obtain it

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TERRITORIAL ACKNOWLEDGEMENT

# Family Caregivers of BC



Family Caregivers  
of British Columbia

- Non-profit charity dedicated to the well-being of family caregivers.
- Serving across B.C. since 2010, with the past 5 years as part of the Ministry of Health's Patients as Partners Initiative.
- Three pillars: caregiver support, education and engagement and collaboration.

## CAREGIVER SUPPORT

- Support Line: 1-877-520-3267
- Informational, referral & navigation
- Support groups
- Caregiver coaching
- Online resource center
- Virtual support circle

## EDUCATION

- Resource library: webinars and podcasts
- Newsletter publications, e-news, articles and blogs
- Support group facilitator training
- Outreach to community groups

## ENGAGEMENT AND COLLABORATION

- Caregiver engagement quality improvement health policy
- Participation in health committees
- Collaborations: condition specific org, health authorities, Ministry of Health research, etc.

# Learning Objectives



Upon completion of this webinar, you will be able to:

- ✓ Describe Caregiver Friendly Healthcare and its benefits
- ✓ Utilize practical tips to identify and support caregivers
- ✓ Explore how to obtain consent for caregivers supporting patients (or clients)

# Caregiver Friendly Health Care

- Caregiver Friendly health care ensures family and friend caregivers feel
  - valued,
  - supported and,
  - included as **partners in care**.
- We believe that EVERYONE can help accelerate Caregiver Friendly Health Care when they focus on *their places of influence across systems*.

*Being Caregiver-Friendly is about transforming the systems and processes that create caregiver invisibility into systems that include family caregivers for what they are: invaluable and irreplaceable.*

# Family Caregiver Support

Family Caregivers are a valuable member of a Primary Care Network

Family caregivers provide support by:

- Getting medication,
- Getting equipment for home use,
- Providing key medical, functional and emotional information and/or concerns on the person they are caring for
- Monitoring and logging appointments, recovery, and health status, and
- Booking and attending follow-up appointments.

# IDENTIFY Family Caregivers

1

Ask patients with complex, chronic and life-limiting conditions:


- **“Is there a family member or friend who helps you manage things at home?”**

2

Embed identification of caregivers into care processes:

- Ask the question at intake
- Keep asking at later appointments

# Refer Family Caregivers

 Provincial Family Caregiver Program  
**CAREGIVER REFERRAL & CONSENT FORM**

Please complete this form and fax to 1-250-361-2660 or call us at 1-877-520-3267 toll free within BC or email [info@familycaregiversbc.ca](mailto:info@familycaregiversbc.ca)  
We will follow up with the family caregiver within 2 business days.

Date of Referral: \_\_\_\_\_

Name of Caregiver: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Best time to contact the caregiver:  AM  PM

Referral made by:

Self  Family Practice  Community Agency: \_\_\_\_\_

VIHA  VCHA  FHA  IHA  NHA Title: \_\_\_\_\_

City/Community: \_\_\_\_\_

Other: ( \_\_\_\_\_ )

**CAREGIVER CONSENT**

I consent to be contacted by the Family Caregivers of BC about their Provincial Family Caregiver Program.

Verbal consent received Date: \_\_\_\_\_

Caregiver Signature: \_\_\_\_\_


City/Community: \_\_\_\_\_

Health care providers can identify caregivers and refer for support by:

← FCBC Referral Form →

RX Caregiver Prescription

**FCBC Caregiver Support Line**  
**1-877-520-3267**

**Family Caregiver **

Name: \_\_\_\_\_

In your role as a family caregiver you'll need help. Here are some free services available through Family Caregivers of British Columbia:

**Caregiver Support Line in BC 1 877 520 3267**  
Mon-Fri: 8:30am-4:00pm

- One-to-one emotional support
- Help navigating the health care system
- Access to support groups
- Newsletter with timely articles
- Referrals to other community resources


**Visit the Virtual Resource Centre:**

- Educational webinars, workshops and online modules on topics such as:
  - Caregiver health and wellness
  - Family dynamics and caregiving
  - Communication and assertiveness skills
  - Sharing the care
  - Navigating the health care system
- Resource Guide for Family Caregivers, 2nd Edition

Comments \_\_\_\_\_

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**Family Caregivers of British Columbia**  
— Let us help —

[www.familycaregiversbc.ca](http://www.familycaregiversbc.ca) 250 384 0408



# Caregiver Trajectory



# Obtain Consent\* for Caregivers

## Implied Consent

- Extends to parties who provide care to a patient and form part of the patient's "circle of care"
- "Circle of care" are specialists, referring physicians, lab techs
- Family and Friend Caregivers are not considered to be part of that circle of care

## Express Consent

- Required when personal information is intended to be collected, disclosed or used outside the "circle of care"
- Family and Friend Caregivers would need express consent provided by the patient to be included or to have information shared with them

# CONSENT: It's All in the Ask!

**WHEN ASKING PATIENTS FOR CONSENT to share personal health information with family caregivers**, avoid inviting an automatic "no" response with hard questions like, "Can I share your personal information with your family?" Take a softer, more supportive approach.

Family support can have a very positive effect on your recovery. You deserve to have this support. Have you thought of someone you'd like us to call?



Who can we call to let them know you are here and that you're safe?

To better help you, I sometimes need to talk with people who care about you—like your mom or brother. This won't include information about your personal life. Only things to help you get better. I assume that's OK. Right?

# CONSENT: It's all in the ask!

**IF THE PATIENT SAYS "NO" THE FIRST TIME...** repeat the request when you see an improvement in the patient's clinical status. If clinically appropriate, explore why they don't want you to share information.

If you want, you can even give us a list of what you don't want us to discuss with your family.



I know you didn't want us to call anyone when you first came here, and I respect that. But, I wonder if you've thought of someone you'd like us to call now?

**IF THE ANSWER IS STILL "NO"** assure the patient...that their medication, treatment plan and progress will not be shared.

# CONSENT: It's all in the ask!

**WHEN YOU DON'T HAVE CONSENT...and are speaking with family caregivers, acknowledge the difficulty this poses.**

Be polite, supportive and sensitive to the caregiver's needs. Your client/patient's illness has also had a major impact on the family. Assure the caregiver that their loved one is OK and getting good medical treatment. Also offer a little hope.

I know it's difficult to hear that [*patient's name*] hasn't given us permission to collect information from the family or share information about their care with you. But we can ask again when the patient is feeling better.



How are you doing?  
What are you doing to take care of yourself?

# CONSENT: Benefits of Including Caregiver

## Caregivers **KNOW** things from providing care, supporting and arranging things:

- They schedule medical, specialist or therapy appointments – they know the care team
- Keeping track of information, medications, therapies, exercises
- Providing emotional support
- Observing mood, activity, behavior, energy levels, and other signs in their care recipient that they can share with you

**Mom seems a lot more tired these past 3 months. When I first got here 6 months ago, she could walk to the corner store. Now she can't. She's not eating much. Mom loves her TV shows but doesn't want to watch them anymore.**



**Mom's mood has been low, too. She talks about wanting to be with Dad, who passed on 10 years ago.**

# Resources

- NIDUS – Consent Series: “What is informed consent for health care?” ([www.nidus.ca](http://www.nidus.ca)), 2013
- NIDUS – Health Care Consent in BC: Your Rights and the Law, 2020
- [http://www.nidus.ca/PDFs/Nidus\\_HealthCareConsent\\_YourRights-BC.pdf](http://www.nidus.ca/PDFs/Nidus_HealthCareConsent_YourRights-BC.pdf)
- Doctors of BC “BC Physician Privacy Toolkit: A guide for physicians in private practice” 3<sup>rd</sup> Edition ([www.oipc.bc.ca/guidance-documents/1470](http://www.oipc.bc.ca/guidance-documents/1470)), 2017
- Health Care (Consent) and Care Facility (Admission) Act, 2000. Chapter 181, Part 2, Sections 4, 5, 6, 9  
[https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96181\\_01](https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/96181_01)
- Health Care Providers’ Guide to Consent to Health Care, Ministry of Health, July 2011:  
<http://www.health.gov.bc.ca/library/publications/year/2011/health-care-providers'-guide-to-consent-to-health-care.pdf>
- Consent to Care Facility Admission, Ministry of Health -  
<https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/accountability/consent-to-care-facility-admission>
- Practice Guidelines for Seeking Consent to Care Facility Admission, Province of British Columbia, September 2019: [https://www2.gov.bc.ca/assets/gov/health/accessing-health-care/finding-assisted-living-residential-care-facilities/practice\\_guidelines\\_for\\_seeking\\_consent\\_to\\_care\\_facility\\_admission.pdf](https://www2.gov.bc.ca/assets/gov/health/accessing-health-care/finding-assisted-living-residential-care-facilities/practice_guidelines_for_seeking_consent_to_care_facility_admission.pdf)

# Additional Resources

These resources help both caregivers and care providers better understand health privacy and consent rules so they can work as partners in care to optimize care and support for patients

- **Understanding Health Privacy and Consent in Ontario: a Guide for Caregivers and Care Providers**
- **At a Glance: Understanding health privacy and consent in Ontario – For Caregivers**
- **At a Glance: Understanding health privacy and consent in Ontario – for Care Providers**

Four companion resources also provide answers to frequently asked questions by caregivers:

- **FAQs on Privacy and Consent for Caregivers Supporting Someone Capable of Making Their Own Decisions**
- **FAQs on Privacy and Consent for Caregivers Supporting Someone Incapable of Making Their Own Decisions**
- **FAQs on Privacy and Consent for Caregivers of Children and Youth**
- **FAQs on Privacy and Consent for Caregivers Supporting Someone in the Mental Health and Addiction System**

This resource has been adapted from materials originally created through the Changing CARE: Embrace Project by The Change Foundation, the Cornwall & District Family Support Group, and Cornwall Hospital's Community Addiction and Mental Health Centre. We thank the caregivers who gave their time, insights and feedback to make this work possible.







Family Caregivers  
of British Columbia

— Let us help —



**BC Toll-Free Caregiver Support Line**

**1-877-520-3267**



**Caregiver Support Groups**

**Virtual and in-person - Visit our  
website**

## OUR **SERVICES**



**Caregiver Learning Centre**

**Watch - Read - Listen - Take a Class**



**Caregiver Connection Newsletter**

**FCBC e-News**

[www.familycaregiversbc.ca](http://www.familycaregiversbc.ca)