



**Family Caregivers
of British Columbia**

“Talk the Talk” - Building Cooperative Relationships

November 2018

Guest Presenters: Sheila Armstrong & Wendy Johnstone
Host & Moderator: Family Caregivers of British Columbia

Who We Are

- **Family Caregivers of BC (FCBC) is a non-profit charity dedicated 100% to the wellbeing of family caregivers.**
- **29 years, first of it's kind in Canada.**
- **Serving B.C. since 2010, past 5 years as part of the Ministry of Health's Patients as Partners Initiative.**



CAREGIVER SUPPORT

Information, referral & navigation
1-1 Caregiver Coaching
Support Groups
Online Resource Centre

Toll Free Line: 1-877-520-3267

Call 1-877-520-3267 for an assessment

Visit <https://www.familycaregiversbc.ca/find-resources/> for listing

Visit <https://www.familycaregiversbc.ca/find-resources/> for resources

EDUCATION

Online Resource Centre
Webinars & Workshops
Events & Presentations

Caregiver Connection Newsletter & eNews @
<https://www.familycaregiversbc.ca/caregiver-connection/>

Register @

<https://www.familycaregiversbc.ca/events/webinars/>

Events Calendar @

<https://www.familycaregiversbc.ca/events/>

COLLABORATION & ENGAGEMENT

Health System Improvement
Participate in Research

Contact us to engage as a voice for family caregivers in the health care system

<https://www.familycaregiversbc.ca/research-family-caregivers-2/>

Webinar Norms

- **Confidentiality is essential.**
- **Each person has the right to take part in the discussion or not.**
- **Every group member is welcome to provide feedback.**
- **Equal sharing time for all members.**
- **Be aware that experiences expressed are unique and may not reflect your own.**

Tonight's Presenters



Sheila Armstrong, Retired RN

- **Sheila Armstrong** has an extensive background in nursing from the whole person perspective.
- This means she understands that caregiver health includes consideration of mental, emotional AND physical well being.
- Sheila's career spanned the whole continuum of the health care system, from acute to community with a large portion of time spent overseeing the placement of care recipients into facility-based care when needed.



Wendy Johnstone, Gerontologist

- **Wendy Johnstone** is a program consultant with Family Caregivers of BC and brings almost 20 year's experience as a Gerontologist to her role.
- Wendy supports family caregivers in 1:1 Caregiver Coaching sessions to make informed decisions and action plans, providing invaluable emotional support while they navigate health care and social systems.
- She is also actively involved in FCBC's health sector engagement work and writes articles for family caregivers in INSPIRE Senior Living magazine.
- Wendy also runs her own company – Keystone Elder Care in the Comox Valley.

Learning Objectives

- **Build on our webinar “Accessing Community Resources” aired October 18th (now available as a recording on our website <https://www.familycaregiversbc.ca/events/webinars/>)**
- **Learn how to establish yourself as part of your care recipient’s health care team.**
- **Understand where and who to go to for your health care needs.**
- **Learn how to speak the health care system language.**
- **Learn communication strategies you can use with anyone on the care team and the person you are caring for.**

Caregiver Concerns

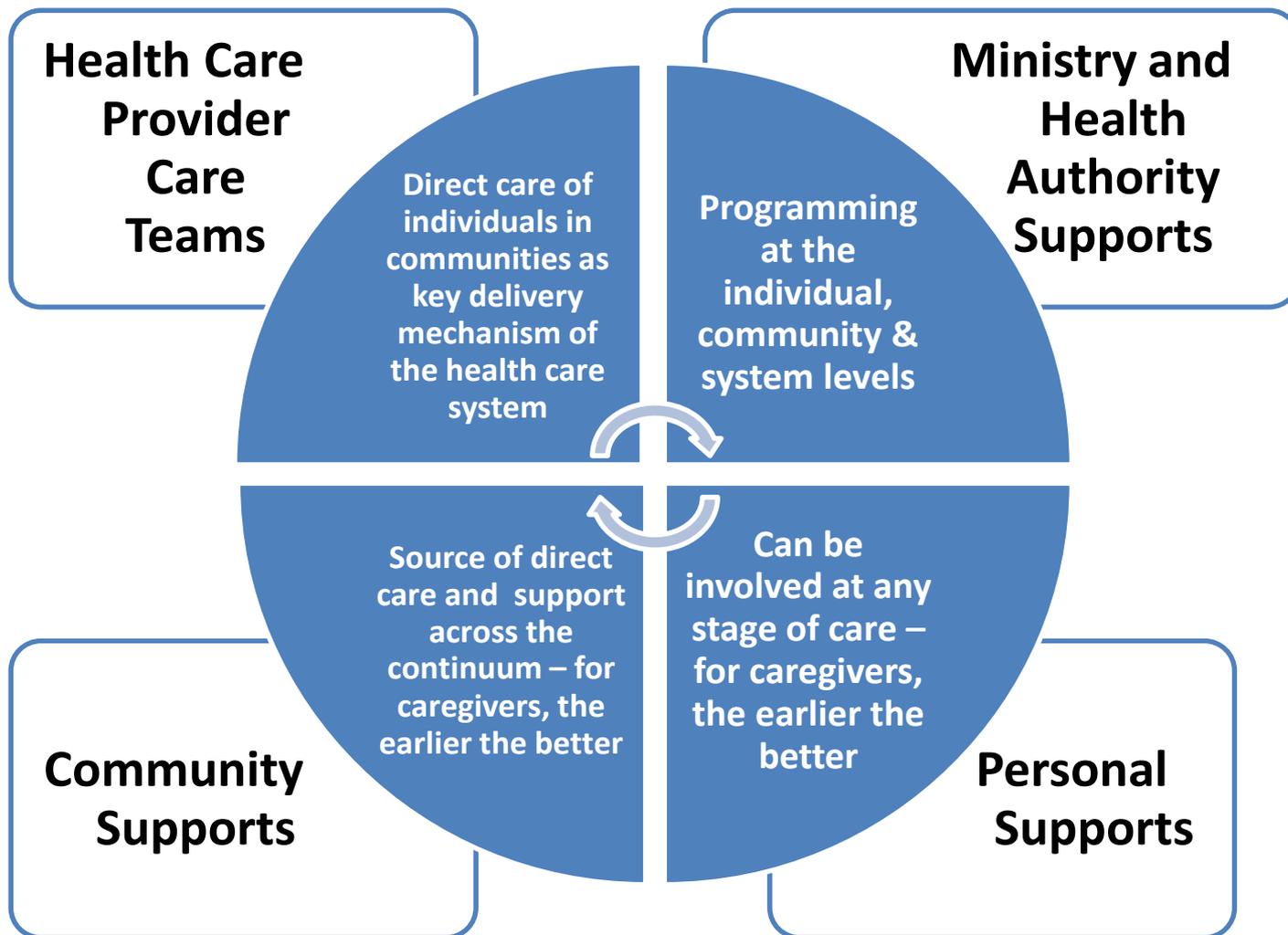
- Our Caregiver Support Line ([1-877-520-3267](tel:1-877-520-3267)) and Caregiver Support Groups give us a window into caregiver concerns
- What we hear is:
 - Caregivers aren't sure what their "rights" are.
 - They aren't sure who to speak to about a specific situation.
 - They aren't sure how to approach health care providers.
 - They are unsure about sequences and when to speak.
 - They don't know if they have been heard and understood.

Common Misconceptions

We also encounter common misconceptions about the health care system:

- **Publicly-funded doesn't always mean services are FREE.**
- **People can only use publicly-funded OR private pay services.**
- **Using private services affects your ability to access publicly-funded services.**
- **Members of the Health Care Provider Team all speak to each other.**
- **If you tell one person your story or concerns, it will get captured in your electronic medical record.**

Map of Health Care Services



Health Care System At-A-Glance

Public, Mixed and Private Systems of Health Care

	Funding	Administration	Delivery
Public Canada Health Act services (hospital and physician services plus) and public health services	Public Taxation	Universal, single-payer provincial systems. Private self-regulating professions subject to provincial legislative framework	Private professional, private not-for-profit, private-for-profit and public arm's-length facilities and organizations
Mixed goods and service, including most prescription drugs, home care and institutional care services	Public taxation, private insurance and out-of-pocket payments	Public services that are generally welfare-based and targeted, private services regulated in the public interest by governments	Private professional, private not-for-profit and for-profit, and public arm's-length facilities and organizations
Private goods and services including most dental and vision care as well as over-the-counter drugs and alternative medicines	Private insurance and out-of-pocket payments including full payments, co-payments and deductibles	Private ownership and control; private professions, some self regulating with public regulation of food, drugs and natural health products	Private providers and private for-profit facilities and organizations



Canada Research
Chairs

Chaires de recherche
du Canada

Individual factors contribute to which systems apply in which situations

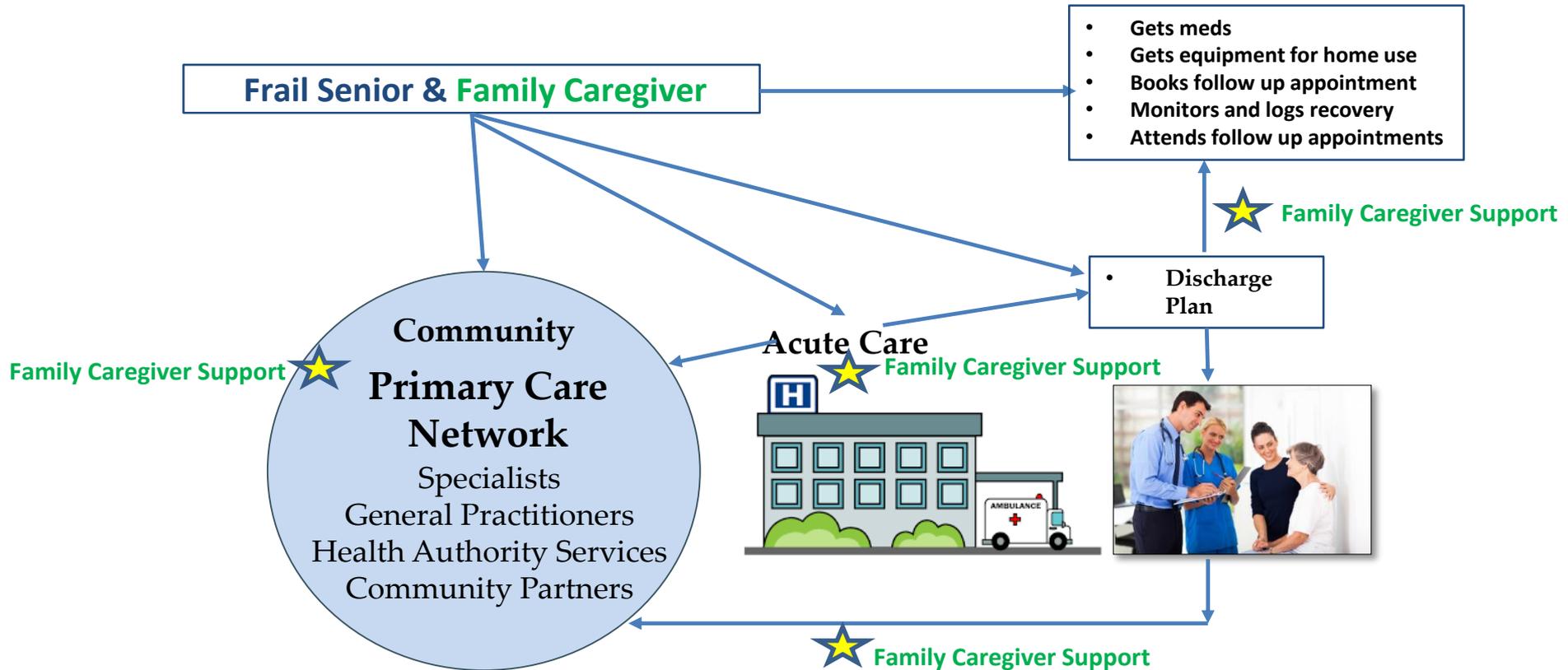
Where Caregivers & the Health Care System Intersect

Family caregivers intersect with:

- Family Physicians and Specialists during appointments.
- Health Care Providers in hospital during acute episodes.
- Acute Care Liaison Staff during discharge planning from a hospital stay or ED visit.
- Community Health Care Providers when supporting the care recipient in community.
- Facility Placement Staff during transitions to Long Term Care.

Ministry of Health Patients as Partners Initiative funds Family Caregivers of BC to support caregivers and work collaboratively with the system

Acute Episode Example - Patient & Family Caregiver Journey



The Family Caregiver is often the link-pin who provides transport, administers meds, books appointments & follow-ups, etc.

Challenge

**Despite massive
contributions and presence
in our health care system,
family caregivers report
feeling:**

Invisible

Unsure

Excluded

Value of Building Relationships

- The health care system is primarily designed for the person receiving care.
- Family caregivers have key and essential information about their ability to care, what supports there are, home environment, financial situation, etc.
- Being seen, heard and involved in the process is critical and will result in:
 - Better care for the care recipient
 - Better support for you as a caregiver

becoming Part of the Care Team

- In all cases, building cooperative relationships is about:
 - Being a Team Member
 - Being a Voice
 - Being Prepared
 - Being Realistic
 - Being Persistent and Kind

Being a Team Member

- Establish where your care recipient is in terms of his / her care needs in relation to the health care system.
- With your care recipient - develop an action plan with goals for care.
- Identify questions in advance & prepare so you can be concise and specific about what you / your care recipient needs.
- Identify the correct person to ask.
- Keep a written record of questions and answers with information about who you have spoken to.

Being a Voice

- Have a discussion with the person you are caring and establish your role as their “partner in care”, advocate and “voice”.
- Formalize your role. Do you need to get any documentation in place?
- Establish yourself as the “voice” or advocate for the person you are caring for with Health Care Providers.

Being Prepared

- **Develop an action plan with goals for care.**
- **Prepare questions in advance & rehearse so you can be concise and specific about what you need.**
- **Organize important questions first.**
- **Be aware you can also approach a concern as a discussion vs. a question.**
- **Keep a written record of questions, answers and conversations with contact information.**

Being Realistic

- **It's about collaboration – this is about working with Health Care Providers to meet your care recipient's needs.**
- **Be clear about what you need help with.**
- **Health Care Providers can't arrange everything but they can help with information.**
- **Sometimes Health Care Providers are following policy directives so don't shoot the messenger – your issue may need to be dealt with on a different level.**

Being Polite & Persistent

- Make sure you are addressing the right person and the timing is good.
- Present your ideas positively.
- Be pro-active and goal-oriented.
- Listen to the other person – be patient.
- Focus on the conversation.
- Reflect on what they say.
- Don't give up – persistence produces results.



Health Care Speak

- Ask for clarification about terms you may not understand eg. what is an “assessment”, what happens as a result; what is a “care plan”, who is responsible for overseeing, who tracks, etc.?
- Understand “referral” processes – who is making a referral, what is your role, what is the expected outcome?
- Address questions to health care providers based on their roles and “scope”. For example:
 - The most responsible provider, usually a family physician, is supported by a team and directs care in the practice and into the community (including specialist care). They should be your first point of inquiry.
 - Home Support needs and changes should be directed to a Case Manager.
 - Problems with Home Support services should go to a Home Support Supervisor *after speaking with the Case Manager.*

Real Life Caregiving Stories

Mark has been living with dementia for 5 years. Mary, his spouse, is frustrated and overwhelmed, and pre-existing issues in the marriage and family are making things more complicated. Mark is 85 years old and Mary is 78 years old. The family's experience with getting diagnosed has also been frustrating and has taken months. Mary has expectations that care will be provided in their home. The family is often disappointed to learn about the level of service they qualify for and are surprised that their case is not seen as a priority for the health care system.

Health Care System intersects: Usually the Family Doctor and Health Care Team and Community

Real Life Caregiving Stories

Susan's mom has had 3 falls in the past 6 months. Most recently she fell in the night and was taken to the ED. They sent her back home; she lives in Independent Living. Mom was discharged with no instructions or follow up. Susan's mom currently doesn't have any additional home support. Susan works full time and has two kids still at home. Susan isn't sure who to talk to or how to communicate in a way that makes sure she is heard and that both her mom's and her own needs are met. Susan is also concerned about how to manage transitions and the care needs ahead.

Health Care System intersects: Usually the Family Doctor and Health Care Team; Discharge and Community

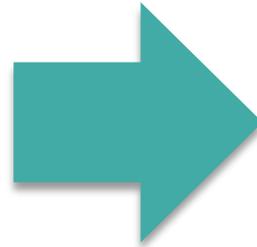
Real Life Caregiving Stories

Sarah's 75 year old mother's health has been failing for more than a year. Sarah's mother Jean had been seen by her family physician who ordered some tests and examinations. The family physician felt that there was the possibility of Jean having a neurological disorder. After nearly a year of tests and appointments Jean was diagnosed as having ALS (Amyotrophic Lateral Sclerosis). The diagnosis was devastating to both Jean and Sarah. Sarah lives in a city an hours drive from her mother. She is working full time at a stressful job and also has one son still living at home. Sarah is the only caregiver and her mother lives alone in her own home. Sarah is very supportive of her mother. Sarah is struggling with the caregiving for her mother, work and maintaining a home for her and her son. Finding and following up with resources to support Jean has been a struggle.

Health Care System intersects: Usually the Family Doctor and Health Care Team; Neurologist and Community

Quick Poll

**How many of you
will try one or two of
these suggestions?**



**If not – what would
prevent you?**



Don't Care Alone

CALL US

Caregiver Support Line:

toll free 1-877-520-3267

Browse our Website

www.familycaregiversbc.ca

- Caregiver Support Groups
- Live & Recorded Webinars
- Articles and Resources
- Newsletter



Thank you!



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