

Caregiver Centered Care

Supporting Family Caregivers in Healthcare

Webinar Series

Building a Better System to Support Canadian Family Caregivers

Conversation #3 Partnering with Family Caregivers

October 18, 2022



UNIVERSITY OF ALBERTA
FACULTY OF MEDICINE & DENTISTRY
Department of Family Medicine

Panel Presentation: Strengthening Family Partnerships in the Care Team

Barb MacLean, Executive Director
Family Caregivers of BC



**Family Caregivers
of British Columbia**

— Let us help —

What we do

... so that family caregivers are recognized, valued and supported as partners in care.



Caregiver Support

- BC Caregiver Support Line
Information, Referral, and Navigation
- 1:1 Caregiver Coaching
- Peer Support
- Greater Victoria Caregiver Support
Pilots and tests of change



Education + Training

- Online Resources
- Webinars and Workshops
- Training Series
- Presentations
- Podcasts & Blog
- Caregiver Connect Newsletter



Collaboration + Engagement

- “Caregiver Friendly” Health System
Improvement
- Caregiver RX Initiative
- Participate in Research
- Inform Policy
- Caregiver Support Network capacity
building



Family Caregivers
of British Columbia
— Let us help —

We need family caregivers

An iceberg floating in the ocean. The tip of the iceberg is above the water line, while the vast majority of the iceberg is submerged below the surface. The text '80%' is overlaid on the submerged portion of the iceberg.

80%

10:1

For every hour
the public system
provides,
caregivers give 10

Hermus, G., Stonebridge, C., Theriault, L. & Bounajm (2012).. Home and Community Care in Canada: An Economic Footprint. Conference Board of Canada.

What is Caregiver Friendly Health Care?

What words come to mind for you?

- Caregiver Friendly health care is when family and friend caregivers feel valued, supported and included as partners in care.
- When they are identified, offered support and treated as a member of the team, they will no longer feel excluded, unsupported and unappreciated.
- We believe that EVERYONE can help accelerate Caregiver Friendly Health Care when they focus on *their places of influence across systems*.



This is about transforming the systems and processes that create caregiver invisibility into systems that include family caregivers for what they are: invaluable and irreplaceable.

Caregiver Friendly Health Care



1. Identify, Refer & Include

Work with MOH, GPSC, PCN's and other selected non-PCN integrated communities to integrate caregiver identification, support, and referral.



2. Build Relationships

Continue to build strong relationships with healthcare stakeholders, community organizations.



3. Strive for Policy Change

Continue identifying opportunities for systemic inclusion of caregivers in care planning (Partners in Care).



Caregiver Friendly Health Care



HCP referrals
33% of all
Caregiver
Support Line
calls

Health Sector Engagement

- Connected with 28 communities across 5 Health Authorities
- Education for health care providers: webinars watched =348
 1. Helping Family Caregivers Feel Seen and Heard
 2. Timing It Right – Providing Support and Resources for Caregivers along the Caregiving Trajectory
- Continued focus the need to identify, refer and include caregivers as partners in care.
- Paper: How Social Prescribing is Helping Health Care Providers Support Family / Friend Caregivers in BC (draft)
- Ministry of Health Committees
- Regional committees
- PCN committees

Higher Needs Family & Friend Caregiver Support Program Demonstration Project



United Way of BC
Partnership
Ministry of Health
funded

- FCBC is Co-backbone support for 16 programs across BC
- Targeting family caregivers who are caring for seniors with “high needs” to live better and longer at home
- Collaboration and co-creation model
- Capacity building as a growing sector
- Cross promotion, resources sharing, network building
- Trainings: Support Group Facilitator + Circles of Care for Caregivers
- Objectives being evaluated:
 1. Increase psychosocial support for caregivers
 2. Increase caregivers’ skills, knowledge and confidence to care
 3. Increase caregivers’ sense of social connectedness
 4. Improve caregivers’ connections with health care teams as a partner in care
 5. Increase caregivers’ regular use of formal and informal respite (breaks that provide relief from caregiving duties)
 6. Reduce unnecessary health care utilization due to caregiver burnout



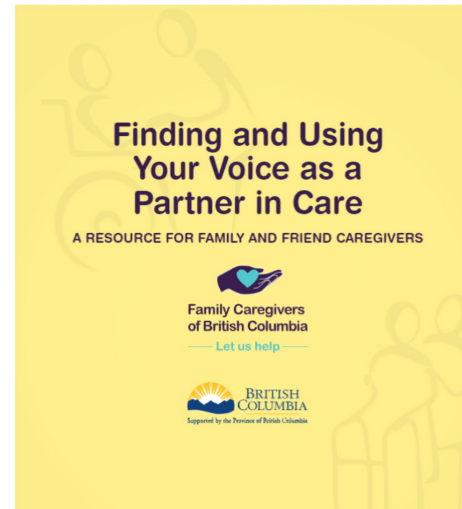
Family Caregivers
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Social Prescribing – Caregiver RX

- Health Care Provider referrals increased by 150% over last fiscal – so ...
- ✓ ... Social Prescribing - our Caregiver Rx Project efforts are working!



call volumes
63% higher
than before
COVID



What do caregivers want?



Recognition of, and respect for, the caregiving role.



To feel **informed** with timely communication based on their needs and role.



To be **included** in care planning of the person they are caring for.



To be **empowered** to look after their own health and well-being, and gain knowledge, skills and confidence in their caregiving role.^{1, 2}

Finding and Using Your Voice as a Partner in Care

A RESOURCE FOR FAMILY AND FRIEND CAREGIVERS

¹ British Columbia Ministry of Health. Patient, Family, Caregiver and Public Engagement Framework 2018.
<https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/patients-as-partners-framework.pdf>

² Patient and Family Centred Care Resource Kit: How to Improve the Patient Experience at the Point of Care. (2014) Alberta Health Services. Quality and Healthcare Improvement. Engagement and Patient Experience Department



Why They Should Be Included



Financial and Legal



Managing Medications

Family Caregivers are managing many aspects of care and often know the care recipient better than the care team



Health Advocacy



Monitoring Health



Housing Needs



End of Life/
Palliative



Transportation



Community -
Based Services



Emotional and
Cognitive Health
of Care Recipient

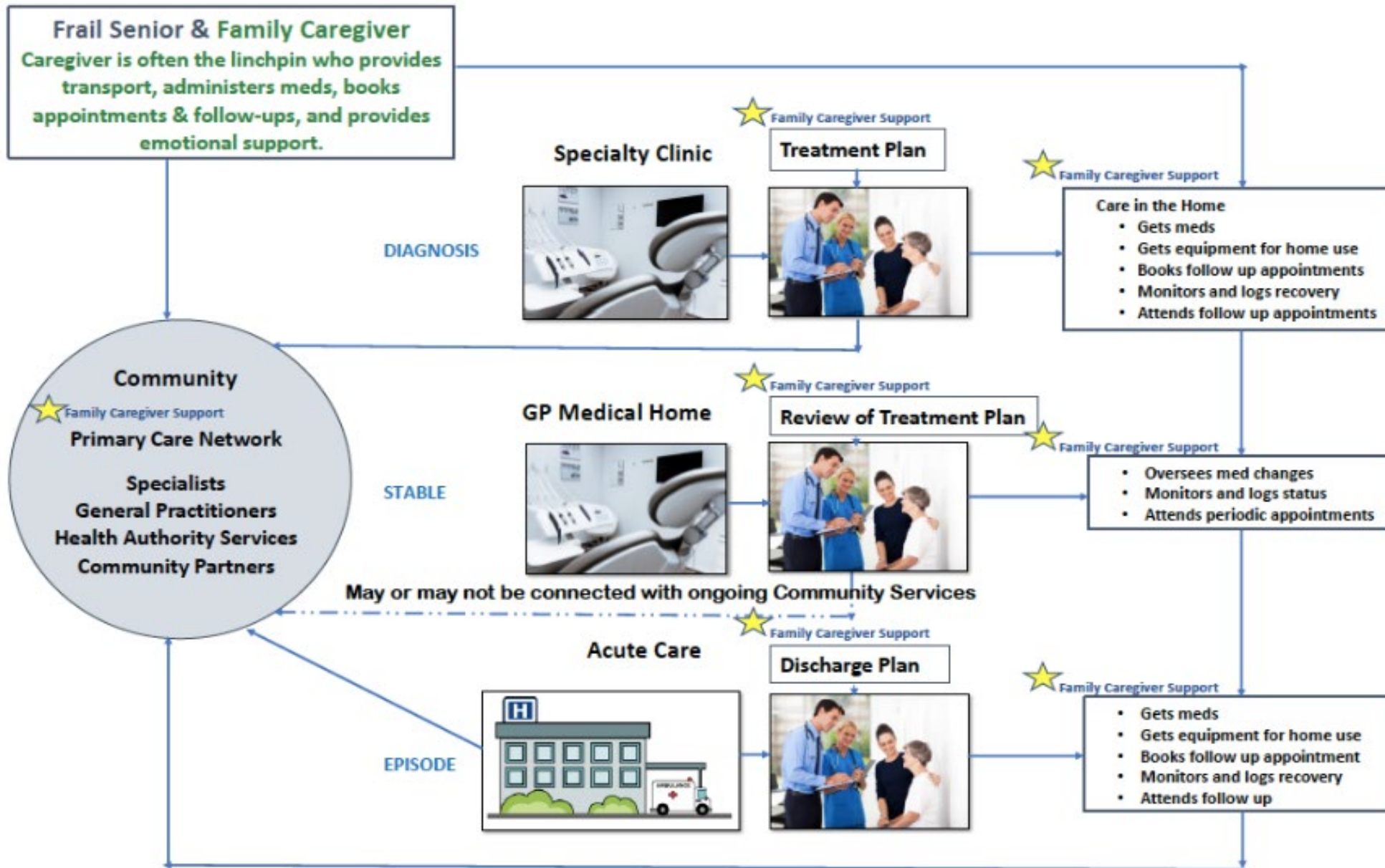


Home support/care
and instrumental
activities of daily living

https://www.familycaregiversbc.ca/archives/3d-flip-book/finding-and-using-your-voice-as-a-partner-in-care?fbclid=IwAR3Kk4ZWpVhMd4DFfq5TaDho1vDU6OIFGAeaTA8FS7202RhNvkEm6Qd_y4w



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Caregivers are everywhere = many opportunity for partnership lens

Health Care System Levels - Definitions[1]

MICRO: Provider-Family Caregiver Interaction

E.g. a health care team/clinic or individual care provider including physician, case manager, social worker, O/T, specialty services such as a Geriatric Outreach Clinic, etc.



Example of Family Friendly Health Care

- FCBC Newsletter and other Family Friendly education/marketing material in waiting room
- 10 second hand-off "Caregiver Rx" tear-off pad
- Completed Caregiver Consent and Referral form (online or faxed)

MESO: Health Care Organizations & Community

Level of responsible for service areas/clinical programs/initiatives providing care for a similar group of patients and their families (e.g., Health Authority, Primary Care Network, initiative with a Division of Family Practice).



- Collaboration in developing initiatives with identification and support for family caregivers included in objectives.
- Embedding caregiver identification and support into processes, i.e., patient intake, caregiver assessment, clinic order sets

MACRO: Legislation, Policy, Mandates

The highest (strategic) level of the system affecting policy change including Ministry of Health, Shared Care, Doctors of BC, etc.



- Access to family caregiver support listed as strategic health priorities in Health Authority Mandate letters
- Embedding "family caregiver" in patient-centred care documents and processes
- Family caregiver representatives at policy level

[1] Adapted from: Incident Analysis Collaborating Parties. Canadian Incident Analysis Framework. Edmonton, AB: Canadian Patient Safety Institute; 2012. Incident Analysis Collaborating Parties are Canadian Patient Safety Institute (CPSI), Institute for Safe Medication Practices Canada, Saskatchewan Health, Patients for Patient Safety Canada (a patient-led program of CPSI), Paula Beard, Carolyn E. Hoffman and Micheline Ste-Marie.

Who's on the team?

<https://teambasedcarebc.ca/>

TEAM-BASED CARE BC

What is Team-Based Care?

Find Resources

Events Calendar

About Us



Your Role as a Patient, Chosen Caregiver and/or Family Member

Patients, chosen caregivers, family members and anyone else who is a part of a patient's support system have important roles in supporting the transition to team-based care.

[Learn more](#)



Your Role as a Care Provider and/or Team Member

Care providers and team members provide and/or support primary care delivery, and function as equal partners in the delivery of high-quality care for patients.

[Learn more](#)



Your Role as a Planner, Designer and/or Improver

Planners, designers and improvers influence and support high-quality, team-based care without directly delivering care to patients.

[Learn more](#)



Family Caregivers
of British Columbia

Barriers to a partnership approach

1

I don't have time

2

It is not my job

3

I have nothing to offer

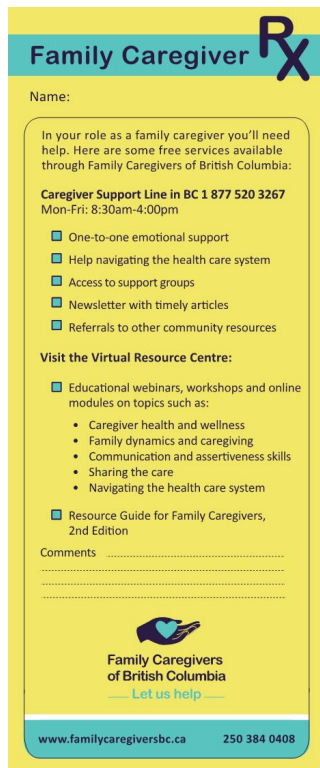


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Solutions ~~Barriers~~ to a partnership approach

1 I don't have time

✓ The 10 Second Handoff



The form is titled "Family Caregiver Rx" and includes a "Name:" field. It contains a paragraph about the role of a family caregiver and a list of services available through Family Caregivers of British Columbia. The services listed are: One-to-one emotional support, Help navigating the health care system, Access to support groups, Newsletter with timely articles, and Referrals to other community resources. Below this is a section for "Visit the Virtual Resource Centre:" which includes a list of 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, and Navigating the health care system. There is also a checkbox for "Resource Guide for Family Caregivers, 2nd Edition". At the bottom, there is a "Comments" field and the Family Caregivers of British Columbia logo with the tagline "Let us help". The website address "www.familycaregiversbc.ca" and the phone number "250 384 0408" are at the very bottom.

✓ The 5 Minute Huddle

"I'm wondering how you're doing with Jan's care at home. If we sat down for 5 minutes, is there one thing on your mind you'd like to talk about?"

✓ The "Book it Danno" Planning Session

- 20 – 30 minutes
- MSP Physician Billing Codes
- Eg: Complex Care Planning and Management
- Home Health Case Manager Planning Session

Solutions ~~Barriers~~ to a partnership approach

2

It is ~~not~~ my job

Person and Family Centered Care
Caregiver Centered Care
Team Based Care
Person Centered Care
Patient Centered Care

“Nothing about me
without me.”

Person- and Family-Centred Health Care

We collaborate with a range of stakeholders and work to provide leadership, tools and resources that help integrate patients' and families' voices, choices and representation in health-care system decision making. <https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/patients>

Essential Together <https://www.healthcareexcellence.ca/en/what-we-do/all-programs/essential-together/>

Essential Together is a program designed to support the safe reintegration of Essential Care Partners into health and care settings, during COVID-19 and beyond.

- The Essential Together Pledge
- Essential Together Huddles: Connecting for peer-to-peer learning and support
- Essential Together Learning Bundles
- Bringing Evidence to Life and Busting Myths through Stories
- Policy Guidance for the Reintegration of Caregivers as Essential Care Partners
- Evidence Brief: Caregivers as Essential Care Partners
- Policy scans of essential care partner presence policies

AH0900-VISITATION AND PRESENCE OF FAMILY AND PARTNERS-IN-CARE [Policy 2019]

1.0 PURPOSE

Interior Health (IH) has adopted and is committed to Person and Family-Centred Care. IH recognizes that family members/partners-in-care are vital to an individual's safety, comfort, physical and psychological health and wellbeing. This policy supports and encourages family presence in all IH sites while balancing with the highest standards in quality of care and safety.



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Barriers + solutions to a partnership approach

3

I have ~~no~~ something to offer

“I wish they knew that it is okay to ask me how I'm doing.”

Mrs. Carter, how are you doing today?

“I often feel invisible. I'm spending my life juggling this care. Does anyone know?”

Hello Mrs. Carter. It's good to see you. You're doing a wonderful job, a difficult job.

“I am the person who stands between my husband living at home and the heart-breaking day I can't care for him anymore. Sometimes I'm overwhelmed.”

Everyone has limits and your life matters too. Talking about it is important. Here is a caregiver support pamphlet – research shows that getting support early on helps your own well-being. If you want, I can make a direct referral to Family Caregivers of BC and they will call you.

“I am rarely asked my opinion. Sometimes I leave feeling really angry. I try to speak up. I am a partner but don't always feel respected.”

Mrs. Carter, after we go over our recommendations, could we get your input please? It's important that we work on this as a team, and you know your situation best.



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Examples

Caregiver Identification

The Ontario Caregiver Organization and The Change Foundation, in collaboration with family caregivers, developed:

- Partners in Care Toolkit
- Caregiver ID tag, sticker or card

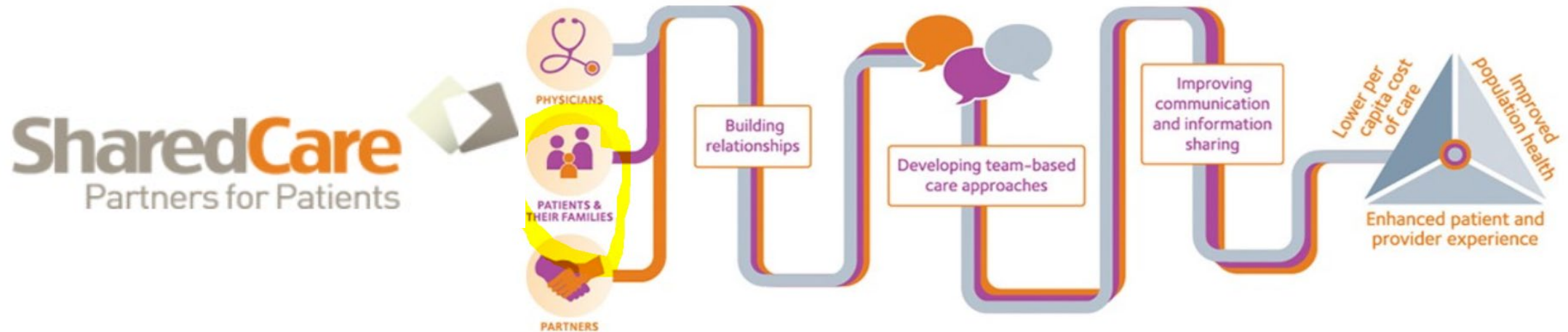
The Change Foundation's Changing CARE Projects - multiple sites used Caregiver ID
Huron Perth Healthcare Alliance
Pandemic Response & Adaptation

LESSONS FROM CHANGING CARE: SUSTAINABILITY AND SPREAD OF CHANGE INITIATIVES

- Caregiver ID was used to recognize essential caregivers and for staff to validate that the essential caregiver had passed screening.
- gave an opportunity to converse about personal protective equipment (PPE)
- The highly visual tool made the process of welcoming essential family caregivers much smoother at a time of such confusion and uncertainty.
- the Caregiver ID initiative was adapted to directly support the Alliance in maintaining their commitment to the deeply embedded culture.



Examples from BC



A joint initiative of the BC Ministry of Health and Doctors of BC, the SCC's mandate is to support family and specialist physicians, health care partners, patients, families and caregivers, to collaborate on health care improvement initiatives together.

Patient/caregiver partners are an integral part of the project and engaged throughout the lifespan of the work.

EOI/Proposal Details — Please complete prior to submission to SCC contact

If submitting an EOI, please provide brief outlines to the questions below, and indicate where information is not yet available.

If submitting a Proposal, please provide more detailed information to the questions.

You are not required to complete #s 1-15 if this is an Additional Funds Request.

1. Please outline a brief patient story that illustrates the challenges faced or gaps that need to be addressed.

What is the current experience for patients, families and/or providers, and how does it impact the provision of coordinated, quality care?

7. How will you engage the patient and family caregiver voice, and capture the patient experience and improved patient outcomes?

Examples

BC Patients as Partners Initiative

- Engaging patients and families in health system improvement efforts
 - Self-Management Supports
 - Family Caregivers of BC
 - Pain BC
 - Self Management BC
 - CCMI
- Family Caregiver Engagement Tip Sheet
- <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/family-caregivers-engagement-tip-sheet.pdf>

Engagement Tools and Resources

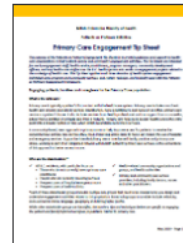
[Expand All](#) | [Collapse All](#)

[Patient, Family, Caregiver and Public Engagement Framework](#) ▼

[Engagement Planning Guide](#) ▼

[Tip Sheets for Engaging Different Populations](#) ^

The tip sheets provide guidance and support to health-care organizations in their patient, family and community engagement activities.



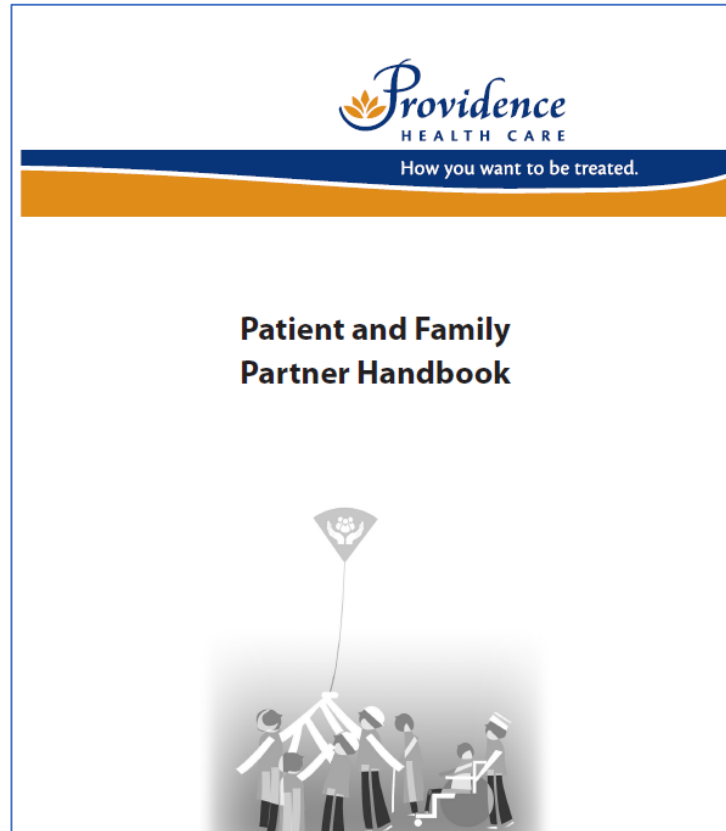
- [Primary Care \(PDF, 251KB\)](#)
- [Mental Health and Substance Use \(PDF, 241KB\)](#)
- [Seniors with Complex Medical Conditions \(PDF, 251KB\)](#)
- [Surgery \(PDF, 275KB\)](#)
- [Rural and Remote \(PDF, 241KB\)](#)
- [Intercultural Communities \(PDF, 249KB\)](#)
- [Family Caregivers \(PDF, 228KB\)](#)
- [Tips for Writing Policy Related to Person- and Family-Centred Care \(PDF, 416KB\)](#)

[, Conflict of Interest](#) ▼

[S](#) ▼

<https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/patients>

Examples



Patient
Voices
Network

ADMINISTERED BY
BC PATIENT SAFETY & QUALITY COUNCIL



Resource Guide for Older Adults and Caregivers

This resource guide accompanies the BC Guideline [Frailty in Older Adults – Early Identification and Management](#)

This resource guide includes information on the following topics:

▪ Physical Activity	2	▪ Managing Chronic Conditions	3
▪ Fall Prevention	2	▪ Help at Home (Medical and Non-Medical Support)	4
▪ Nutrition	3	▪ Caregiver Support	4
▪ Social Connections	3		

Examples

Inpatient Mental Health Unit



Cornwall Community Hospital
Hôpital communautaire de Cornwall

RIGHTS OF THE FAMILY CAREGIVER

YOU have the right:

- To staff who are caring and understand that the entire family is affected by your loved one's addiction or mental health
- To be treated with respect, empathy and understanding in a non-judgmental, recovery-oriented environment
- To a health care team that actively encourages family involvement... where sharing your observations and concerns about your loved one is both expected and valued
- To a hospital setting that actively encourages your loved one to allow you to be part of the recovery process
- To receive information on your loved one's diagnosis, prognosis, treatment and discharge plan (with his/her consent)
- To receive information on hospital and community resources

FAMILY CAREGIVER SURVIVOR TIPS

TAKE CARE OF YOURSELF

You can't care for your loved one if you don't take care of yourself.

SEEK HELP FROM OTHER FAMILY CAREGIVERS

Explore the caregiver support groups, caregiver education, and counselling services that are available in our community (see Resources for caregivers).

Clinical Order Set	Demographics
RJH Seniors Outpatient Clinic and Specialist Memory Clinic	
Page 1 of 2	
Referral to GSS Clinician within SOPC (specify reason and urgency – more room for notes on pg. 2)	
<input type="checkbox"/> Clinical Pharmacy: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> Nurse Continence Advisor: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> Occupational Therapy: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
OT referral for <input type="checkbox"/> Functional Cog Assess <input type="checkbox"/> Cognition <input type="checkbox"/> Pre-driving <input type="checkbox"/> Home safety	
<input type="checkbox"/> Physiotherapy: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
PT referral for <input type="checkbox"/> Physical function Assess <input type="checkbox"/> Class Consideration <input type="checkbox"/> Community Prog. <input type="checkbox"/> Home exercise program	
<input type="checkbox"/> RN/RPN: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> Social Work: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> Clinician to discuss "SOPC Permission to Contact for Research Purposes" Program	
Internal Consult / Referral (specify reason and urgency – more room for notes on pg. 2)	
<input type="checkbox"/> Geriatric Medicine: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> Geriatric Psychiatry: (specify reason for referral on reverse side of this pg.) _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> Nurse Practitioner: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> Behavioural Neurology: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> GSS-MHSU, formerly SORT (fill out separate internal referral sheet)	
Diagnostic Imaging / Investigations (requisitions to be filled out separately)	
<input type="checkbox"/> MRI <input type="checkbox"/> EKG <input type="checkbox"/> Laboratory	
<input type="checkbox"/> CT <input type="checkbox"/> Holter <input type="checkbox"/> Other _____	
<input type="checkbox"/> SPECT <input type="checkbox"/> EEG	
<input type="checkbox"/> X-Ray <input type="checkbox"/> Ultrasound	
Referral to Community Access – Island Health Community Health Services (specify reason)	
<input type="checkbox"/> Case Management: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> Nursing: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> Occupational Therapy: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
<input type="checkbox"/> Physiotherapy: _____ <input type="checkbox"/> routine <input type="checkbox"/> semi-urgent <input type="checkbox"/> urgent	
External Referrals	
<input type="checkbox"/> First Link (Alzheimer's Society of BC) <input type="checkbox"/> Family Caregivers of BC	
<input type="checkbox"/> PD Connect (Parkinson's Society of BC) <input type="checkbox"/> Headway (Victoria Epilepsy and Parkinson's Centre)	
<input type="checkbox"/> Coaching for Health Program (Pain BC) <input type="checkbox"/> BC Association for Living Mindfully (BCALM) Classes	
<input type="checkbox"/> Boost Your Brain Power (provide information to patient to make self-referral)	
<input type="checkbox"/> Road Safety Report of a Condition (fill out separate report form)	
Plan	
<input type="checkbox"/> Follow up at SOPC in _____ months, or <input type="checkbox"/> after investigations complete	
Length of appointment will be <input type="checkbox"/> 30 min <input type="checkbox"/> 1 hour <input type="checkbox"/> Other _____	
<input type="checkbox"/> Discharge <input type="checkbox"/> Please ask referring MD to send re-referral (3333) with ICD code _____	
Space for additional orders/notes on the reverse side of this page	
Signature, Designation _____	College License # _____ Date _____
Page 1/2	
DRAFT for SOPC Specialist Memory Clinic PDSA Cycle – Oct 2019 Author: chm@viha.ca	

1



Reflection + Action

What's ONE THING you will do to strengthen your partnerships with family caregivers?

Thank you



Family Caregivers
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— Let us help —