“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 its kind in Canada.
- Serving B.C. since 2010, past 5 years as part of the Ministry of Health’s Patients as Partners Initiative.
What We Do:  

**CAREGIVER SUPPORT**

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

**What You Can Do:**

- Toll Free Line: 1-877-520-3267
- Call 1-877-520-3267 for an assessment
- Visit [https://www.familycaregiversbc.ca/find-resources/](https://www.familycaregiversbc.ca/find-resources/) for listing
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**EDUCATION**

- Online Resource Centre
- Webinars & Workshops
- Events & Presentations

**What You Can Do:**

- Caregiver Connection Newsletter & eNews @ [https://www.familycaregiversbc.ca/caregiver-connection/](https://www.familycaregiversbc.ca/caregiver-connection/)
- Register @ [https://www.familycaregiversbc.ca/events/webinars/](https://www.familycaregiversbc.ca/events/webinars/)
- Events Calendar @ [https://www.familycaregiversbc.ca/events/](https://www.familycaregiversbc.ca/events/)

**COLLABORATION & ENGAGEMENT**

- Health System Improvement
- Participate in Research

**What You Can Do:**

- Contact us to engage as a voice for family caregivers in the health care system [https://www.familycaregiversbc.ca/research-family-caregivers-2/](https://www.familycaregiversbc.ca/research-family-caregivers-2/)

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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 18\textsuperscript{th} (now available as a recording on our website [https://www.familycaregiversbc.ca/events/webinars/](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) 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 Provider Care Teams**
  - Direct care of individuals in communities as key delivery mechanism of the health care system

- **Ministry and Health Authority Supports**
  - Programming at the individual, community & system levels
  - Can be involved at any stage of care – for caregivers, the earlier the better

- **Community Supports**
  - Source of direct care and support across the continuum – for caregivers, the earlier the better

- **Personal Supports**

Source: www.familycaregiversbc.ca
### Health Care System At-A-Glance

#### Public, Mixed and Private Systems of Health Care

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

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

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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!

Family Caregivers of British Columbia

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