FAMILY & FRIEND CAREGIVER

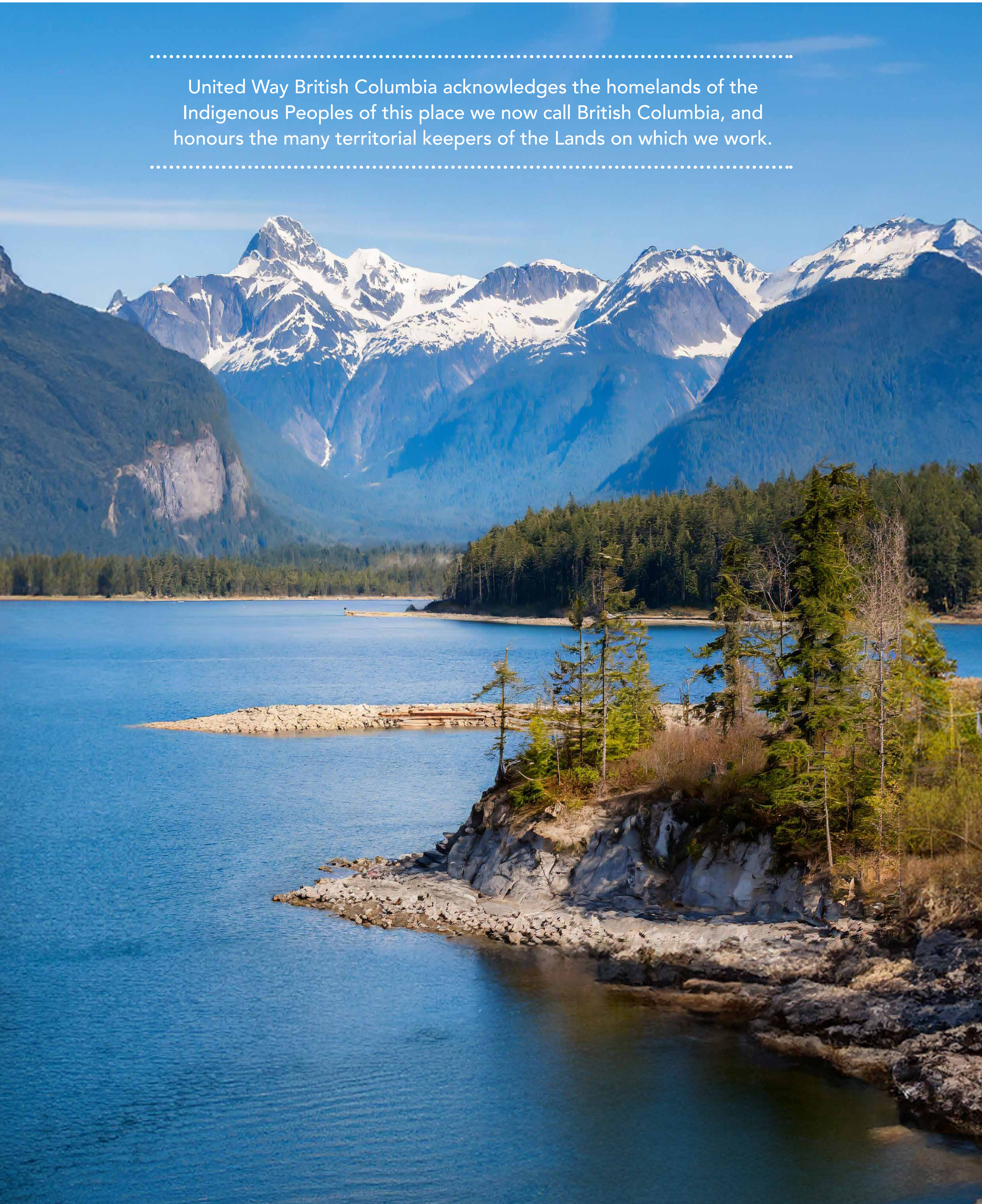
SUPPORT PROGRAM

A Handbook for
Family and Friend Caregiver Support Coordinators

United Way
British Columbia

Working with communities in
BC's North, Interior, Lower Mainland,
Central & Northern Vancouver Island

United Way British Columbia acknowledges the homelands of the Indigenous Peoples of this place we now call British Columbia, and honours the many territorial keepers of the Lands on which we work.



WELCOME/INTRODUCTORY MESSAGE FROM THE UNITED WAY

Welcome to United Way British Columbia's Family & Friend Caregiver Support Programs (FFCS) Handbook.

At United Way BC, we are dedicated to fostering healthy, caring, and inclusive communities by strengthening vital connections that support those in need. Within our Healthy Aging department, we are committed to empowering seniors and Elders to age independently at home while remaining active, connected, and engaged in their local communities.

Recognizing the invaluable role that caregivers, often unpaid, play in supporting the health and well-being of our aging demographic, the FFCS programs aim to provide essential support and resources. This handbook is specifically crafted for Family and Friend Caregiver Support Coordinators who are pivotal in executing these invaluable programs. It serves as a comprehensive overview of program elements, and functions as a foundational training guide for both Coordinators and the organizations involved in delivering FFCS programming within their communities.

Funder Acknowledgement

Funded by the Government of British Columbia and Managed by United Way British Columbia.

Our Vision

A healthy, caring, inclusive community.

Our Mission

We strengthen vital connections that support people in need in our local communities.

Healthy Aging Programs

Healthy Aging programs are designed to help British Columbians remain active, connected, and engaged in their existing communities. Based on these simple essentials, Healthy Aging develops and supports a range of programs and activities that support seniors including the Family & Friend Caregiver Support (FFCS) programs.

ABOUT THIS HANDBOOK

This handbook was created as a reference guide for the Family & Friend Caregiver Support programs (FFCS). Information found in this handbook provides an overview of the different program elements and serves as a basic training guide for Caregiver Support Coordinators (CSC) and the organizations that deliver the FFCS programming in their communities.

This handbook was inspired by the work and insight of the many wonderful FFCS program staff throughout the province of BC, who work collaboratively through the FFCS Community of Practice meetings, including: Abbotsford Association for Healthy Aging, Beacon Community Association, Burnaby Seniors Outreach Services Society, Caregivers Network for East Kootenay Seniors Society, Cowichan Family Caregivers Support Society, DIVERSEcity Community Resources Society, Family Services of the North Shore, Lake Country Health Society, Mount Pleasant Neighbourhood House, Nelson and District Hospice Society, OneSky Community Resources, Prince George Council of Seniors, Richmond Cares, Richmond Gives, Ridge Meadows Seniors Society, South Vancouver Neighbourhood House, and Terrace Hospice Society.

The handbook was written by Amanda Marchand with content and editing support from Linda Dirksen Gale at the Cowichan Family Caregivers Support Society. The United Way has provided marketing and promotional information and recommended training. A special note of appreciation is extended to Marcy Cohen, Co-Chair of the Community-Based Seniors' Services Leadership Council, for her remarkable efforts and many contributions to this handbook. Special thanks also go to Bobbi Symes, Elayne McIvor, and Wingsi Kan for their stalwart support in the development of the Community of Practice meetings.

A special appreciation for Laurie Kohl, Shelley Iberg, and Tricia McKay for their generous contributions to the Community of Practice meetings that helped inform this handbook.

PROGRAM DESCRIPTION

FFCS is a community-based program designed to provide support and resources for family and friend caregivers who are taking care of older adults living in the community with higher needs, including chronic disease, frailty, or other life-limiting conditions. This program serves as a valuable resource offering comprehensive information, educational materials, and additional support to help caregivers enhance their skills and foster a sense of confidence in their caregiving roles. The FFCS program includes five Core Elements (essential programming) and three Optional Elements:

Core FFCS Program Elements:

- One-to-One Support (including emotional support)
- Support Groups
- Healthcare System Navigation
- Connection to Community Services
- Knowledge and Skill Enhancement

Optional FFCS Program Elements:

- Social and Self-Care Activities
- Informal Respite
- Circles of Care (A Family Caregivers of BC model)

Important Note: Each FFCS program is unique and may offer other optional caregiver support services.

CONTENTS

WHO BENEFITS FROM THE SUPPORT OF FFCS PROGRAMS?

There is an understanding that program resources will focus primarily on caregivers who are experiencing considerable stress and are vulnerable to a chronic state of physical, emotional, and mental exhaustion.

Caregivers who commonly need the most engagement and program resources are:

- Individuals who are supporting complex and high-needs situations in a home environment, where others cannot easily replace their critical role. Examples include people, usually close family members, who are caring for someone diagnosed with dementia, chronic illness, palliative care needs, and those needing substantial support with activities of daily living (ADL) and/or instrumental activities of daily living (IADL).
- Caregivers experiencing their own substantive health conditions and whose health is negatively escalated by caregiving responsibilities.
- Caregivers who are overwhelmed and in crisis.

Caregivers who have experienced other challenging factors related to discrimination, systemic racism, trauma, and isolation may also benefit significantly from support:

- Indigenous caregivers, caregivers who speak English as a second language, newcomers, those living in rural/remote and medically underserved areas, LGBTQ2IA+, and those experiencing poverty.
- Socially isolated caregivers who don't have stable family or community relationships, including those who don't have access to the Internet.

Other considerations can put caregivers at risk of not accessing services until they are feeling overwhelmed or experiencing signs of "burnout":

- Traditional and cultural social structures can prevent women, particularly seniors, from recognizing themselves as caregivers. While they may need support, they often don't readily distinguish their new caregiving responsibilities as separate from their traditional caregiving roles as wives and mothers.
- In general, men are underrepresented as caregivers because of gender norms. This may put them at risk of being underserved in FFCS caregiving programs.

It is important to note that caregivers at the beginning of their caregiver journey also benefit from early support and intervention. Proactively addressing, managing, and avoiding chronic states of physical, emotional, and mental exhaustion can help support caregivers to have better health outcomes. In addition, caregivers who self-refer to services can be highly motivated to make early changes. Addressing and supporting caregiver well-being with a proactive lens should be an important consideration as these groups generally use less time and fewer resources. (See Addendum IV: One-to-One Support at the Different Phases of the Caregiving Journey for more discussion on suggested service delivery levels for each phase in caregiving.)

DEFINITIONS FOR THE FFCS PROGRAM

Agency: any community or non-profit organization delivering FFSC programming.

Caregiver: a partner, family member, friend, or neighbour who has a significant personal relationship with, and provides a range of assistance for, an adult with a chronic, disabling, or life-limiting medical condition in a non-professional capacity.

> *Note: we avoid using the term 'unpaid caregiving' because some family caregivers receive modest/partial financial compensation while engaging in caregiving work. Examples include caregivers who receive federal caregiver benefits, caregivers on paid caregiving leave provided by their workplace or collective agreements, informal economic arrangements within families, and supplemental insurance benefits for family caregivers.*

Care Recipient: an adult needing care support due to aging, a chronic illness, a disability or medical condition, or a life-limiting diagnosis. A care recipient needs regular, ongoing assistance with everyday tasks to function, due to substantially reduced independence.

Caregiver Support Coordinator (CSC): staff who deliver the FFCS program to caregivers.

Health Authority (HA): healthcare services provided by the provincial, regional, and First Nations Health Authorities to provide care to all British Columbians.

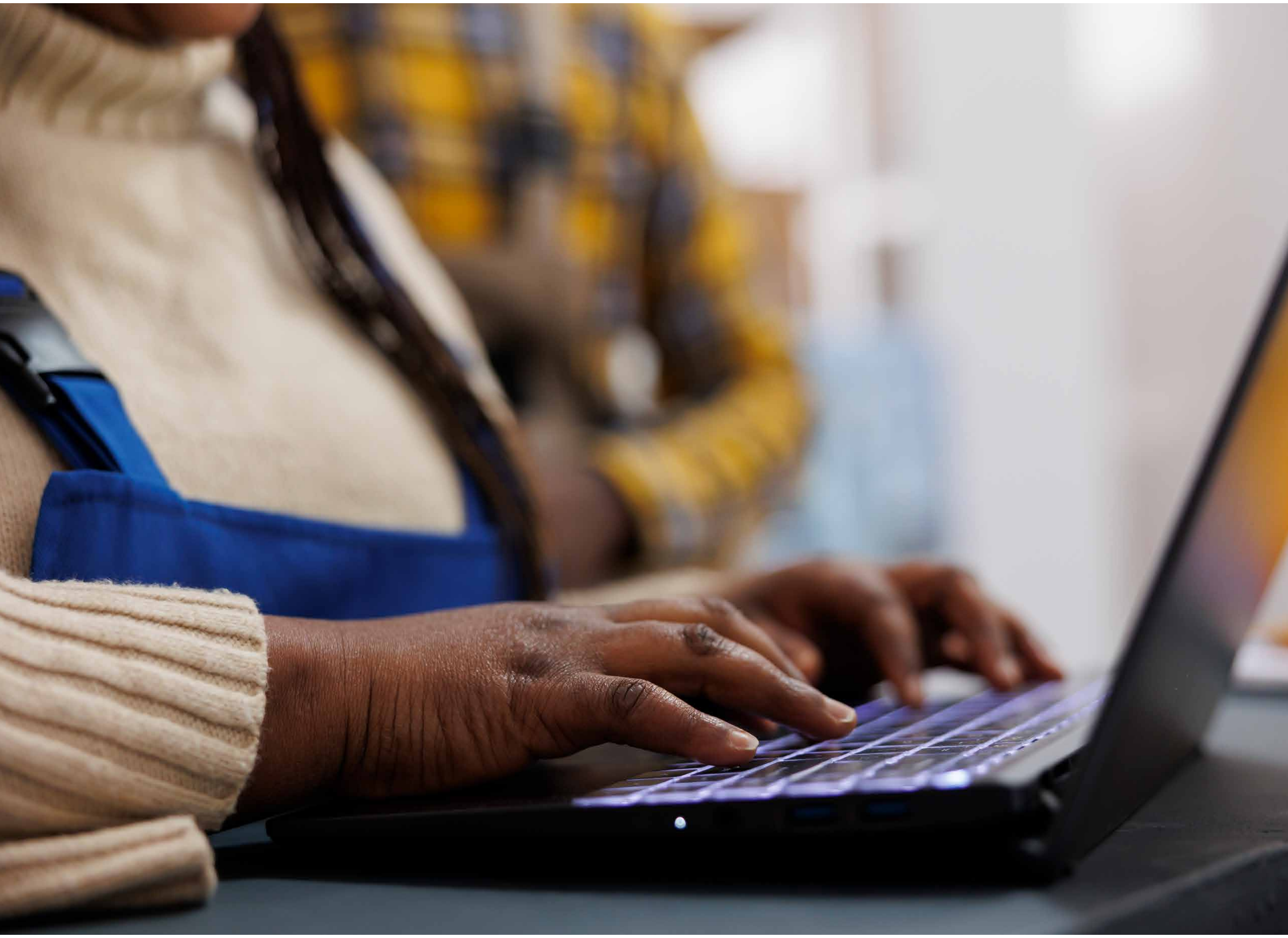
Home Environment: refers to various scenarios where a care recipient resides at home with a caregiver's support. This includes care recipients living in their own homes, living at home with the caregiver, living in a seniors' independent residence, and living in assisted living. This can also be called 'living in community'.

> *Note: FFCS programming is intended for those caregivers supporting the care recipient in a home environment. However, an important exception exists for caregivers who provide daily and essential caregiving for care recipients living in Long-Term Care or hospital/critical care environments.*

Activities of Daily Living (ADL): the basic self-care tasks, including ambulating, feeding, dressing, grooming, toileting, bathing, transferring, etc. The degree of support varies from needing a little help (such as a reminder or coaching through a process) to requiring someone else to do the task for them.

Instrumental Activities of Daily Living (IADL): self-care tasks that require more complex thinking skills including; organizational skills, managing finances, managing transportation, shopping and meal preparation, housecleaning, home maintenance, managing communication, and managing medications.

INFORMATION MANAGEMENT & CASE NOTES



Information management refers to various administrative operations, including case note management and tracking service delivery details. Information management also refers to an agency's ability to accurately record and store a caregiver's information while upholding the agency's best practices and policies for protecting client privacy and confidentiality.

FFCS programs utilize the United Way's information management system - iUnite - for some aspects of their information management. In addition, some programs utilize their own information management systems (IMS). IMS both stores and provides access to personal information about the caregiver including; contact information, referral source information, points of contact, case notes, and service delivery records.

IMS help us achieve the following:

- Records essential caregiver contact information
- Stores and organizes case file management
- Tracks which program components are being used
- Helps collect data for LQA and outcome reporting
- Supports decision making about service provision for caregivers

Case notes are written or digital records of each point of contact between a caregiver and a CSC support person. They are a brief chronological record of every interaction with a caregiver and include observations and interventions when applicable.

Good case notes are an essential internal process for providing consistent, chronological documentation of all service delivery and outline the caregiver's engagement with our services.

Case notes are necessary internal administrative documentation that provide a brief chronological history of all service delivery details for outcome reporting.

Case notes help us achieve the following:

- Provide a record of important referral details.
- Support our ability to recall details, assess, plan, coordinate, and evaluate our services for caregivers.
- Record valuable, subjective information provided by the caregiver: their opinions, goals, concerns, feelings, perceptions, and the current status of their caregiving journey.
- Assist us with continuity whenever case files are transferred to other staff, or service provision is shared by a team.
- Outline our understanding of individual caregiver risk, barriers, and resilience factors.
- Outline action plans or strategies developed with caregivers.
- Provide documentation of key conversations with caregivers about your agency's policy/best practice areas. For example, consent, privacy, and professional boundaries.
- Support opportunities for clinical support or peer consultation.
- Encourage transparency and reflection regarding the quality of service delivery.
- Support consistent service delivery for one-to-one support.

Case notes are written with important consideration and should be:

- Clear and concise
- Factual and professional
- Objective and impartial
- Valuable: to include helpful information and omit unnecessary details
- Timely: written as soon as possible after the interaction
- Specific and relevant to the provision of our support
- Easy to review with attention to grammar and punctuation
- Written with inclusive language
- Avoid derogatory or emotive language
- Avoid the use of unverified medical diagnoses

Essential information should be included in case notes:

- Name of caregiver
- Name of the CSC delivering the services
- Date of service delivery (point of contact) (*not the date the case note was written*)
- All service delivery methods (i.e. in-person, phone, email, etc.)
- Location of in-person service delivery site
- Identify any referrals made
- Identify any caregiver educational resources provided
- Next date of contact (scheduled or projected)

PROFESSIONAL BOUNDARIES

In this section…

1. What are Professional Boundaries?

Professional boundaries are "a set of guidelines, expectations, and rules which uphold the ethical and technical standards in the social care environment."[1] They are the essential limits of appropriate conduct that exist to maintain a safe therapeutic environment for clients, staff, and volunteers.

Professional boundaries are the framework that inform our clients about what behaviour they can expect from us while receiving support, and also what is expected of them. This framework helps protect staff, volunteers, and clients from physical and emotional harm.

Professional boundaries can also refer to the training and support provided by a program to encourage a positive relationship between the caregiver and the support person.

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[1] Cooper, Frank. Professional Boundaries in Social Work and Social Care. Jessica Kingsley Publishers, 2012

As Caregiver Support Coordinators, we are responsible for taking the lead and maintaining professional boundaries with the caregivers we support.

If you experience a challenging situation, please seek assistance by contacting your agency as soon as possible.

We can uphold these professional boundaries by:

- Understanding and adhering to our program's policies and/or best practices related to confidentiality, privacy, and/or professional standards.
- Communicating our program's policies and/or best practices to clients early in the service delivery.
- Setting clear expectations with caregivers about what they can expect and what is expected of them.
- Providing clarity about the role of a CSC, including the limits of service (example: location and frequency).
- Being clear and assertive by letting caregivers know if they are behaving inappropriately or acting in a way that makes you feel unsafe.
- Keeping support services in line with the program, including scope of practice, location, and length of support.
- Maintaining consistent communication standards.
- Avoiding or limiting self-disclosure.
- Remaining conscious of challenging personal feelings and seeking support whenever needed.
- Remembering that endings are inevitable; saying goodbye to caregivers is part of your work.

Please refer to the section on Emotional Support for more information on the scope and limitations of emotional support, and how to provide support that upholds professional therapeutic boundaries.

As caring professionals, it is vitally important that we remain conscious of our own service delivery. We must be alert for signs of 'over-involvement' or the desire to 'take sides' with a caregiver we are supporting. We must also be aware of our own internal judgements. Professional boundaries require us to support someone with compassion while remaining relatively objective. If our boundaries are not clear and consistent, we may experience emotional fragility, exhaustion, grief, and burnout. We may also develop feelings of cynicism. We can support ourselves to maintain boundaries by using a reflective process that encourages self-awareness about possible biases and assumptions. Our consistency allows caregivers to feel confident in the support they will receive.

2. Signs of Unclear (or a Loss) of Boundaries:

- Difficulty setting limits with caregivers
- Inappropriate advice or the desire to control the outcome of a caregiver's decisions
- Inappropriate emotional responses to a caregiver's sharing (internal or exhibited)
- Consistently feeling sad, anxious, fearful, or angry after supporting a caregiver
- Over-involvement or losing oneself in the work
- Feeling fragile or hopeless
- Feeling cynical and experiencing hardened feelings
- Compassion fatigue: where a support person is overwhelmed from being exposed to the trauma of others (secondary traumatic stress)
- Having our own emotional needs met through a relationship with a caregiver
- Feeling 'burned-out'
- Inability to let go of personal judgements; disliking a caregiver
- Inability to provide deep listening for a caregiver without offering solutions or trying to fix or improve the caregiver

Some common examples of Unclear and/or a Loss of Boundaries:

- Knowing that you have the right solution for a caregiver
- Allowing a caregiver to 'hijack' a support group meeting with their own needs
- Trying to convince a caregiver to move their loved one into LTC
- Telling a caregiver how they should talk to a difficult family member
- Feeling disappointed or angry at a caregiver's choices
- Experiencing extreme feelings of judgement or disgust when a caregiver is sharing
- Feeling callous toward a caregiver who is making unhealthy life choices
- Feeling unmotivated to support a caregiver who shares the same challenges at each support session

3. Supporting Caregivers; Supporting Ourselves

When someone says the word 'caregiving,' people usually think about the act of caring for another person. They think of the effort and energy it takes for one person to care for another. Through our work with caregivers we know that for caregiving to be sustainable, the caregivers must also include ***themselves*** in the care plan. Caregiving consists of the other and the self. This is a priority we often share with our caregivers.

As professionals supporting caregivers, we must then also see ourselves on this caregiving spectrum. For our work as CSCs to be sustainable, it is vital that we also take care of ourselves. Committing to personal growth, reflection, and self-care helps our caregiving work to be sustainable, and can assist us in addressing feelings of despair, burnout, and compassion fatigue.

Self-care practices that strengthen Professional Boundaries:

- Connecting with your emotions, acknowledging your uncomfortable feelings, and practicing self-compassion
- Creating a practice that allows you to let your feelings go at the end of the day
- Taking breaks, taking time off, and planning rest
- Limiting the number of one-to-one support sessions per day
- Physical movement between support sessions

- Practicing mindfulness and deep breathing between support sessions
- Creative self-expression that nourishes you
- Actively seeking out positive social interactions
- Speaking to a Program Manager about any concerns you have
- Asking for help when you need it
- Continuing education opportunities
- Advocating for self-care in the workplace

FFCS Pro Tip

With your colleagues, or on your own, create a 'basket' or container where you can unload both your own feelings and your client's emotions at the end of the day. This basket can be metaphorical, or it can be an actual basket! (Be sure to "empty" the basket whenever it gets full.)

Affirmations that strengthen Professional Boundaries:

- I maintain boundaries in all my helping relationships
- I am not the only person who can help family caregivers
- My work with family caregivers does not define me
- I am allowed to experience my feelings and let them go, without judgement
- I develop healthy sleeping, eating, and exercise patterns
- I deserve to lead a joyful and whole life

Key Takeaways:

- Professional Boundaries are essential to your work
- Proactive and consistent communication about these boundaries is important
- Self-awareness is vital when supporting caregivers
- Personal reflection time is an invaluable tool for personal growth and providing consistent, quality support

4. Peer Consultation

FFCS programs are encouraged to provide opportunities for regular, confidential peer consultation meetings, where staff and volunteers can provide mutual and supportive feedback to one another. Peer consultation encourages problem-solving that can enhance confidence and improve service delivery over time. As staff share their challenges in a safe and supportive setting, they also have the time and opportunity to reflect on their own practice and support one another by sharing skills, knowledge, and experiences.

The following are some attributes of an effective Peer Consultation environment:

- A well-defined 'container' for peer consultation (ie. meeting at regular intervals with mindful and supportive facilitation)
- Upholding privacy and confidentiality
- Safety: staff can share freely, without the risk of punitive actions or judgmental comments
- Mutual respect
- Curiosity; clarifying questions are encouraged
- Opportunity for multiple perspectives that honours complexity
- Self-reflection: considers the 'self' and how our own perceptions, beliefs, and values impact our service delivery
- Supports learning opportunities for growth and development
- Structural/operational issues related to workload management are noted
- Offers follow-up support for complex or challenging caregiving situations

A note from the FFCS frontlines...

"We have a virtual peer consultation every two weeks. Everything said is completely confidential. We can talk about challenging client situations and one-to-one support meetings that have been difficult. We share and listen to each other without judgment, and then we review our procedures or brainstorm different ideas. Having the space to 'vent' about our challenges while providing caregiver support creates strong collegial relationships and keeps us all from burning out."

Some helpful questions for Peer Consultation meetings:

- Can you say more about that?
- How are you feeling about supporting this caregiver?
- What worries you most about this situation?
- What are the effects on you? What are the impacts on others?
- Has your view of this situation changed over time? If yes, how?
- What challenges do you think you might continue to have?
- Is there anything about this situation that has helped you or your support with other caregivers?
- Does this person remind you of anyone?
- Do you have any other thoughts and feelings that you have not expressed yet?
- Do you need more help to support this client? Is there someone else that needs to be involved?

5. Frequently Asked Questions Related to Professional Boundaries

I have a caregiver that wants to bring her husband, the care recipient, to our one-to-one meetings. Is this ok?

Since the focus of FFCS programming is to support caregivers, some agencies have a best practice that keeps one-to-one meetings exclusively for caregivers. This ensures caregivers have the much-needed opportunity to receive individual, confidential support that allows space for the complex feelings often associated with caregiving. It is recommended that each agency have guidelines around care recipients joining one-to-one support meetings.

I know a caregiver personally whom I would like to refer to our program. Can I support this caregiver?

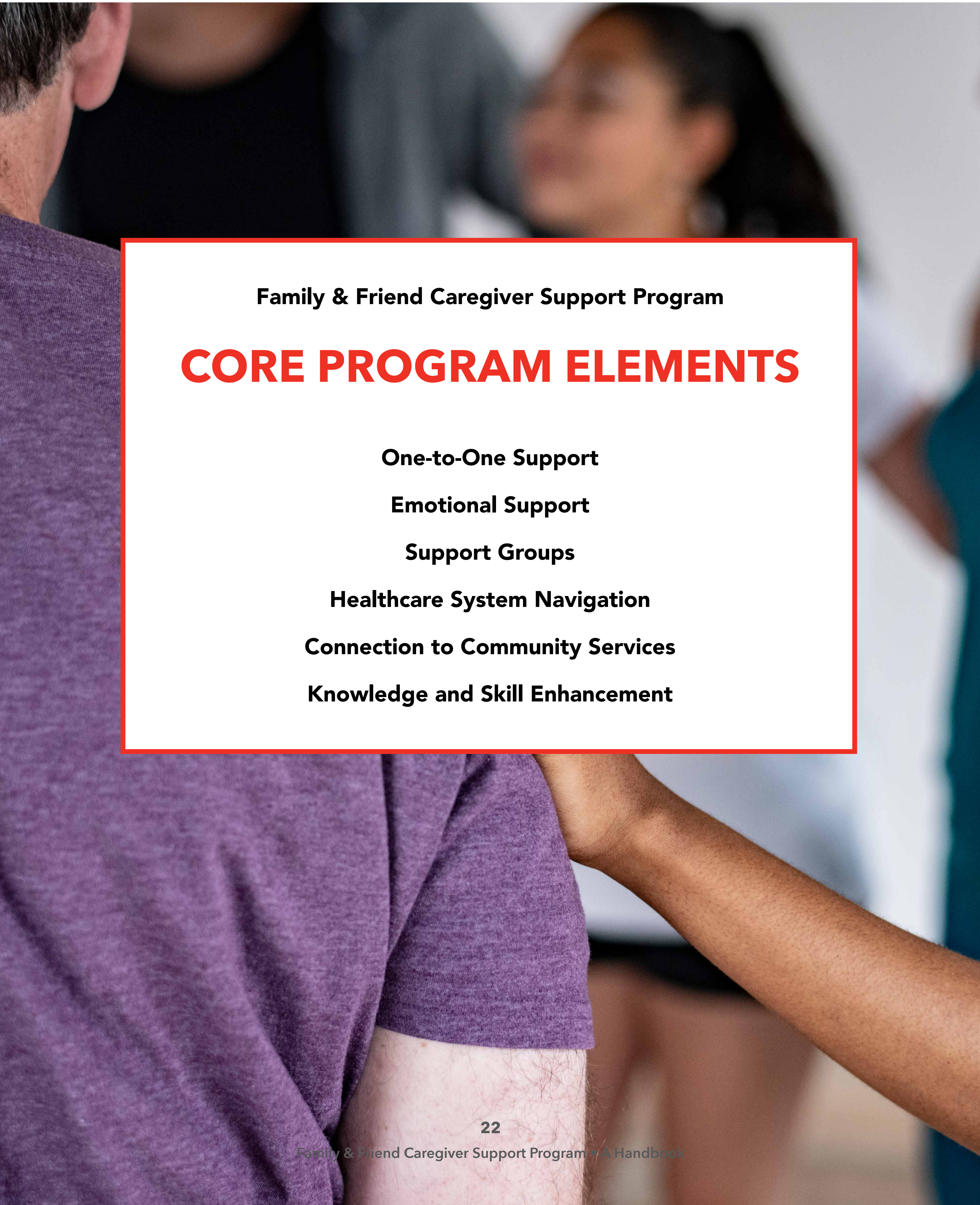
It is recommended that each FFCS Coordinator or agency set a clear professional boundary that ensures staff are not supporting caregivers they know or have a prior relationship with. This best practice ensures that both the staff and clients safely avoid blurred professional boundaries, requests for support outside of work hours, and the potential for personal or organization harm in the event of a challenging situation. It is recommended that each agency create their own best practice to support the CSC's professional boundaries.

I have a caregiver that made racist/sexist/homophobic comments during our support session. What should I do?

Caregivers are supported to express themselves honestly and sometimes that means supporting a caregiver whose viewpoints don't align with your values. However, if you are supporting a caregiver who is making comments or sharing in a way that makes you feel unsafe or uncomfortable, you can firmly remind them of the FFCS participation agreement and your agency's code of conduct policies. It is recommended that all FFCS programs have clear policies and that CSC's receive training around professional boundaries, including scenarios where racist, sexist, or homophobic comments are made.

FFCS Pro Tip

Peer consultation meetings are an excellent opportunity for staff to role-play responses to difficult conversations that can arise during caregiver support sessions.



Family & Friend Caregiver Support Program

CORE PROGRAM ELEMENTS

One-to-One Support

Emotional Support

Support Groups

Healthcare System Navigation

Connection to Community Services

Knowledge and Skill Enhancement

ONE-TO-ONE SUPPORT

In this section…

1. One-to-One Support: An Overview

One-to-one support provides dedicated and customized person-centered support to a caregiver. This support is based on the caregiver's needs and experiences and is tailored for each unique caregiving journey.

One-to-one support services are delivered by a dedicated and trained caregiver support person and can include trained coordinators and facilitators (CSCs), or trained volunteers.

One-to-one support can include the following:

- Emotional support
- Healthcare system navigation
- Knowledge and skill enhancement
- Connection to community services
- Any other individualized support innovated by the agency, such as professional counselling and informal respite.

One-to-one support can be delivered in different ways:

- In-person meetings
- Phone
- Email, text, or online (virtual meetings)
- It can include one caregiver or multiple caregivers where caregiving teams exist (ie. siblings caring for a parent)

FFCS Pro Tip

It is important for each agency to develop its own best practices and procedures for texting with caregivers.

One-to-one support is an essential tool for assessing if a caregiver could be further supported through other FFCS program elements, such as:

- Support Groups
- Social or Self-Care Activities
- Circles of Care (*Family Caregivers of BC Model*)

2. Guiding Principles for One-to-One Support

For further discussion of the Guiding Principles, please refer to Emotional Support.

Meeting the Caregiver "Where They Are At"

We nurture and support a caregiver's health, well-being, and growth, by working with them from a place of acceptance and non-judgement. This person-centered support approach focuses on listening and getting to know the participant.

- As facilitators, we listen empathetically and without judgment while acknowledging the caregiver's experiences.
- We recognize the caregiver's individuality and build a support plan tailored to their needs, interests, and availability.
- The quality of connection that a caregiver experiences (during a one-to-one support session) is essential to the outcome.

> Person-centered support means meeting participants where they are at and tailoring their support to what they need in that moment. It means giving them some responsibility to take care of themselves while also treating them with respect, dignity, and compassion.
>
> Summary Report: Informing the Development of Program Guidelines, Best Practices & Operating Procedures Manuals for Family and Friend Caregiver Programs, Revised January 2023, Howegroup.

Building Trust Over Time

Trusting relationships are built and strengthened over time, through consistent support with the same person (and/or team). Research suggests that lasting and supportive therapeutic relationships support more adherence to self-care, help people build capacity, and support better outcomes for caregivers facing systemic barriers[2].

- We allow caregivers time to get to know our services and their CSC support person.
- See the Service Delivery Levels Model for an example of one agency's strategy for service delivery that prioritizes consistency and long-term relationship building in their one-to-one support for caregivers.

A caregiver's message...

> "I so appreciate that you reach out. Your consistency is incredible. There is only so much anyone can do, but I appreciate the ongoing simple check-in; it makes me feel like someone hears me, and someone cares and knows what I'm going through."

Empowering the Caregiver

When one-to-one support is provided with an atmosphere of acceptance and understanding, it creates space and possibility for the caregiver to develop the knowledge, skills, and confidence to find their own insights.

- We support caregivers to manage and make informed decisions about their care recipient's health and health care.
- We support caregivers to manage and make informed decisions about their own health and health care.
- We offer a variety of supportive processes to empower the caregiver in a one-to-one session, including Deep Listening and/or Active Facilitation.

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[2] Starfield & Macinko. The Connection of Primary Care to Healthy Systems and Health". Millbank Quarterly, vol. 83, no. 3, 2005, pp. 457 – 502.

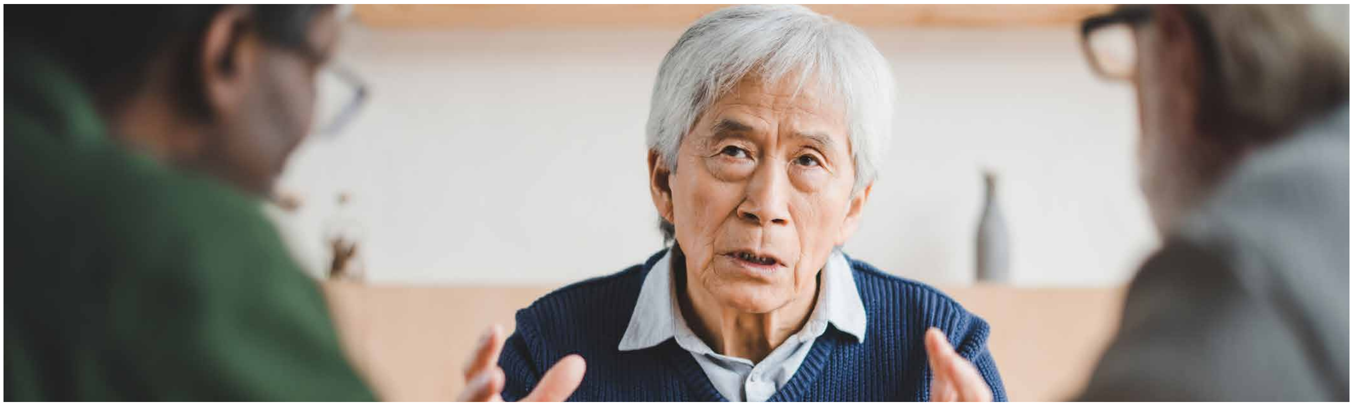
A caregiver's message...

> "I just wanted to thank you for meeting with me today. I felt comfortable talking with you. I don't, as a rule, reach out asking for help (being an introvert and private person), but I did sense that you were a kind, caring, compassionate, non-judgmental person. After our meeting, I felt more level-headed and clearer in myself. I feel more ready to face the challenges of another day. I'm so glad. I look forward to meeting again."

Deep Listening

Deep listening supports caregivers to explore and release emotions uninterrupted. It helps them get to the 'heart' of the matter. It can be a helpful prelude to the process of active facilitation.

- We listen carefully and empathetically to a caregiver's experience.
- We pay attention to non-verbal cues.
- We refrain from offering advice or perspective while a caregiver is sharing; wait until we know the caregiver has finished sharing their thought.
- Before the session closes, we may offer a summary of the session. This lets the caregiver know how deeply they were listened to and ensures we have understood correctly.



Active Facilitation

During active facilitation, we play a much more engaged role in the caregiver's process

- After listening deeply, we might ask questions to help explore strategies or interventions.
- We may support the caregiver to consider what has worked well and what hasn't in their challenges.
- We can help the caregiver narrow down their challenges and identify their top priorities.
- We may ask for the caregiver's permission to share with others what has worked well for them.
- We can provide specific resources or referrals.
- We can co-create an action plan to address specific needs. These action plans can be revisited in future sessions.
- Even within the process of active facilitation, the ideas are inspired by the caregiver, not the support person.

FFCS Pro Tip

Asking a caregiver *"how best can I support you right now?"* is a simple but effective way for the caregiver to feel instantly supported.

A caregiver's message…

> "Thank you for listening to me. Through your gentle questioning and wise support, I realized that our time together enabled me to acknowledge my readiness to take the steps towards placement for my husband and to accept residential respite in the meantime. Now I can start to shift from this downward spiral of burnout that I have been in. I feel more ready to accept recommendations from the Geriatric Specialty Services team and implement some of the ideas we worked on."

Benefits of these Guiding Principles for Caregivers:

- Affirmation of their experiences and struggles
- Unique caregiving needs are better understood
- Being acknowledged for their multiple roles
- Understanding their identity as a caregiver (including any resistance to that identity)
- Finding insight or comfort in knowing they belong to a community or network of other caregivers
- A positive impact on their health and well-being
- Better equipped to make difficult decisions
- An increased awareness of services in their communities, with the ability to access them, and the confidence to participate
- A deepened support network and willingness to expand their circle of support/care
- An increased ability and confidence as a caregiver

Research suggests a connection between caregiver capability and caregiver health and well-being, "strengthens caregivers' competence and confidence, improving their mastery, defined as the amount of control that a person feels over the forces that are impinging upon him or her." Caregivers with the higher levels of mastery of the care situation have more positive responses to providing care because they perceive themselves as able to meet care demands. Caregiving mastery can reduce caregiver distress by influencing the availability of health problem-coping strategies to meet care demands. The control associated with caregiver mastery is also associated with a lower stress response and more positive health-related behaviours amongst caregivers.

(Patient Safety and Quality: An Evidenced-Based Handbook for Nurses. Hughes RG, editor, 2008, page 9).

Supporting Ourselves…Building trust over time is not only good for caregivers, but it is also good for us. Ongoing relationships with clients create a sense of personal and professional fulfilment. Professional boundaries can support us to 'stay in our lane' and while we do this important work.

Caregivers were asked to describe what changes the program made for them, such as differences in their physical health, mental health, and sense of connectedness. First and foremost, caregivers expressed their programs normalized their experience and helped them understand their experience and their situation. Caregivers further indicated the program increased their confidence to provide care, improved their mental health by increasing their understanding and acceptance, and increased their knowledge and skills in providing care. All caregivers acknowledged the program provided support unparalleled by any other, in terms of understanding, timeliness, kindness, and information.

Howegroup, Background Data Points: Family and Friend Caregiver Manual. April 21st, 2023

3. In-Person Service Delivery for One-to-One Support

There are many inherent benefits to meeting with caregivers in person. By offering one-to-one support services in-person, we can provide the following:

- A neutral, supportive, and confidential space for caregivers to share and explore their experiences.
- An opportunity for a caregiver to feel a more profound sense of connection and support.
- A private and confidential space where other service delivery options are not possible (phone, email, etc).
- The opportunity to assess caregiver stress levels and burnout.
- A deepened connection through non-verbal communication.
- Fewer distractions for the caregiver.
- Support that isn't heavily reliant on caregivers' access or competency to digital technology.

Primary In-Person Meeting Sites

Most often, the agency's designated offices are the primary meeting sites for one-to-one support sessions. Designated offices support a safe working environment for the CSC. They are often assessed for access for people with disabilities and can be readily booked.

> *Note: The ability of an agency to offer in-person support can be impacted by several factors, including agency-specific policies, office space, public health orders, and limits due to geographical considerations (for example, large and rural regions). Please refer to your agency's policies and best practices regarding in-person meetings.*

Alternative In-Person Meeting Sites

An agency may also support alternative meeting sites for in-person support. Alternative sites can be beneficial when caregivers have privacy/confidentiality challenges or barriers preventing them from travelling to primary meeting sites. The following are examples of alternative meeting sites:

Parks and outdoor spaces:

- Can support caregivers who find it difficult to sit in traditional therapeutic settings due to past experiences.

- Are helpful for caregivers concerned about indoor virus transmission.
- Are beneficial for caregivers who want to be active while receiving support. This can be part of a therapeutic process that includes nature, mindfulness, and walking.

Coffee shops:

- Can be appropriate when a caregiver has an expressed benefit to meet in this setting. Examples may include caregivers who have had negative experiences in therapeutic settings, caregivers who feel more comfortable receiving services in a casual or relaxed environment, youth caregivers who may find private meeting rooms too formal, caregivers who cannot travel to a primary office site, and caregivers who cannot receive services at home.

Facility sites:

- May be appropriate where a caregiver cannot leave the caregiving site easily or where joint service delivery with another organization is appropriate. Examples include hospitals, residential care, and hospice facilities.

At the caregiver's home:

- May be appropriate where a caregiver cannot travel outside of the house due to their own medical conditions, transportation barriers, or specific caregiving challenges.

Note: Agencies should develop best practices for assessing safety, appropriateness, and the availability of a confidential space in the caregiver's home.

A note from the FFCS frontlines...

> **"One-to-one support can be effectively delivered through email correspondence and phone support. This is especially valuable for caregivers with mobility challenges, difficulty achieving privacy, or where travel is a barrier."**

4. Best Practices for Beginning and Ending a Support Session

Beginning a Support Session

There are several important considerations when meeting with a caregiver for the first time. The information below highlights the best practices we can use during the first support meeting and can also apply to subsequent caregiver support sessions.

Orientation:

- Before the first support meeting, most caregivers will have received a general introduction to the program and any agency communications about program offerings, privacy, and confidentiality.

Environment:

- When meeting a caregiver at the office, ensure the room is comfortable and private and has provisions such as tissues, water, pens/notepads, etc.
- Having an 'in-session' sign on the door prevents unnecessary interruptions. Some programs make comfortable chairs, pillows, blankets, space heaters, and fans available.
- If speaking to a caregiver by phone, ensure the audio connection is sound.

FFCS Pro Tip

Using a headset can free up your hands to take case notes during phone support.

Invitation:

Many caregivers are keen to talk about their experiences and challenges. They don't need an invitation to share their stories. Others may need time to get comfortable. We may ask them supportive questions to help the conversation flow. Some caregivers may present as cautious or even skeptical and guarded. If a caregiver has been referred for support, they may even resist receiving services. We can affirm the Guiding Principles of One-to-One Support in our invitation to the caregiver by letting them know that we are here to listen in an open-hearted way and that we will not "tell them what to do." A caregiver's experience in the first one-to-one session is vital for creating an atmosphere of trust that will be built and strengthened with ongoing support.

A caregiver's message…

> "Sorry to be such a grouch at our first meeting. I've been through the wringer; I didn't know what to expect from it. I already feel like I'm doing so much wrong, and things seem hopeless sometimes. I got a tear in my eye after I left. You never once told me what I should do. You listened, and you cared. I was so touched that you emailed me after too."

Bringing a Support Session to a Close

There are several tools we can use to complete a one-to-one support session in a safe, supported, and timely way for the caregiver.

Summarizing:

- Briefly summarize the caregiver's process in the one-to-one session and acknowledge what was shared.
- Reflect and reiterate the challenges, insights, and perspectives the caregiver may have gained.
- List the resources and/or referrals you plan to follow up with after the session. If there wasn't time to address all the topics, let the caregiver know you have noted it for the next support session.

Feedback and acknowledgement:

- Provide a simple statement acknowledging the caregiver's strengths and gifts in their work as caregivers.
- Reiterate the challenging nature of caregiving and acknowledge their efforts.

Co-create the support plan:

- Check-in with the caregiver to assess if the one-to-one support they receive meets their needs and explore other opportunities for support.
- Adjust the time between support meetings, depending on the caregiver's current needs and situation.
- Inform the caregiver when you will contact them (in 3-4 weeks, for example) or schedule the next session. This can provide comfort to the caregiver that support is ongoing and will build continuity and trust.

Support the caregiver's self-care:

- Acknowledge the caregiver's work in the one-to-one session, especially when it has been emotional or complex. For example: *"You've done some hard work here today; is there one thing you might be able to do in the rest of the day to balance that work? Or is there something you can do to comfort or nourish yourself?"*
- Depending on the caregiver's temperament, you might suggest they wrap a blanket around their shoulders when they get home, go to bed early, or make time for a cup of tea.

5. What Happens After a One-to-One Support Session?

Our support work continues in several ways after a one-to-one session. This includes:

- Write and file Case Notes to ensure you have captured the important details from the meeting. (Please refer to Information Management and Case Notes for more information.)
- Reflect on the session and organizing any next steps for services.
- Following up with the caregiver regarding requested referrals to other program elements (ie. support groups).
- Following up with the caregiver to provide any requested referrals and/or information for external agencies (to which the caregiver has consented).

- Following up with the caregiver to provide supplemental resource materials and educational opportunities.
- Entering the next point of contact (or scheduled meeting) on the calendar.
- Seeking peer consultation if we need reflection and/or support after a session.
- Seeking peer consultation for support with high-risk and/or complex caregiving situations.

Supporting Ourselves…Take a moment to check in with yourself after providing one-to-one support. Acknowledge yourself for the support you gave. What self-care might be needed before you start your next support call or appointment? (See Professional Boundaries for valuable self-care tools to use between support sessions.)

6. Important Considerations When Providing One-to-One Support:

- One-to-one support can be effectively delivered through email correspondence and phone support. This is especially valuable for caregivers with mobility challenges, difficulty achieving privacy, or where travel is a barrier.
- Case file management is an essential internal process that supports consistent service delivery for one-to-one support.
- Case notes should be completed after each one-to-one session to ensure our ability to recall important details; to assess, plan, coordinate, evaluate, and adapt our services for each caregiver. Case notes are stored according to your organization's policies and procedures related to confidentiality and protection of personal information.
- Some agencies offer a co-current informal respite program for care recipients, delivered during in-person caregiver support sessions.
- Some agencies offer professional counselling as a part of their one-to-one services. In this case, the CSC will refer to the agency's best practices to assess if/when the caregiver needs more support from a trained therapist.

FFCS Pro Tip

One-to-one support may be considered a medical appointment for caregivers needing respite options (from their Health Authority) to participate in the program.

7. Frequently Asked Questions about One-to-One Support

Why is one-to-one support so important?

Though caregivers benefit from the support in various FFCS program elements, one-to-one support provides the most comprehensive, confidential, flexible, and customized support available within the program.

Why are support groups not a replacement for one-to-one support?

Support groups are an important service delivery offering that provide an opportunity for caregivers to experience facilitated peer support, engage in caregiver education, and help to increase social and community connections.

They are not a substitution for one-to-one support for a number of reasons. One-to-one support provides flexibility and can be scheduled at a time that works best for the caregiver. It assures privacy and confidentiality (within organizational limits) and supports deeper exploration and disclosure. It provides customized support for caregivers and supports the development of trusting relationships. For more information on the strengths and inherent limitations to the support group format, please refer to the chapter on Support Groups.

Does one-to-one support ever involve supporting more than one caregiver?

Though less common, some caregivers may benefit from one-to-one support with a friend or family member who is involved in the caregiving situation.

However, it is important for the support person to ensure the caregiver team understands that one-to-one caregiver support cannot facilitate mediation or accommodate dispute resolutions. In this case, it is advised to refer the caregiver team to external community or agency resources that offer conflict/resolution support.

Can care recipients attend the one-to-one support sessions with their caregiver?

Some caregivers might ask if the care recipient can attend their one-to-one support meeting. They may express that their loved one also needs emotional support, health care system navigation, and other supports.

One-to-one support is designed for the caregiver. This time is for them; to share and explore their caregiving situation freely. This time invites caregivers to focus on their voice, needs, and experience. This may be unexpected for some caregivers who have not been invited or supported to look at their own needs and situation from their perspective. This differentiation can be an essential start toward alleviating caregiver stress and shifting/preventing burnout patterns.

Sometimes, we may learn that a caregiver feels guilty for receiving this support without the care recipient. (Please refer to Emotional Support for suggestions when this occurs.) In some cases, we can offer other agency or community services to support the care recipient's needs that have been identified by the caregiver.

How can I accommodate a caregiver with limited availability for one-to-one support?

While some caregivers have flexible schedules and can readily receive one-to-one support, many have limited time and opportunity. As facilitators, we strive to organize meeting logistics that support the caregiver's time limitations. To the best of our ability, we work alongside the caregiver's informal or formal respite schedule for their care recipient.

We can offer flexible meeting times for working caregivers, young caregivers, and caregivers engaged in intense or complex caregiving scenarios. Some programs may provide evening or weekend support for working caregivers.

We continually offer a range of flexible modalities, including phone calls, video calls, emails, and in-person meetings.

What if a caregiver needs respite to receive one-to-one support?

Some caregivers can only receive one-to-one support if they organize respite for their care recipients in advance. Your program, agency, or an external community agency may offer opportunities for informal respite and can connect caregivers to these opportunities through information and referrals.

Formal respite options are available through all Health Authorities in BC: through the Home and Community Care program. This includes caregiver respite, Adult Day Programs (ADP), and residential respite. It is important to be aware of these available services so we can provide caregivers with current and reliable Healthcare System Navigation.

Some caregivers have access to private respite or may be able to ask a family member, neighbour, or friend for coverage, so they can receive one-to-one support.

Some agencies maintain lists of private care options in the community that include paid professionals offering caregiving services or 'companion care.' It is important to note that private lists should not be endorsed by the program and are offered as an un-vetted resource.

Supporting caregivers to navigate respite options is an important way to provide tangible support, while expanding caregivers' awareness and knowledge of available options.

What if a caregiver needs to access one-to-one support without the care recipient knowing?

If a caregiver has specific requests or needs around communication and privacy, this should be noted in the referral and case notes. Some caregivers cannot comfortably or safely share (with their care recipient) that they are receiving support for their caregiving journey. They may need special consideration about how they are contacted. For example, they may be unable to speak on the phone and prefer email or text to set up meeting times.

FFCS Pro Tip

Good case management ensures that vital information is prioritized and readily accessible for review before follow-up support sessions.

What if a caregiver doesn't need one-to-one support?

Some caregivers have their needs met through other program elements, such as support group participation. It is good practice to remind these caregivers that one-to-one support is available should they need it in the future.

A caregiver may need to access one-to-one support when facing a transition or challenge or when their caregiving responsibilities change. Consistently offering one-to-one support ensures that caregivers with shifting responsibilities and stress levels can accept more support when they need it. Regardless of whether the caregiver accesses one-to-one support, they feel comforted knowing the support is available.

What if a caregiver needs much more support than I can provide?

It happens. Sometimes we receive referrals that are beyond the scope of our services.

Having a clear understanding of the service delivery limits in your FFCS program will help you 'stay in your lane' as a service provider. It will also help you to identify and communicate with a caregiver in a timely way if their needs require additional support and/or external referrals to other community agencies and/or the Health Authority.

(Please refer to Professional Boundaries for more discussion.)

What if a caregiver discloses alarming information regarding the health and safety of themselves or their care recipient?

Please refer to the Emotional Support section regarding; limitations to emotional support, suicide safety, trauma awareness and anti-racism, cultural safety, and humility. Please also see your agency for information on policies and CSC training opportunities.

EMOTIONAL SUPPORT

In this section…

1. Emotional Support: An Overview

Emotional support is a key feature of the One-to-One Support we offer caregivers through the FFCS program. Caregivers may also need emotional support during Support Groups, Healthcare System Navigation, and Circles of Care.

Emotional support can be described as a skilled practice used by the Caregiver Support Coordinator (CSC) to help caregivers feel safe and heard as they share their experiences. Learning to show care and empathy in ways that empower the caregiver is at the heart of this practice.

Empathy refers to our ability to identify and understand other people's emotions. Learning how to attune and respond empathetically to caregivers as they describe their experiences promotes understanding and builds trust.

Extensive literature and research also affirm the benefits of social and emotional support, especially how it can 'protect" caregivers' health and well-being[3].

> CSCs have shared that when caregivers receive emotional support, it can help them feel more resourceful in dealing with the challenges that arise in caregiving. Caregivers have reported improved physical and mental health, increased sense of belonging, and improved quality of life.
>
> Summary Report: Informing the Development of Program Guidelines, Best Practices & Operating Procedures Manuals for Family and Friend Caregiver Programs, Revised January 2023, Howegroup.

The **Guiding Principles for One-to-One Support** describes the general values that guide support in a one-to-one context, and we employ these values whenever providing emotional support. These include:

- Meeting caregivers "where they are at"
- Building trust over time
- Empowering the caregiver
- Deep and active listening

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[3] Reblin, Majar and Uchino, Bert. "Social and Emotional Support and Its Implications for Health." Current Opinion in Psychiatry, Vol 21(2), March 2008, pp 201-205. https://journals.lww.com/co-psychiatry/Abstract/2008/03000/Social_and_emotional_support_and_its_implication.21.aspx

These Guiding Principles have been developed further through the lens of providing emotional support.

Meeting the Caregiver "Where They Are At"

We nurture and support a caregiver's health, well-being, and growth by working with them from a place of acceptance and non-judgment. The values that guide this approach include curiosity, respect, dignity, self-determination, equity, belonging, and community. Below are some examples of ways we can meet caregivers where they are at:

- Recognition and compassion that some caregivers struggle to express their feelings or feel ashamed to ask for emotional support.
- Offer empathy and understanding and provide a 'safe zone' for emotions to be experienced and felt. Make space for the healthy expression of tears, frustration, anger, and laughter.
- Help the caregiver stay with their emotions; don't distract them from their feelings with too many questions.

A caregiver's message...

> **"I needed to cry it out. It has been very therapeutic talking things through with you. The journey that I have been on has been, for lack of better words, "completely surreal" and largely incomprehensible to most people. Having the opportunity to speak with you and have some validation has been terrific and much less isolating."**

Supporting Ourselves…To maintain our well-being while being empathetic, we can think about how a person may feel rather than attempting to feel someone else's emotions. The question is: "What feelings could this person be experiencing right now?" and not "How would I feel in this situation?" Identifying too much emotionally with a caregiver may trigger your own distress, making it difficult to be present for the caregiver. If you find a caregiver's emotional situation (trauma, depression, or grief) is bringing up personal emotions for you, this is a sign that your professional boundaries are becoming blurred.

Building Trust Over Time

Trusting relationships are built and strengthened over time through consistent support with the same person or team. This helps create a sense of **relational continuity**. Relational continuity is where the accumulated knowledge about the caregiver's values, preferences, and context builds for the Caregiver Support Coordinator over time, increasing the potential that the support provided is meaningful and effective.

- Proactively schedule ongoing caregiver check-ins to provide consistent emotional support.
- Commit to getting to know a caregiver's story over time.
- Acknowledge previous information shared by the caregiver when it is helpful.
- Discuss with the caregiver in advance about limits to confidentiality. (Please refer to Supporting Caregivers; Supporting Ourselves in Professional Boundaries for more information.)

A caregiver's message…

> **"Before I met with my support worker, I was an emotional wreck, I would cry at 'the drop of a hat'. Speaking with her has allowed me to vent my frustrations, she gave me good insight and encouragement. I'm feeling more confident and calmer. I know help is only a phone call away whereas before I was floundering."**

Empowering the Caregiver

A safe environment and a commitment to building a trusting relationship with their support person can empower the caregiver to take the lead in their caregiving journey.

- Ask open-ended questions that invite conversation and discovery.
- Encourage self-compassion. “Let’s try to bring some understanding towards ourselves when we suffer or feel inadequate.” Refrain from offering advice or solving issues, or phrases such as, “it could be worse” as this is making a judgement.

A caregiver’s message...

> **“Thank you again for your warm empathy and validation during our chat. You were helpful on many levels!”**

Deep Listening

For the conditions of deep listening, we create an attentive and attuned environment. Emotional support is provided with the understanding that when caregivers are presented with the conditions of safety and respect, they can allow themselves to be known and deeply heard. We don’t push caregivers to share more than they feel comfortable sharing. We support the strengths and resources of a caregiver, their community, and their environment rather than placing their problems or pathologies at the centre of the process.

- Give your undivided attention.
- Listen carefully and empathetically to the experiences.
- Pay attention to nonverbal cues (how we communicate without words. For example: facial expressions, hand gestures, etc.)
- Listen for the feeling underneath the words.

A caregiver's message…

> "I appreciated your warmth and the genuine, caring person you are. I was feeling so relieved and at the same time energized after we met today. Our conversations have really helped me find and keep a healthy perspective. Your deep listening, guidance, and validation has been immensely helpful in setting and maintaining boundaries - thank you!"

Examples of empathetic responses:

- "It is understandable that you feel angry about…"
- "It is normal to feel a mixture of feelings."
- "I see why you feel that way when…"
- "That must be so hard."
- "I can only imagine how difficult that is for you."
- "I am sorry that you are going through this."
- "I think you are being brave by looking at this."
- "This is a difficult situation, and I think you are showing a lot of creativity in your responses."
- "I'm here for you."

Laurie Kohl from the North Shore Community Resource Society offers a way of inviting a 'deepening' from caregivers by using these four steps:

1. Reflect on the content: "I heard you say.... or you said…"
2. Validate their experience: "That makes sense because…"
3. Use empathy: "I imagine you might feel…"
4. Check in: "…does this sound right?"

A PROGRAM EXAMPLE **USING A 'DEEPENING' TECHNIQUE**

A caregiver named Francis arrives for a one-to-one support meeting visibly upset. As she sits down, she begins to tear up. Pema, the CSC, provides a warm and reassuring smile and says, "Take your time." Francis shares about her hectic and stressful morning, trying to get her caregiving tasks done quickly before Home and Community Care arrived to provide a respite block for her father who has dementia.

Pema says, "I heard you say that mornings like this really drain your energy and that there have been more bad days than good lately. That makes a lot of sense because you have so many tasks to get done each morning that get impeded by your dad's repeated questions. I imagine you might be feeling overwhelmed and tired. Does that sound about right?" Francis responds, "That's it, although tired doesn't begin to describe it. I feel it is too much, and I wonder how long I can keep doing this."

Francis is invited to go deeper in her exploration, allowing Pema to gain insight into how difficult the situation has been. This conversation allows Francis to fully recognize her challenges and also reflect on her strengths and resilience. With Pema's encouragement, Francis is able to consider new ways she could bring in additional support for her caregiving efforts.

2. Important Considerations When Providing Emotional Support

Stigma

Receiving emotional support can feel particularly vulnerable for some. Not all caregivers feel confident, or even safe, to tell their families and care recipients that they are receiving support for their caregiver role. We always prioritize and support caregiver privacy and confidentiality.

Being aware that some caregivers may feel conflicted, guilty, or at risk of stigma for receiving emotional support, helps us anticipate and work through potential barriers for a caregiver. By listening in a caring and empathetic way, we can provide a safe and nurturing space for caregivers to express their concerns, fears, or anxieties about receiving support. Through this experience the caregiver learns they can trust the process, and it can encourage them to find creative ways to continue receiving support.

Professional Boundaries

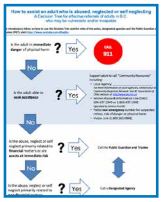
Clear professional boundaries create a safe space that protects the caregivers we serve and ourselves. Boundaries inform the therapeutic relationship and set essential limits for both our caregivers and ourselves. Please refer to Professional Boundaries for more discussion on the importance of creating and maintaining professional boundaries when providing emotional support.

Limitations to Emotional support

There are limits to the emotional support we can safely provide caregivers within our role. There may be times that we need to assess when caregivers should be referred to professional services with counsellors, social workers, or mental health professionals. This includes urgent or rapid services, such as walk-in mental health support or toll-free emergency support lines.

Some caregivers face severe problems in social functioning and may need support services for relationship counselling, suicide/self-harm, elder abuse/violence, unresolved trauma that keeps resurfacing, serious mental health issues (paranoid/delusional/anger that can't be calmed), difficulties in parenting, domestic abuse, etc.

Always communicate and seek the support of your agency to understand the internal protocols and processes for challenging or high-risk support situations.



The Public Guardianship and Trustee of BC has created a helpful 'Decision Tree' for supporting professionals to know when a referral is needed for adults in BC who may be vulnerable, at risk, or incapable.

See Decision Tree Here

Please also refer to The Public Guardianship and Trustee of British Columbia for information about how to help an adult get support to report abuse and neglect.

See The Public Guardianship and Trustee of British Columbia Here

As discussed in Connection to Community Services, when we are aware of the local agencies that offer support, we may be able to refer caregivers to more appropriate services if they are available:

- Support confidence in utilizing 911
- Low-cost or free counselling services
- Peer support services
- Hospice support services
- Provincial crisis lines
- Mental health organizations
- Health Authority: Mental health and substance abuse
- Health Authority: Rapid access clinics for mental health and substance abuse
- User-pay counselling and social work services

A note from the FFCS frontlines...

"Our staff and volunteers receive training and are experienced at providing emotional support to seniors and caregivers; we have Registered Clinical Counsellors on the team to provide professional counselling via phone, in person, and online."

Suicide Safety

Professionals, volunteers, and other helpers need to know how to effectively and safely help persons with thoughts of suicide. ASIST (Applied Suicide Intervention Skills Training) is a leading suicide intervention skills-building workshop. This training is invaluable and is highly recommended for CSCs who are providing emotional support.

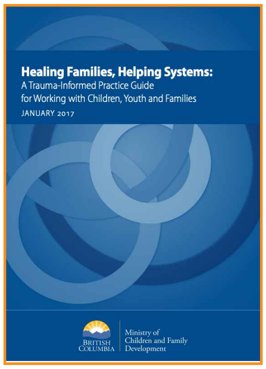
As an ASIST-trained first aid intervention professional, you will be better able to:

- Identify people who have thoughts of suicide
- Understand how your beliefs and attitudes can affect suicide interventions
- Seek a shared understanding of the reasons for thoughts of suicide and the reasons for living
- Review current risk and develop a plan to increase safety from suicidal behaviour for an agreed amount of time
- Follow up on all safety commitments and access further help as needed

Trauma Awareness

Agencies may support staff to have trauma-informed awareness by providing training and resources. Trauma-informed awareness refers to a strengths-based framework grounded in an understanding of and responsiveness to the impact of trauma.

The BC government has created a guide for families, children, and youth to help increasetrauma-informed awareness: "Healing Families, Helping Systems: A Trauma-Informed Practice (TIP) Guide for Working with Children, Youth and Families." This guide is helpful for anyone who would like to learn about trauma-informed practice:



Healing Families, Helping Systems:
A Trauma-Informed Practice Guide
for Working with Children, Youth and Families
JANUARY 2017

British Columbia
Ministry of Children and Family Development

Excerpt from Healing Families, Helping Systems: A Trauma-Informed Practice (TIP) Guide for Working with Children, Youth, and Families:

Strengths-based framework grounded in an understanding of and responsiveness to the impact of trauma. It emphasizes physical, psychological, and emotional safety for everyone and creates opportunities for survivors to rebuild a sense of control and empowerment. The guide will coach you using a trauma-informed approach to support children, youth and families in your teams and/or personal life.

- *from* Healing Families, Helping Systems

Anti-Racism, Cultural Safety, and Humility

First Nations Health Authority
Health through wellness

#itstartswithme
Creating a Climate for Change

Cultural Safety and Humility in Health Services Delivery for First Nations and Aboriginal Peoples in British Columbia

How can we ensure that emotional support takes place within an anti-racist framework that supports cultural safety and humility? The First Nations Health Authority and it's partners have undertaken significant work to create a BC First Nations-led Standard regarding anti-racism, cultural safety, and humility. This Standard, and the supporting resource materials and training, are essential to understanding how to engage in and provide emotional support; with awareness about key issues.

Excerpt from the Anti-Racism, Cultural Safety, & Humility Framework:

Cultural safety is an outcome based on respectful engagement that recognizes and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination, where people feel safe when receiving health care.

Cultural humility is a process of self-reflection to understand personal and systemic biases and to develop and maintain respectful processes and relationships based on mutual trust. Cultural humility involves humbly acknowledging oneself as a learner when it comes to understanding another's experience.

– *from* Creating a Climate for Change

3. Frequently Asked Questions about Emotional Support

When is it ok to share my personal experiences with caregiving?

As a best practice, we typically don't share personal experiences because it shifts the focus from the caregiver to us. The caregiver may become distracted from their own experience or draw comparisons, and this can diminish the caregiver's feelings. Moreover, some caregivers may feel they need to take care of us. We make exceptions when we discern that briefly sharing our personal experiences will serve the caregiver in a meaningful way.

How can I support a caregiver who doesn't want to be a caregiver?

Sometimes caregivers need time and a safe space to come to terms with their role as a caregiver. (For more information, please refer to Addendum IV: One-to-One Support at Different Phases of the Caregiving Journey.) Other times, we may recognize that the caregiving role is not possible for everyone, and it may not be in the best interest of either the caregiver or the care recipient. We continue to provide empathy and understanding for these caregivers as they often need support to transition away from their caregiving role.

What do I do when the caregiver is expressing thoughts and feelings that don't align with my values?

Offering empathy and understanding isn't the same as agreement. As CSCs, it is our job to provide the 'space' for caregivers to express themselves honestly and without judgement. We don't have to agree with a caregiver to provide meaningful and authentic emotional support.

FFCS Pro Tip

Keep your personal affirmations accessible. Setting an intention before providing support to caregivers you find challenging is an excellent way to support your own Professional Boundaries.

SUPPORT GROUPS

In this section…

1. Support Groups: An Overview

Support groups are a core element in the Family and Friend Caregiver Support program for caregivers interested in building connections with other caregivers and developing strategies to increase their level of well-being through group support.

Support groups are facilitated by trained staff or trained volunteers who are knowledgeable about providing caregiver support, and have skills in group facilitation.

Though group facilitation techniques and formats vary, many psychosocial benefits can be cultivated for caregivers through their participation in support groups. These caregiver benefits can include the following:

- Enhances social connection and strengthens social networks
- Provides a sense of belonging and generates feelings of acceptance
- Develops learning for new coping strategies
- Supports self-disclosure in a non-judgmental setting
- Provides others with empathy, love, and care
- Receiving compassion, love, and care from others
- Validation and mutual affirmation, which can help strengthen confidence
- Reduces stigma and isolation
- Sharing and receiving helpful resource information
- Empowerment through mutual aid (receiving and giving help)

Note: In a support group meeting, facilitators may provide other elements of the FFCS program, including Healthcare System Navigation, Connection to Community Services, Emotional Support, *and* Knowledge and Skill Enhancement.

A note from the FFCS frontlines…

"Support Groups are an effective way for caregivers to connect, communicate, socialize, and resource-share with other caregivers. Caregivers say they have the best time in these weekly groups."

Support Group Participants & Meeting Locations

Caregivers are informed about support group meetings through the FFCS intake process, where they learn about the range of support and services available in the program. Caregivers may also learn about support group meetings through one-to-one support, resource guides, newsletters, posters, community support services, or other programs or organizations.

Caregiver support group meetings can be offered in-person or online and are generally considered 'closed.' This means the meetings are not usually open for general public drop-in. Some meetings are further designed to have specific membership definitions such as young caregivers, language/dialect-specific meetings, dementia focused, etc.

In-person meetings can be held in a variety of spaces including: meeting rooms at the agency, community centres, health care facilities, external agency's venues, and libraries. Ideally, venues support basic privacy considerations and flexibility for ease of connection.

A note from the FFCS frontlines…

> **"We have three support groups…two of the groups are dedicated to individuals caring for their loved ones with dementia. Our volunteer group facilitators are trained, experienced, and committed to supporting caregivers.…the feedback from caregivers on the impact of the support group is very positive.…participants find the support they receive in our groups to be a 'lifeline'."**

The Difference Between One-to-One Support and Support Groups

Support groups are facilitated with a focus on the overall group health, providing social connection and limited opportunities for sharing by individual caregivers. In contrast, one-to-one support gives the caregiver much more room to discuss their caregiving journey, explore challenges, and develop strategies for improving their caregiving experience. The one-to-one sessions provide an opportunity for private, customized, and tailored support.

Support Group Structure and Format

There are many different ways to structure support groups, the most successful are designed to support emotional safety and simplicity.

Emotional safety can be described as a caregiver's visceral feeling of being accepted or embraced for who they are. Facilitators can help create an environment of emotional safety by supporting confidentiality (within organizational limits), upholding respect for boundaries, and creating a welcoming space for shared feelings.

Keep it Simple

Simplicity is a commitment to keep the meeting format basic so that it becomes regularized, easy to follow, and comfortable for caregivers. Caregivers may come to meetings feeling anxious, upset, or overwhelmed. It can be comforting for the caregiver to know that a simple format will support them to regulate their emotions. Caregivers can be supported through **co-regulation** with the facilitator, who strives to maintain their emotional equilibrium during meetings. Co-regulation is the ability to regulate one's emotions and behaviours to soothe and manage stress with the support and direction of a connecting individual.

When information or resources are shared at a support group meeting, a commitment to simplicity requires keeping the details for those offerings at a basic level. After the meeting, detailed information can be provided through follow-up emails or printed materials.

2. Supporting Group Facilitation

As facilitators, we can support group health by bringing warmth, humour, respect, boundaries, and genuine caring energy to the group setting.

- We encourage group members to talk about themselves and their own experiences, while ensuring everyone has an opportunity to speak.
- We acknowledge when other members have expressed good support, reaffirming positive aspects of the group's culture.
- We provide a written set of support group guidelines before members join.
- We encourage members to listen to each other. We do this by modeling active listening, including:
    - Positive body language
    - Gentle, warm eye contact
    - Brief encouraging statements
    - Nodding and affirming gestures
    - Reflecting, repeating, or paraphrasing what was shared

Family Caregivers
of British Columbia

Family Caregivers of British Columbia (FCBC)

- FCBC offers group facilitation training opportunities and regular community of practice (CoP) meetings for staff and volunteers focused on support group facilitation.
- They also offer a range of online support group meetings to meet caregivers needs.
- For more information visit https://www.familycaregiversbc.ca/

A caregiver's message…

> "I have made some very good friendships through the support group that I will cherish. I will always strive to make this a better world for everyone by focusing on the little things, because this is what the group did for me."

The facilitator aims to create and maintain a safe, productive, and nourishing meeting for everyone. Facilitators play a crucial role in providing the framework and space for a positive group culture to develop, allowing trust and mutually beneficial support to deepen over time.

Facilitators strive to keep a balance; supporting the group's communication flow, and actively intervene when there are challenges. When facilitators feel they need to intervene, it is important to do this in a way that is considerate and supports the participant's dignity and inclusion.

As facilitators, it is our responsibility to intervene proactively to ensure group safety.

Intervention is necessary when a support group member is:

- Offering unsolicited advice to another member.
- Expressing excessively critical opinions about specific facilities, healthcare workers, or services.
- Interrupting another caregiver.
- Using more than their allotted time to share.
- Struggling emotionally in a way that impacts group safety.
- Making comments that are not helpful.
- Behaving in a way that will negatively impact the group. This could include making racist, homophobic, sexist, or abusive remarks.

If a participant behaves in a way that negatively impacts the culture of safety and trust in the group, such as making racist, homophobic, or sexist remarks, we quickly remind the caregiver of the group guidelines and set a clear boundary. Please seek support from your agency about policies, best practices, and training opportunities to support a safe support group environment. (Please also refer to Professional Boundaries and Emotional Support for more information.)

If a participant is making critical or blanket comments about the healthcare system or another program, it is incumbent on the facilitator to step in and reinforce the group guidelines. We can acknowledge that the caregiver feels strongly and remind them that excessive negative opinions may not support other caregivers, and may not reflect everyone's experience. The facilitator can also offer to meet with the caregiver individually for one-to-one support.

Sometimes, a caregiver may struggle emotionally during a meeting. Examples of this can include uncontrollable crying, sharing inappropriate information, appearing to want to flee the meeting, etc. If a participant's distress level starts to create alarm for other group participants, facilitators take the lead, bringing the group back to a place of safety. This can be done in a variety of ways:

- Compassionately acknowledge and summarize the challenges the caregiver is facing.
- Acknowledge the time limits for individual sharing.
- Ask the caregiver if they can meet after the meeting where we can provide further emotional support.
- Arrange priority follow-up one-to-one support when needed.

A caregiver's message...

> **"Thank you for your skills as a support group leader. You always add just what we need to hear and are very knowledgeable about many aspects of a caregiver's journey. These meetings give us the strength to carry on."**

Supporting Ourselves... Group facilitation requires a significant amount of energy, particularly when there is deep sharing or complex caregiver dynamics. While it is helpful to leave space in your schedule to write case notes after a support group meeting, it is also beneficial to take time for yourself as well. Taking a walk or sitting outside in the fresh air can be a helpful way to leave what was shared in the circle.

Facilitation Plans

There are generally three styles of caregiver group facilitation plans:

1. Check-in focused
2. Topic focused
3. Curriculum-based

Check-in focused:

The facilitator provides guidance and active facilitation without any pre-planned themes. This type of meeting allows the caregiver sharing to organically 'guide' the meeting while the facilitator holds space and ensures safety. Members are given a set time to share individually, and discussions emerge based on the needs of the attending participants at the meeting.

Topic focused:

The facilitator offers a topic for discussion and participants share and reflect on the topic presented. Themes will still organically emerge, but the facilitator guides the meeting back to the topic when necessary. Materials may be provided after the meeting to support further exploration of the topic.

Examples of themes in topic-focused support group meetings include: boundaries, strategies for building resilience, self-care, grief, getting through the holidays, lack of patience, relationship changes, anticipatory grief, bereavement, mindfulness, journaling, dealing with guilt, dealing with anger, dealing with abuse related to dementia or memory loss, how to mitigate difficult dementia behaviours, change in social supports, advanced care planning, emergency planning, complex feelings associated with caregiving, caregiver burnout, and caregiver advocacy.

Curriculum-based:

The facilitator usually incorporates specific information, materials, and tools over several meetings. Though members have a chance to share, it is generally facilitated towards affirming the curriculum.

Practical suggestions for group meetings:

- Provide new participants with meeting guidelines before the day of the meeting.
- Send meeting reminders to group participants a few days before the meeting.
- Ensure that meeting spaces are physically accessible for all participants.
- Arrive at the meeting space early to set up the meeting space and welcome caregivers.
- Start and end the meetings on time. (This is important for people using respite services.)
- Provide name plates or name tags. This ensures everyone can easily address each other by name and encourages a sense of community.
- Consider providing some refreshments.
- Have a side table with various printed caregiver resources for caregivers to browse.
- Keep the number of registered participants manageable to ensure everyone has a chance to participate.
- Keep the number of registered participants sufficient to remain functional, as not all caregivers can attend every meeting.
- Offer written generic check-in style prompts that provide caregivers with some sharing ideas if needed.

FFCS Pro Tip

Passing around a basket containing prompts or open-ended questions is a simple but effective way to encourage group sharing. Example questions may include: “What has been working well?” or “What does the expression, ‘caregiver guilt’ mean to you?”

AN EXAMPLE OF A **SUPPORT GROUP FACILITATION PLAN**

Below is a detailed example of a group facilitation plan and timeline for a check-in-focused support group. In this example, the support group is held twice a month in the agency's meeting room for 1.5 hours. Twelve caregivers are registered, with an average of nine caregivers attending.

12:30 pm: The facilitator sets up the room, tables, and chairs, and adjusts the temperature if necessary. The facilitator sets out materials on a resource table for caregivers to browse if they wish. Trifold paper nameplates are placed on the resource table so that when caregivers enter the room, they can put their nameplates on a chair and then feel free to move about before the meeting begins. Caregivers often arrive early for social conversations and help themselves to water and tea.

1:00 pm: The facilitator starts the meeting on time and opens with a warm welcome. Before the check-in round begins, the facilitator provides any 'housekeeping' notes about practical matters. The facilitator welcomes any new members and briefly reminds the group about guidelines that may need reviewing.

The facilitator asks if anyone needs to leave the meeting early to ensure they have an opportunity to share. The facilitator lets everyone know they have up to 8 minutes each to check in. The facilitator opens the sharing time with a caregiver who is very comfortable with the meeting structure, ensuring any new members are later in the check-in so they have a chance to experience the group culture and process.

1:10 pm: Caregivers take turns sharing. Some share with the group what they have experienced since the last meeting. Others chose to share how they are feeling at that very moment. Others explore challenges and successes. Caregivers may offer brief, supportive comments to one another and understand (from the group guidelines) that they may only offer advice if there has been an invitation from the sharing caregiver. Not all group members will use their entire 8-minute time allocation to share, so any leftover time used for facilitated group discussion arises organically from the check-in round.

2:25 pm: The facilitator engages in a simple facilitation technique for bringing the support group meeting to a close on time and offers any parting announcements.

2:30 pm: Warm goodbyes between group members and the facilitator. The facilitator offers to follow up with one-to-one support for any caregivers who may need extra support. Some group members may linger to connect socially. The facilitator cleans up the room and packs up.

What Happens After a Support Group Meeting?

Our support work continues in various ways after and between support group meetings. This can include:

- Writing and filing brief case notes about each participant in the support group meeting.
- Following up with individual caregivers with requested referrals and any opportunities for Connection to Community Services.
- Following up with the group or individual caregivers to provide supplemental support materials for Knowledge and Skill Enhancement.
- Following up by phone with any new members to check in about their experience at the meeting.

Supporting Ourselves... What self-care might be needed for you after a support group meeting?

3. Inherent Limitations in Support Groups

There are inherent limitations in the support group format that are important to recognize:

- Setting times may present a scheduling conflict for caregivers.
- Guidelines cannot always eliminate challenges to confidentiality and privacy.
- Cold and flu virus transmission can occur in group settings.
- Caregivers have a limited time to share.
- Not all caregivers thrive in a group environment.
- The support group setting cannot offer in-depth customized support to individual caregivers.

It is also important to be aware of the challenges associated with the social dynamics of a support group setting:

- Participants may not all be culturally sensitive.
- Participants may offer unwanted advice-giving.

- Caregivers often compare their caregiving experiences and, as a result, may feel less confident about their own caregiving skills.
- Challenging dynamics between participants can occur.
- Caregiving realities can sometimes be overgeneralized.
- Caregivers can sometimes feel overwhelmed.
- A participant may not be able to achieve emotional safety in the group, causing distress and increasing the feeling of isolation.

4. Supporting a Caregiver Whose Loved One Has Died

This work begins early; when support group participants join, it is helpful to provide support group guidelines that gently, but clearly define how long a caregiver may continue attending support group meetings after their care recipient dies (for example, up to 3 months). This clarity indicates an important container or boundary for the service offerings and helps manage expectations.

The individual may find it beneficial to continue to attend for up to several months after to stay within their community, process their loss, as well as the loss of the caregiving role. However, now that they are no longer caregiving, participants will not relate to most of the support group conversations regarding day-to-day caregiving issues. There are several things we can do to help a person who is no longer caregiving transition from the group successfully:

- Offer clarity and guidance to the participant about the transition process and how long they are able to continue attending meetings.
- Facilitate connection to hospice organizations, grief support, counseling, or other community initiatives.
- Suggest opportunities for peer connection with group members outside of the support group meetings.
- Connect the person to any available volunteer opportunities within your agency such as peer support opportunities.
- Provide one-to-one support for a limited time to help with the transition.

FFCS Pro Tips

When a death is experienced by a support group participant, at the next meeting we light a candle and place it where they sit, as a gentle and loving recognition of their loss.

5. Group Guidelines for Participants

It is important to develop a set of group guidelines for support groups and share them with each participant before they attend their first meeting. These guidelines can be referred to as needed during support groups. In addition, a program's policy about confidentiality may also be provided. Please refer to Addendum I: Support Group Meeting Guidelines Template (developed by the Cowichan Family Caregivers Support Society).

HEALTHCARE SYSTEM NAVIGATION

In this section...

1. Healthcare System Navigation: An Overview

Healthcare system navigation is a core program element in the Family and Friend Caregiver Support Program. It is a common focus in both One-to-One Support and Support Group meetings.

Healthcare system navigation refers to the work of Caregiver Support Coordinators (CSC) to support caregivers in two ways. The first is to help caregivers understand the key programs and services offered by the Health Authority (HA) that are designed to support them in their caregiving role (**knowledge**). The second is to provide caregivers with the basic knowledge they need to access these services successfully (**access**).

The services provided by the healthcare system can help make it possible for family members to care for their loved ones with more support; helping to address the feelings of overwhelm or burnout that caregivers often experience from their caregiving responsibilities and workload.

Healthcare System Navigation Includes:

Knowledge

- Increasing caregiver understanding and awareness of the most common services provided by Home and Community Care when they need more support.
- Explaining how the local HA access (or intake) phone line works, and how to make an effective connection with this service.
- Supporting the caregiver's belief in their own ability to have a positive influence in the situation.
- Supporting caregivers to prepare for care plan meetings, hospital discharge meetings, and meetings with case managers.
- Supporting caregivers with awareness and sensitivity about systemic barriers in healthcare system engagement.

Access

- Directing caregivers to the local Health Authority's access (or intake) phone line.
- Supporting caregivers to be proactive in accessing healthcare services in a timely manner. This is particularly helpful when a caregiver has identified a need for services, but lacks the practical information on the access points for these services. (Ex. the range of available respite programs offered in their region.)

- Informing caregivers about the access points available for raising concerns about 'quality-of-care' issues.

To work effectively as CSCs, we need to maintain a basic knowledge of local HA resources, particularly the services that are regularly needed and accessed by caregivers. We also need to be familiar with the basic terminology that caregivers encounter when accessing services from the healthcare system so we can help caregivers understand what that terminology means and how it can benefit their caregiving situation.

A note from the FFCS frontlines...

"Staff are trained to develop their understanding of the local healthcare channels, as well as the steps caregivers need to know about in order to access services. We organize staff tours of healthcare facilities and attend on-site presentations to help provide our caregivers with knowledge of facilities and services."

2. Understanding Home and Community Care

The healthcare system is vast and dynamic, with many branches and entry points. While we can't be expected to know every aspect of the healthcare system, it is important that we develop our navigation skills in the area most commonly accessed by caregivers: **Home and Community Care**.

Home and Community Care (HCC) is available in every Health Authority in BC and is the primary point of contact for anyone providing caregiving support in a home environment.

It is important to become familiar with the information about Home and Community Care services provided on the BC Ministry of Health's website.

The following services are described in more detail on the BC Ministry of Health's website.

- **Case Management**: a Case Manager is a nurse who assists clients with chronic health care needs to obtain Home and Community Care services.
- **Home support**: helps clients with personal care such as bathing, personal hygiene, assistance with dressing, ambulation, etc.
- **Nursing support**: helping clients who require acute, chronic, palliative, or rehabilitation support.
- **Palliative care support**: specialized medical care for people with serious illness at home or in the community.
- **Respite services**: provides breaks at home through home support services, in the community through adult day services, or on a short-term basis in a long-term care home, hospice, or other community care setting.
- **Access to assisted living**: assessment and application processes.
- **Access to long-term care**: assessment and application processes.
- **Community rehabilitation**: provided by a licensed physical or occupational therapist to clients who require acute, chronic, palliative, or rehabilitative support.
- **Choice in supports for Independent Living**: a self-directed option for eligible home support clients.
- **Advanced Care Planning (ACP)**: while making future healthcare plan decisions, clients may work with care providers to ensure planning is based on accurate medical information. ACP also refers to financial and estate planning.

In most cases, the local Health Authority's website will also have a HHC page, and it is important to review the available HHC services and processes in your region. This information is available online and may also include digital pamphlets, booklets, and videos. Take the time to learn about these programs and services, including becoming versed on how caregivers can access them in your region.

Over time, often in response to questions from caregivers, we learn about other services available, either through HCC or through other branches in the healthcare system. These include: seniors specialty teams and clinics, gerontologists, social workers, palliative care, 811, the First Nations Health Authority, details about Adult Day Programs and services in our community, long-term care wait lists, pharmacy services, travel and accommodation assistance, hospital discharge plans, rate reduction processes, care plans, surgery-related processes, etc.

FFCS Pro Tip

Meeting regularly with other team members who serve similar clients and sharing the information you have learned can support your colleagues' learning and enhance your organization's knowledge base.

3. Developing Knowledge to Support Caregivers with Healthcare System Navigation

Healthcare system navigation is a skill that takes time to learn. The following five strategies will improve your navigating skills:

1. Read the 'Home and Community Care' information provided on the Ministry of Health website, as well as your local HA website. This will help you learn the basics about available programs and how caregivers can access the programs.
2. Develop a good understanding of the services caregivers refer to most (such as respite), and how they operate in your community.
3. Share challenges and insights about healthcare system navigation through Community of Practice (CoP) meetings, interagency mentorship, and colleague-to-colleague peer support.
4. Strengthen interagency collaboration and partnership with your HA, especially Home and Community Care teams and/or seniors specialty teams and clinics.
5. Organize facility and program tours for Adult Day Programs and Services, Assisted Living, Long-Term Care facilities, and others.

When providing healthcare system navigation, it is important that we are aware of the common challenges that caregivers may encounter.

The following are some examples of healthcare system challenges:

- Institutional and community factors, including waitlists and system issues.
- Interpersonal processes, including conflicts between caregivers, care recipients, and HA staff.
- Systemic barriers for caregivers who have experienced racism, trauma, or have vulnerabilities related to formal healthcare systems.
- Low literacy levels which can negatively impact system access and navigation.

By keeping these challenges in mind as we support caregivers, we can offer a more sensitive and conscious approach to healthcare system navigation.

When providing healthcare system navigation, it is important that we '*stay in our lane*' and understand the limits and boundaries of our caregiver support role.

The following are some examples of support scenarios to avoid. We should not:

- Provide any medical diagnosis or assessment
- Offer medical advice
- Make decisions for caregivers
- Offer assistance outside of our scope of practice
- Provide medical case management
- Offer opinions on services or facilities

A note from the FFCS frontlines…

One organization shared that while training new staff about healthcare system navigation, they offer this affirmation: "We're generalists, not specialists. As generalists, we maintain a broad understanding of the areas of the healthcare system that caregivers are accessing the most; they rest we learn as we go."

FFCS Pro Tip

When caregivers are experiencing stress or burnout, or ask us what they should do, it may be tempting to offer healthcare advice. However, this is an opportunity to provide valuable emotional support and deep listening. By allowing the caregiver to talk through their challenges and articulate what they need, we are in the best position to share information about programs and resources that might be the most beneficial.

4. An Example of Healthcare System Navigation

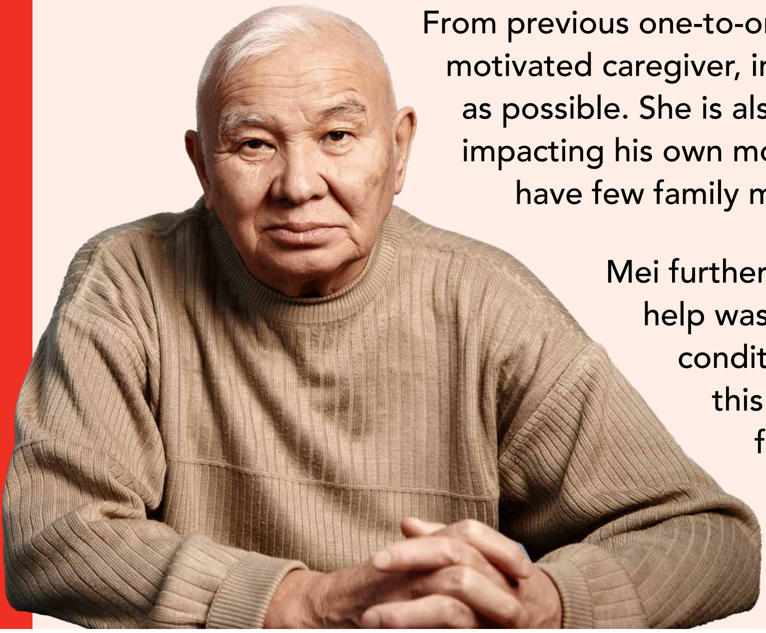
The following program example shows the value of the **Guiding Principles of One-to-One Support** and the need for emotional support during healthcare system navigation:

As the primary caregiver for his wife, Jory received consistent one-to-one support from Mei, his Caregiver Support Coordinator. After three months, a trusting relationship had formed, and Jory began to feel more comfortable talking about the challenges he has faced in caregiving for his wife, Holly, who has Parkinson's and dementia.

At the last session, Mei asked how Jory had been feeling lately. He expressed feelings of sadness and helplessness due to his wife's recent health decline. Jory shared his increased efforts to mitigate health and safety issues in the home. He also shared his new feelings of discomfort when he had to leave Holly at home while he runs errands, attends medical appointments, or attends in-person support meetings. Lastly, Jory expressed his growing irritation at feeling "trapped" at home. He teared up as he described feelings of guilt over losing his patience in certain moments with Holly.

Mei offered compassionate emotional support, providing Jory with deep listening and empathetic understand throughout their one-to-one session. Jory felt understood and said, "I'm ready to bring in some extra help, so I can keep Holly safe at home. I also need some regular breaks. But I have no idea where to start."

Mei assured Jory that she could help him connect to the appropriate healthcare services.



From previous one-to-one sessions, Mei was aware that Jory is a highly motivated caregiver, intent on caring for his wife at home as long as possible. She is also mindful that Jory has some health concerns impacting his own mobility. Jory and Holly are on a fixed income and have few family members or friends who can offer extra support.

Mei further recognized that Jory's reluctance to accept help was tied to his grief about his wife's health condition and their changing relationship. With this awareness, Mei and Jory began their first conversation about healthcare system navigation.

Mei provided an introductory overview of the essential services available from Home and Community Care, as well as the assessment process and the role of a case manager. Mei was mindful that Jory needed to pace the conversation in a way that respected his energy limits, so she allowed him ample time to pause, reflect, feel, and ask questions. In particular, Jory wanted to learn about the range of available respite options, primarily residential respite, because he had a much-anticipated family reunion that we wanted to attend. Mei provided Jory with the access/intake phone number for Home and Community Care services and provided a general introduction about how the process works.

At the end of the session Jory reflected his experience to Mei:

> *"When I first started seeing you, I didn't know what this was about. I thought you might try to tell me how to take care of my wife or tell me to put her into care. But you know me, and that is the last thing I would want to be told. You understand what Holly and I all are about. I'm glad I have you to help me through this next part because it won't be easy for me to accept help."*

When Jory booked another one-to-one session with Mei a month later, he shared that he felt more confident after their last conversation. He had called the intake line and initiated an assessment process with Home and Community Care. He started receiving twice-a-week respite through Home Support and booked one week of residential respite for his family reunion. In time, Jory shared that his irritation towards Holly was much reduced now that he had consistent breaks from his caregiving responsibilities. Jory continued to receive emotional support from Mei as he navigated his wife's changing condition and the different services available from Home and Community Care.

Key takeaways

- Building a trusting relationship with a caregiver over time can provide the foundation for important conversations about healthcare system navigation. Emotional support is often part of healthcare system navigation conversations.
- Supporting a caregiver to assess gaps in care can help them be more ready to articulate their needs and concerns when they meet with healthcare professionals.

5. Frequently Asked Questions about Healthcare System Navigation

The caregiver I'm supporting is getting burned out and needs respite. They have already maxed out asking for help from friends, family, and community agencies. How do I support the caregiver to get some respite organized through the Health Authority?

We can prepare for this kind of healthcare system navigation question by taking the time to become familiar with the basic information about respite provided on the Ministry of Health's website and your local HA's website. There you can find descriptions of available respite options, including: home-based respite, residential/short-term respite, and Adult Day Programs or services.

If you have capacity, you can also research how these programs are implemented locally. For example, what long-term care facilities in your area offer residential respite (short-term stays)? What day programs are operating in your area, where are they located, and are there waitlists?

There are several pathways to initiate the assessment required for respite services. For example, it can be initiated by a family doctor or discharge nurse if the care recipient is coming home from the hospital. However, the most accessible way for families not already receiving services through Home and Community Care (i.e. does not have a Case Manager), is for the caregiver to call the local toll-free access/intake line. A caregiver will be connected to a nurse to discuss their situation (an assessment process).

FFCS Pro Tip

Always have the local HA's toll free access/intake number handy and include it in your caregiver print resources.

We can help the caregiver be prepared for the conversation with the nurse at the access/intake line. When supporting the caregiver in a one-to-one session, we can help them assess the caregiving challenges they are experiencing. Caregivers can explore their situation, collect their thoughts, make a list of the challenges, and be ready to communicate about these challenges and their needs.

The nurse will work with the caregiver (and/or care recipient) to do a provisional assessment. If the assessment indicates that services are likely needed, the nurse will transfer the case information to the local Home and Community Care office. The Case Manager or designate will then reach out to the caregiver and client and begin multi-level assessments to determine what supports can be made available. If a service is offered and then accepted by the caregiver and/or care recipient, the Case Manager becomes the main point of contact for expanding or reducing services provided by Home and Community Care.

These processes take time to complete. We can support caregivers by encouraging them to initiate that first phone call as soon as they are comfortable doing so.

The caregiver I support would like to increase the services their family receives from Home and Community Care. Who do they talk to?

They need to speak to their assigned Case Manager. The Case Manager (a nurse) coordinates care for people with complex health needs requiring extra and ongoing support to live at home independently. If the caregiver is unaware of who the Case Manager is, they can contact their local Home and Community Care Office.

It is important to note that not all caregivers have the authority to make decisions about services on behalf of the care recipient. The care recipient is the Health Authority's client and, in many cases, must provide consent for services. If the authority for decision making is unclear, the caregiver can ask the Case Manager.

The caregiver wants to accept services from Home and Community Care but is experiencing guilt about accepting services.

This is a common challenge. Providing emotional support for caregivers in a consistent and compassionate way is a key aspect of healthcare system navigation and can help caregivers address feelings of guilt. Please refer to Emotional Support for different approaches.

The caregiver wants to accept services from Home and Community Care to avoid burnout, but the care recipient is resistant.

While providing healthcare system navigation, we can provide a safe and supportive space for the caregiver to explore the exact nature of the challenges and consider various strategies to integrate services. Caregivers express that when given the opportunity to openly explore and work through strategies and concerns, they are more likely to find creative ways to respond or communicate through challenges. Over time, we learn about the success by some caregivers to overcome barriers or obstacles and can sensitively offer insights about what has worked for other caregivers. In cases of cognitive impairment we can also offer caregiver Knowledge and Skill Enhancement Opportunities that may help them communicate in more effective ways. We can also encourage the caregiver to bring their challenges to the Case Manager.

The caregiver is supporting a complex number of challenges with their care recipient. Examples of this could include: cognitive impairment with aggression, substance abuse, mental health challenges, and caregiver burnout. What services and supports are available?

In each Health Authority, there is a specialized seniors team or clinic although the names of these teams differ in different HAs. They may be referred to as the Geriatric Specialty Services, Specialized Seniors Clinic, Geriatric Assessment Program, Seniors Outpatient Clinic, Older Adult Mental Health Team etc. These teams are comprised of nurses, social workers, gerontologists, and psychiatrists who specialize in complex health challenges. These services can only be accessed by referral from a primary care provider or through the intake/assessment process that is initially accessed through the general intake line.

CONNECTION TO COMMUNITY SERVICES

In this section…

1. Connection to Community Services: An Overview

As a core program element in the Family and Friend Caregiver Support program, connection to community services refers to the role played by the Caregiver Support Coordinator (CSC) in connecting a caregiver to one or more additional community services and/or programs that can further benefit the caregiver. Most often, this work is done in One-to-One Support sessions, where we have the opportunity to learn more deeply about the caregiver's specific situation and can make tailored recommendations.

Community Services refers to the range of local programs available in a community that offer direct support or assistance to community members. Other non-profits often offer free or low-cost support programs and beneficial services. Many of these programs and services can help caregivers address specific needs, including; social and recreational activities, food resources, financial assistance, advocacy support, employment support, shelter, and health services.

United Way BC has a large range of programs and activities designed to help older adults become active, healthy, and engaged. These programs include:

- Better at Home
- Therapeutic Activation Program (TAPS)
- Social Prescribing
- Navigation and Peer Support
- Digital Learning Program/Active Aging Plus
- Emergency Preparedness and Response
- Men's Sheds

These important programs reduce isolation and feelings of loneliness, and enhance the quality of life for seniors and their caregivers.

Other community organizations offering free support services include:

- Hospice programs and services
- Local volunteer associations
- Programs focused on specific disease diagnoses such as the Alzheimer's Support Society
- Programs focused on particular challenges or barriers, such as Meals on Wheels or literacy programs

Connection to community services can also include the strategic effort to build and strengthen relationships between an FFCS program (and agency) and other community services. Deepening collaboration and trust between community partners over the long term can increase capacity for all collaborating organizations and work to strengthen the overall health and resilience of a community.

A note from the FFCS frontlines...

> **"We have long-term partnerships and we are connected with many community services and resources. We participate in the Seniors Working Group and Seniors Coalition so both staff and trained volunteers can provide a wealth of up-to-date information to caregivers via phone, email, and in person."**

2. Strengthening Community Service Relationships to Support Referrals and Collaboration

Agencies often invest in long-term relationships and networking with other community agencies that provide related services and support. Front-line service providers (including CSCs) are essential in supporting and strengthening these existing organizational relationships, and they often work with their agency to initiate new connections.

Strong interagency relationships have the natural potential to grow into beneficial, long-lasting partnerships. These partnerships encourage and support robust referral exchanges between organizations; engaging in problem-solving strategies in areas of common concern and striving to avoid duplication of services. Partnerships can include individual and regional networks of senior service agencies, community centers, settlement organizations, emergency management groups, and more.

There are also less obvious community sources for relationship building (and referral sources). These can include housing complexes, places of worship, libraries, service clubs, senior centres, neighbourhood houses, community centres, volunteer groups, banks/credit unions, clubs and associations. Nurturing these connections can bring increased awareness about programs and services, provide new referrals, increase donations, and support finding new spaces to offer programming.

FFCS programs have reported that connections with community partners have resulted in the following:

- Increased awareness about programs and services available to caregivers and their families by other community service agencies.
- Increased awareness about the FFCS program and referral process for other community service agencies, resulting in new referrals.
- Ability to offer caregiver support program elements in partner's spaces.
- Donations to caregiver support programs and organizations.
- Positive information exchanges, mutual support/resource sharing, and problem-solving.
- Coordinating program schedules to ensure that caregivers could access services on different days.
- Increasing shared and mutually supported participants.

(Howegroup, FFCS Co-Creation Session #2 Summary: Referrals and Outreach)

3. Frequently Asked Questions about Connecting Caregivers through Referrals and Resource Guides

How do I learn about services/programs available to caregivers in the community?

Most agencies have this information available ‘in-house’ and provide training to their staff about community services that can benefit caregivers and their families. Agencies often develop, maintain, and distribute caregiver resource guides featuring community services for caregivers and their families. These guides can be one of the first helpful resources a caregiver will receive when engaging in our programs and services.

A Caregiver Resource Guide may include:

- A description of FFCS Services
- FFCS staff contacts
- Information about the services available through the Family Caregivers of BC
- Essential healthcare system navigation guidelines, including first steps and ways to access key healthcare services
- Private care companies offering local home support
- Medical alert systems and medical equipment loans
- Community-specific supported transportation options
- Food services (Meals on Wheels, local food banks, etc)
- Helplines
- Low-cost counselling services
- Local social prescribing programs and services

This component of service delivery can be provided during a one-to-one session or after. If information about local services is not readily available at your agency, here are some helpful resources for you and caregivers to learn about community services available in your community:

1. **211**
   211 provides a comprehensive community resource database about programs and services across BC and Yukon. The self-serve version of the 211 database is available here: www.bc.211.ca
2. **Pathways**
   An online resource that lists social and health resources in various communities
   https://pathwaysbc.ca
3. **Fetch (For Everything That's Community Health)**
   An online resource that lists social and health resources in various communities
   https://divisionsbc.ca/provincial/what-we-do/patient-support/fetch

A caregiver's message...

> **"I wanted to say thank you again for your support in my new caregiving role. It means a lot to me knowing you are there as a support.... Thanks for sending me your Resource Guide - I have contacted the Better at Home program and Alzheimer's Support Society and am feeling like I'm less alone already."**

How do I refer a caregiver to community services?

It is important to become familiar with the referral process of any agency you are referring a caregiver to. Often, there will be capacity limits and eligibility requirements that change over time and require our ongoing attention. Sometimes, the caregiver must initiate contact with the agency. In other cases, we can facilitate the referral on their behalf. We call this a 'warm referral' and can be a very supportive action for an overwhelmed or overworked caregiver.

When making a referral on behalf of a caregiver:

- Confirm the caregiver has consented for us to make the referral.
- Ensure the cargeriver understands for the referral process we will need to provide personal contact information to the external agency.
- Reference all information and referrals in the case notes.
- Follow up with the caregiver to provide an expectation on the timeline, if necessary.

Questions to consider before making a referral:

- Is the caregiver eligible?
- Does the caregiver have an interest and willingness to accept a connection with this community service?
- What specific services and supports are available in the program?
- What costs are involved? Is there any financial assistance available if needed?
- What is the current capacity of the program?
- Am I able to recommend a priority or urgent referral to a program with a waitlist?
- Am I being realistic about an organization's ability to deliver services?
- Will an agency and staff be able to work in a culturally sensitive or culturally safe manner with my caregiver?

FFCS Pro Tip

If a caregiver asks about other support services available in the community, it's okay not to have all the answers. Often, the best way for us to learn is by researching other services and resources for a caregiver. This gives us an opportunity to find the right information, follow up with the caregiver, and then share this information with our organization.

How can I be sure that the programs and services I'm recommending will make a good fit for a caregiver?

It is essential to develop current knowledge and understanding of the programs available in our community so we can identify those services that would make a good fit for the caregiver we are supporting. When engaging with caregivers, especially during one-to-one support sessions, we listen closely to learn about a caregiver's situation and challenges, so we can note the possible gaps that could be supported through other community services.

It is important when making recommendations to remember that we are not offering advice. Rather, we are supporting caregivers to self-identify their own needs. In this way, they will be more likely to follow up on a recommendation or accept the suggested services. Caregivers who can explore opportunities for additional support without pressure or expectations often feel more empowered to take action.

CONNECTING A CAREGIVER:
AN EXAMPLE FROM ONE FFCS PROGRAM:

During a one-to-one session, Dena expressed worry and frustration about the cost of medical equipment that would soon be required for her husband to continue living safely and comfortably at home. After providing emotional support and listening carefully to the caregiver's concerns, Dan (the CSC) asked if Dena would like to hear about some community services that may help. Dan was aware of the Red Cross Equipment Loan program (by donation) and another local non-profit organization offering low-cost, second-hand medical supplies (including walkers, wheelchairs, and adaptive equipment). Because Dan was aware of the criteria of eligibility and service limitations of both programs, they were able to provide accurate and helpful information. When Dena expressed interest in learning more about these programs, Dan provided her with up-to-date contact information for both programs. This referral was included in the case notes and Dan made a note to follow up with the caregiver at their next support meeting.

What can I suggest for caregivers seeking greater community connection outside of traditional caregiver programs and services?

Caregivers can be supported to consider a range of options that can expand and deepen their feeling of social and community connection. This can include:

- Free or low-cost programs at community centres and libraries
- Free or low-cost courses and talks at post-secondary institutions
- Service clubs
- Volunteer and charity work
- Work with animals
- Cultural and music events

What can I suggest for caregivers seeking community connection who cannot leave their homes?

There are now a variety of online resources for caregivers, including online support groups, online counselling, podcasts, exercise programs, guided meditation classes, singing or drumming groups, book clubs, language classes, Elder College classes, CBC programs, interactive museum tours, spiritual or religious services, oral histories in museums, and cultural streaming events. These offerings can be vital for caregivers who cannot easily leave home due to mobility challenges or caregiving responsibilities.

For those caregivers who cannot easily leave their homes and don't have technology in their homes, they may benefit from a friendly visiting program by phone or in person.

KNOWLEDGE AND SKILL ENHANCEMENT

In this section…

1. Knowledge and Skill Enhancement: An Overview

Knowledge and skill enhancement is a core element of the Family and Friend Caregiver Support program. It refers to programming that provides opportunities for caregivers to expand their caregiving skills and develop the confidence they need to navigate the many roles and responsibilities of caregiving. It can be integrated into all FFCS program elements, including One-to-One Support, Support Groups, and Healthcare System Navigation.

Some caregivers want to grow their knowledge and skills to feel more successful or proficient in their caregiving work. Other caregivers identify specific areas where they struggle and would like to learn more.

In general, there are two broad categories of caregiving skills that caregivers are seeking to develop: **hard skills** and **soft skills**.

Hard skills refer to the 'technical' skills a caregiver learns through practice, experience, education, or repetition. Examples can include:

- Providing appropriate care for primary physical care tasks (ie: mobility assistance or proper hygiene protocols)
- Medication management
- Household management
- Financial skills
- First aid and CPR training

Soft skills refer to personal qualities and/or traits that help caregivers work well with others and care for themselves in a caregiving context. These are more interpersonal than technical. Examples can include:

- Communication or conflict-resolution skills
- Interpersonal skills such as teamwork
- Creative problem-solving
- Empathy
- Time management
- Organizational skills
- Awareness of boundaries and self-care

A caregiver's message…

> "It has been challenging to stay grounded – but I feel like I am coping most days… some days, it just hits, and then I am in crisis mode for a few days… but because of your guidance, I can find level again. Thank you for the resources about burnout and boundary-keeping. I've also decided to do the Alzheimer's workshop you told me about with my sister; thanks for letting me know about it."

2. Online Resources

There are many quality online resources for enhancing caregiving skills in BC. These include: Family Caregivers of BC, Government of BC, Health Authorities, Alzheimer's Society of BC, BC Cancer Agency, Inclusion BC, Qmunity, The Family Support Institute of BC, Self-Management BC, the Aboriginal Health Authority, and more.

Family Caregivers of British Columbia

The Family Caregivers of British Columbia (FCBC) offers the most comprehensive online resource collection for caregivers in British Columbia. Their Learning Centre offers written materials, downloadable tools, and video workshops.

FCBC also offers a range of articles and webinars related to accessing community resources, caregiver well-being, communication skills, financial information, grief and loss, healthcare system navigation, legal matters, long-distance caregiving, mindfulness, resources for new caregivers, palliative care, support and personal care, emotional support resources, transition to long term care, work and caregiving, and much more. They offer webinars to caregivers about fall prevention, empathetic caregiving, Medical Assistance in Dying (MAiD), and much more.

Caregivers can be encouraged to sign up for the FCBC newsletter and attend the many virtual educational and support group opportunities.

The following are FFCS program strategies for the integration of caregiver knowledge and skill enhancement:

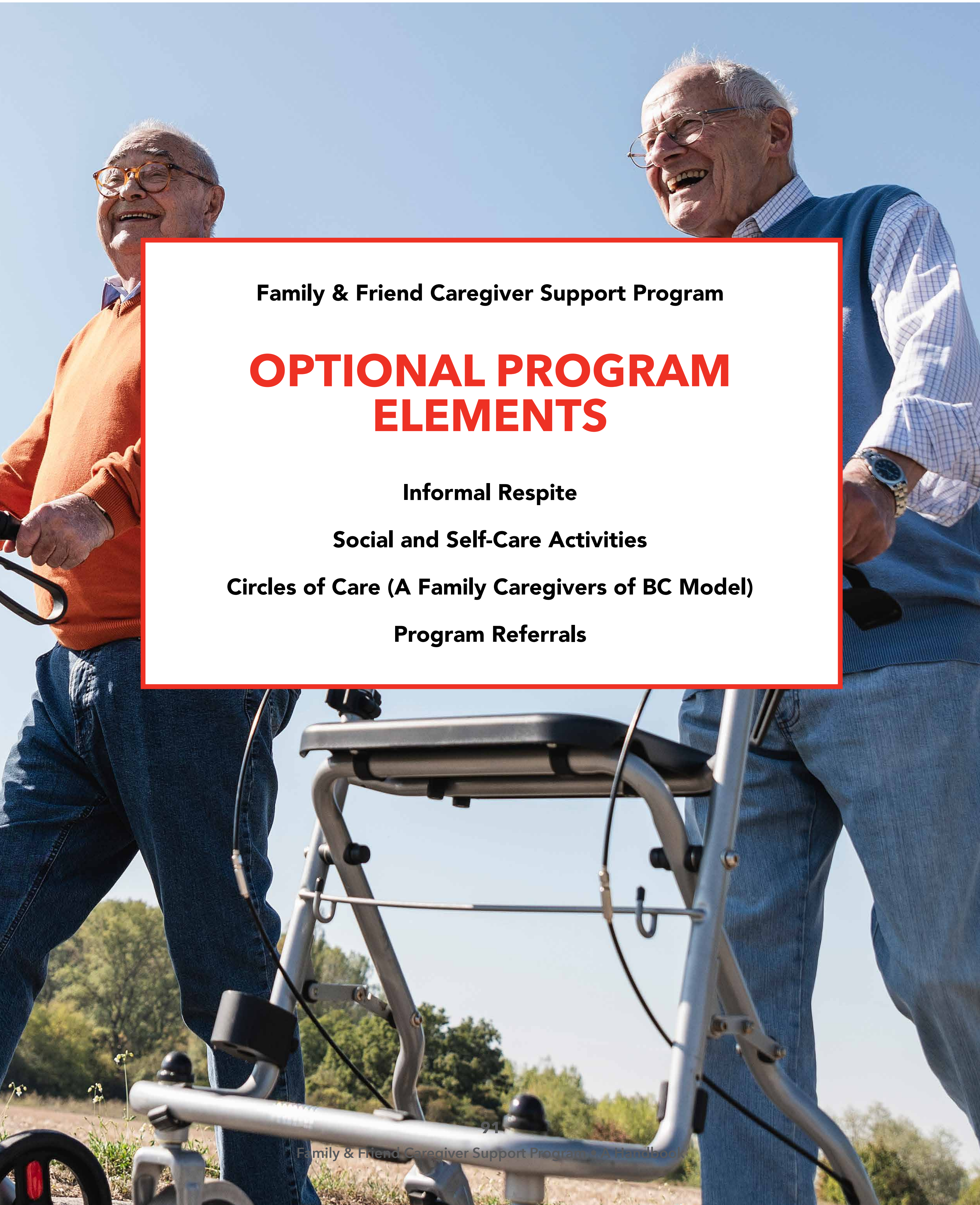
- Trained staff (CSC's) and volunteers know where to access vetted, high-quality information about caregiving that supports a local, BC, or Canadian context.
- Print and digital materials are readily accessible to share during (or after) one-to-one support sessions and support group meetings.
- Helpful information is shared in newsletters, on social media, etc.
- In-house resources are developed to meet local contexts and needs.
- Workshops, educational presentations, and monthly caregiver cafes are offered.
- Promote Family Caregiver of BC's Learning Centre, including an extensive online resource collection, webinars, and newsletters.
- Promote the local Health Authority's information/resource and webinars.
- Promote helpful community resources through Connection to Community Services.

A note from the FFCS frontlines...

"We provide educational content in our monthly caregiver newsletters and additional information from the senior connector communication. Additionally, we have invited guest speakers to participate in our group programs. Lastly, to better understand caregiver needs, we have conducted surveys to gain feedback."

***

"We organize educational workshops in multiple languages (English, Punjabi, Korean, Arabic, etc.). Immigrant caregivers who lack cultural/linguistic supports in the healthcare sector find them extremely useful."



Family & Friend Caregiver Support Program

OPTIONAL PROGRAM ELEMENTS

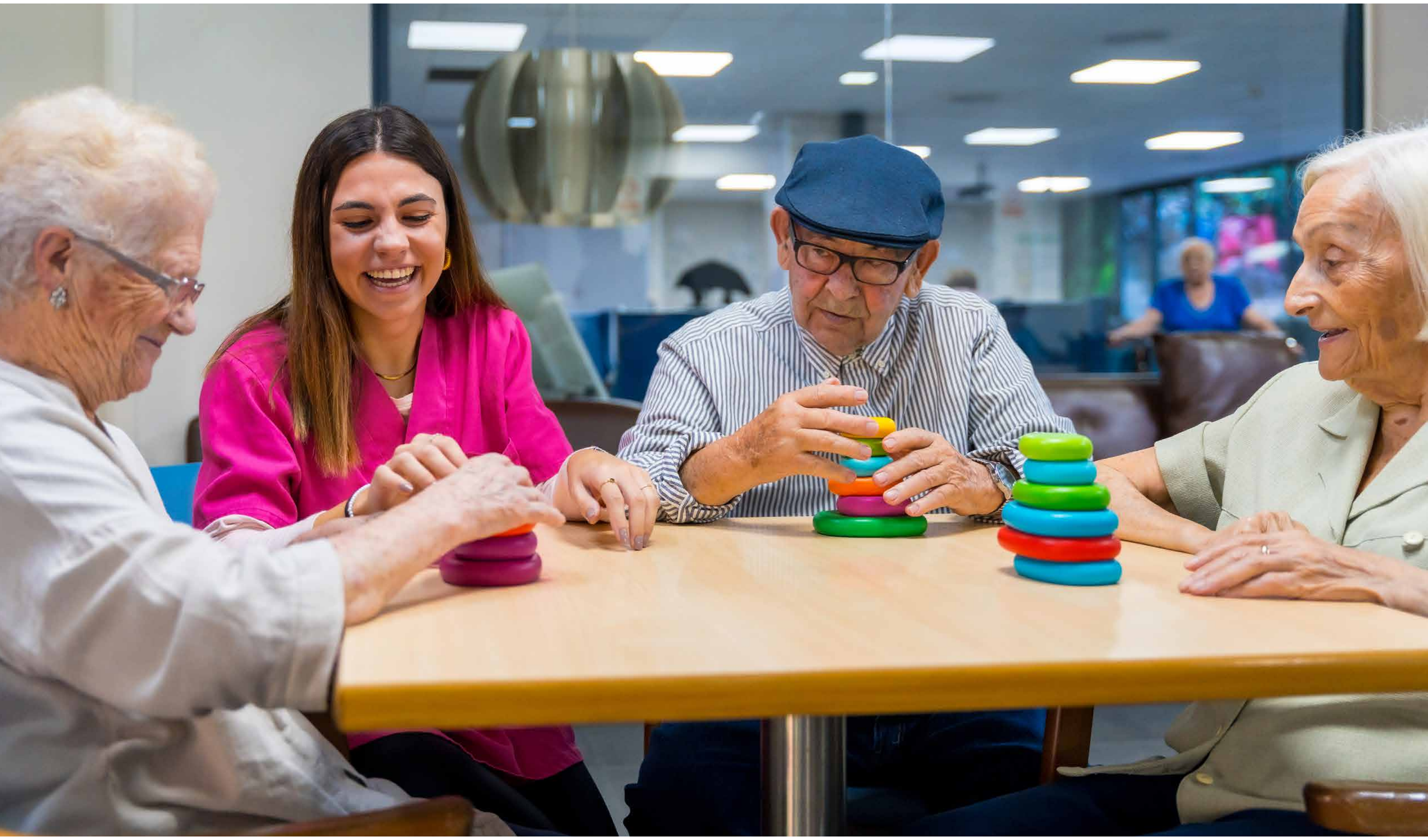
Informal Respite

Social and Self-Care Activities

Circles of Care (A Family Caregivers of BC Model)

Program Referrals

INFORMAL RESPITE



Informal respite is an optional element of the Family and Friend Caregiver Support program and refers to respite programs and activities developed and delivered by the FFSC program or agency. These informal respite services are available for care recipients and are designed to enable caregivers to participate in other FFSC programming.

Informal respite offerings can help caregivers access FFSC programs and services by ensuring the care recipient has a safe activity while the caregiver receives support. This is especially useful in caregiving scenarios where formal respite options are challenging to organize, cost-prohibitive, or cannot be scheduled during the FFCS support program. Moreover, the caregiver may view the informal respite as a positive opportunity for their care recipient because it increases their social connection as well.

<u>Not all informal respite opportunities will be safe or appropriate for all individuals. Agencies that offer informal respite options must develop their own assessment processes for their program offerings.</u>

There are two main kinds of informal respite opportunities:

1. Trained staff or volunteers from the agency provide activities for the care recipient, so the caregiver can rest or receive support services.
2. Therapeutic or social programs for care recipients are coordinated to run simultaneously with FFCS caregiver programming.

EXAMPLES OF **INFORMAL RESPITE OR MATCHING PROGRAMS**:

- An agency organizes social activities for caregivers and care recipients together. The support person ensures that caregivers can have an opportunity to rest while the staff takes care of the bulk of the care recipients needs.
- Trained volunteers plan a friendly visit with care recipients in the agency's facility while the caregivers attend a support group meeting.
- An external community agency, such as Nav-Care, provides a pool of trained volunteers who have friendly visits with care recipients. At the same time, the caregiver attends an FFCS program or event.
- The agency provides a coffee drop-in at the mall so that caregivers can have time to run errands and grocery shop.
- A Therapeutic Activation Program (TAPS) for care recipients runs simultaneously with an FFCS support group meeting or drop-in one-to-one sessions.
- Some caregivers can access professional private-pay respite services. In this case, FFSC programs may want to provide a list of local companies and individuals that offer this service.

A note from the FFCS frontlines…

"We keep an updated list of local companies and individuals that provide services for caregivers and seniors; a Personal & Companion Care Workers Listing. Of course this resource includes a disclaimer: *The inclusion of any organization, agency, service, or individual in the list does not imply or constitute an endorsement or recommendation."

A Note About Formal Respite

It is important to note that various formal respite options are available for caregivers through their local Health Authority, including caregiver respite, Adult Day Programs, and residential respite. Access to these healthcare services requires assessment processes (including financial). Once approved, formal respite occurs in the care recipient’s home and is delivered by Home and Community Care or in a facility setting.

Formal respite options are essential for care recipients who require complex care plans or have health and safety needs that informal respite opportunities cannot support. Formal respite can also support caregivers who cannot bring their care recipient to a program and maintain the confidentiality needed to receive support services.

Please see Healthcare System Navigation for the range of formal respite options provided by your local Health Authority.

SOCIAL AND SELF-CARE ACTIVITIES

Social and self-care activities are an optional program element in the Family and Friend Caregiver Support program. They refer to any organized activity designed to enhance a caregiver's physical, emotional, social, intellectual, or spiritual health.

Social and self-care activities can be included during One-to-One Support, Support Groups, or they can be stand-alone events or programs.

Social and self-care activities can support emotional well-being, inspire relaxation, reduce stress, support resilience, nurture creative abilities, encourage physical activity, increase social connection and friendships, and expand the caregiver's sense of purpose and meaning. Oh, and they can be a lot of fun for caregivers!

By encouraging caregivers to think about what activities interest them, they can be supported to thoughtfully consider their own self-care. For caregivers struggling to prioritize their own needs, this topic can be emotionally vulnerable. Facilitating gentle exploration through 'brainstorming' can lead to an openness about self-care, or a renewed desire to attend social activities and events.

Here are some examples of self-care questions that you can explore with caregivers:

- What activities bring you joy? On your own? In a group?
- How often do you do activities that bring you enjoyment?
- What does it mean to you when you think about relaxing? Define it in your own terms.
- Do you have any routines that help to put you in a good mood?
- If you had time for one activity that was just for you, what would it be?
- How do you feel when you think about doing activities that you enjoy (without your loved one)?
- Do you experience guilt or shame when you think about putting your needs first?

The concept of 'self-care' can be particularly challenging for caregivers who have minimal time and personal resources or may be experiencing increased social isolation as a direct result of their caregiving responsibilities. Acknowledging this inherent tension when exploring self-care (and social connection) with caregivers is both respectful and supportive. (*Nakita Valero, a Toronto-based researcher and community organizer, identified this tension, and the importance of building community, in her 2019 viral Facebook; "Shouting 'self-care' at people who actually need 'community care' is how we fail people."*)

FFCS programs can have a powerful impact on these challenges by facilitating self-care activities and social connections through a community lens. Opportunity for self-care is no longer just a private endeavour, it is a priority we can support through a commitment to social connection, accessibility, and community building.

Below are some examples of social and self-care activities that FFCS programs have organized, creating a variety of opportunities for caregivers. Programs can be used to help connect caregivers to events offered by their own organizations, or events hosted by other community agencies. Some examples include:

- Walking groups (with and without the care recipient)
- Nature groups and community gardening
- Mindfulness or meditation for beginners
- Caregiver book club and chess club
- Farmer's market and library meet-ups
- Social coffee events (with and without the care recipient)

- Luncheons
- Holiday-specific social events
- Creative activities such as crafts, vision boarding, painting, art therapy
- Singing groups
- Movie matinee/evening
- Attending community events together
- Cooking classes
- Field trips
- Picnics or garden parties
- Multi-week programs focused on self-care

A note from the FFCS frontlines...

"We offer several social and self-care activities. We hold two lunches a week, weekly craft activities, weekly music and singing, and this year, we started a community garden. The range of activities enables our program to meet the interests of our caregivers."

FFCS Pro Tip

Social and self-care activities do not need to be elaborate or costly. Simply by creating space and opportunity for caregivers to gather informally, we support connection, self-care, and strengthening our communities.

CIRCLE OF CARE (A FAMILY CAREGIVERS OF BC MODEL)

What is a Circle of Care?

Developed by Family Caregivers of British Columbia (FCBC), the Circle of Care program refers to a psychosocial intervention that helps caregivers to develop and grow their own community support networks through an active facilitation process led by a trained staff (CSC) or volunteer. FCBC offers quality training that includes support materials and a comprehensive training manual to build CSC confidence when facilitating a Circle of Care for a caregiver.

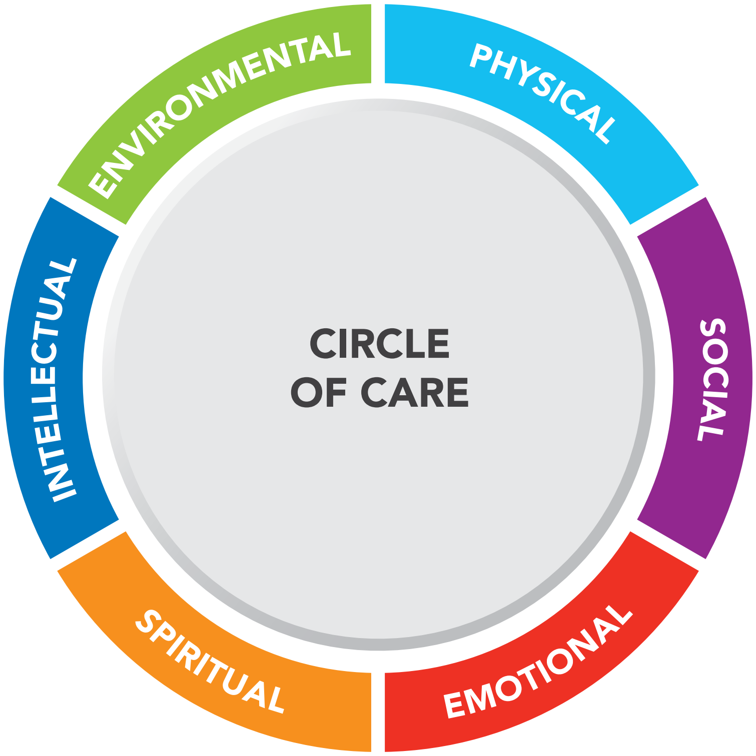
Circle of Care is an optional element of the Family and Friend Caregiver Support program. It is most often developed within the program element of one-to-one support.

"Circles of Care are based on understanding the importance of relationships in our life, and the need for strong support networks. This is especially important for someone vulnerable because of health and social concerns…Each Circle of Care or supportive network is unique, so there are as many different circle arrangements as there are circles."

FCBC Circle of Care, 2022.

The FCBC Circle of Care model uses a multi-dimensional approach to caregiver wellness. It includes assessment of the six dimensions of health:

- Physical
- Social
- Environmental
- Emotional
- Spiritual
- Intellectual



CREATING A CIRCLE OF CARE FOR CAREGIVERS:
MOBILIZING INFORMAL RESPITE

A Circle of Care helps a caregiver identify people that could be in their Circle of Care (including family, friends, neighbours, community members, etc.), and then guide the Circle of Care group to meet on a regular basis to help the caregiver maintain their wellness. The Circle of Care group in essence strengthens and develops the caregiver's informal network of support. A circle can involve two or more people who collaborate to share information and provide whatever type of support the caregiver has identified as a need. They could make follow-up phone calls, help with paperwork and bill payments, grocery shop on a specific day, walk the dog, or do laundry and cleaning. When you are a part of a Circle of Care, you enter into an intimate and vulnerable space where you learn about the private aspects of a person and their care recipient's life. In this space, vulnerabilities are exposed, fears and dreams shared, and common visions developed. The circle comprises community members and at the centre is the family caregiver. The family caregiver guides decisions about who to invite to be part of the circle and the direction in which the circle's energy is employed.

A Circle of Care is facilitated to help caregivers maintain their wellness in whatever aspects they choose while developing and strengthening their support network. This is especially helpful for caregivers who are experiencing some isolation. It may also be beneficial for caregivers who have offers of support, but need help to identify their needs and catalyze connections.

- From the FCBC website

A Circle of Care can create numerous opportunities and benefits, including:

- Providing caregivers with peace of mind and community connection, making the caregiving journey more sustainable, and increasing the quality of life for caregivers and their care recipients.
- Help to develop an action plan for how positive change will be achieved.
- Stretch resources beyond the service hours of professionals.
- Provide a way to deal with crises.
- Reduce demands on the healthcare system.
- A forum for commitment and security – people who know and care will be there over time to ensure the individual is supported and safe.

- Long-term impact on caregivers, seniors, and circle members involved.
- Help extended family members and friends understand what is involved in supporting the person and, therefore, better help with succession planning.
- Address the isolation experienced by caregivers and go a long way toward meeting their needs across different dimensions of health.
- Make the difference between living on the edge of the community and being actively included in it.

Adapted from the FCBC Circles of Care Training Manual, 2022.

AN EXAMPLE OF **A CIRCLE OF CARE FACILITATION**

Emily, a CSC, had been meeting with Joe consistently for about six months. Joe was the primary caregiver for his spouse Marty, who had a medically challenging and progressive disease. Emily met with Joe in person or by phone every 3-4 weeks. During that time, Emily provided ongoing emotional support, healthcare system navigation, and connection to community services. Over time, Joe shared a lot about his caregiving situation and Emily noted that Joe was becoming more and more overwhelmed. When Emily asked Joe about any informal support and connection that he has in his community, Joe shared that he had received a few early offers of support from neighbours and family. However, he was struggling to determine what he needed and how to ask now that so much time had passed.

Emily offered to help Joe identify their needs by facilitating a Circle of Care. At first, Joe was a little overwhelmed by the idea. Emily assured Joe that even if they completed the first step together (evaluating his needs along the six determinants of health), it might help. Joe and Emily spent two meetings exploring the six dimensions of health together. In time, Joe began to feel comfortable in the process with Emily because she went at his speed. Joe began to enjoy the process and identified how he attended to his physical, emotional, intellectual, and spiritual needs. He reaffirmed his commitment to his walking routine (physical dimension of health) and book-reading habits (intellectual dimension of health). With Emily's support, Joe recognized that he was experiencing significant social and environmental gaps. Joe agreed that if he could find a way to address those gaps, not only would his feelings of overwhelm likely diminish, but Marty could also benefit.

Joe worked with Emily to determine what friends, family, and/or neighbours might respond well to a Circle of Care invitation. Because many of Joe's connections were also aging and/

or caregiving, Emily suggested they also connect with the local volunteer centre, to see if any volunteers in the community might want to be involved. Emily found a local volunteer willing to help; she had been doing friendly visits with seniors but welcomed an opportunity to go deeper.

Emily facilitated a fun, upbeat Circle of Care meeting. In the meeting, she acknowledged and honoured the tremendous caregiving work Joe had been doing and shared more about the gaps and challenges Joe was facing. It was decided with Joe that the Circle of Care would come together one Sunday to help move Marty's room from the top floor to the ground-level floor so that he could have more accessibility, social connection, and safety. This move would also mean that Joe could skip climbing the stairs as often. The group also decided to rotate/take turns having a simple soup and sandwich lunch with Joe and Marty at the house so they could experience more social connection and community support. This Circle of Care continued to meet for four months until Marty passed away. At the closing meeting, Joe reflected that so much had changed in their life for the better because of the 'Circle'. He expressed how it gave him the energy to continue his life in a good way after his spouse's death.

We can actively integrate the Circle of Care program's philosophy by understanding the work's value and finding ways to integrate it into services.

A note from the FFCS frontlines...

"Regardless of our capacity to actively facilitate a Circle of Care for our caregivers, we strive to hold these values and philosophy in our one-to-one support. Bringing a 'Circle of Care' mindset to support sessions creates space for dialogue to help caregivers discover, explore, activate, and catalyze their own community support opportunities; in meaningful ways that can grow organically over time. People want to feel helpful and connected in their communities. Everybody wins."

For more information about the FCBC Circle of Care Facilitators training program, please contact the Family Caregivers of British Columbia:

WEBSITE:	www.familycaregiversbc.ca/
EMAIL:	info@familycaregiversbc.ca
PHONE:	Toll-free Caregiver Support Line: 1-877-520-3267 (8:30am – 4:00pm, Monday to Friday)

PROGRAM REFERRALS

Creating a Robust Pathway for New Referrals

Family and Friend Caregiver Support (FFCS) programs strive to provide clear, simple, efficient pathways for initiating, receiving, and processing referrals. Simple and accessible referral processes can attract referrals, while complicated or unresponsive processes discourage them.

Programs receive new referrals through a dedicated email address, by phone, or through an online form that can be submitted through the agency's website. Caregiver Support Coordinators (CSCs) can utilize and adapt the FFCS Common Referral Form (see Addendum II) to best fit their programming.

Some programs choose to utilize a more detailed referral form, which includes more information on the caregiver and the caregiving situation. Other programs offer a simplified referral process (name and contact information) which can increase accessibility and ease for the person making the referral. In this case, once the caregiver accepts services and develops trust in the services, they may share more details to help the CSC provide tailored and customized support.

FFCS Pro Tip

Creating a dedicated referral email address (referrals@) ensures that new referrals are processed consistently through one email address. This helps to ensure that information is held centrally, reporting is simplified, and the referral pathway remains consistent during any staff changes.

Referral Sources

There are many possible sources for referrals. However, key referral sources are usually developed strategically over time through relationship building between the FFCS program and the local Health Authority, or through making connections to community services.

Referral sources can include:

- Your Regional Health Authority (HA):
  - Home and Community Care (including case managers, Adult Day Program staff, and home support staff)
  - Community Access Intake Lines
  - Social Workers
  - Specialized Senior Teams and Clinics. Each Health Authority (HA) has a specialized seniors team or clinic. The names of these teams differ in each HA. They may be called Geriatric Specialty Services, Specialized Seniors Clinics, Geriatric Assessment Programs, Seniors Outpatient Clinics, or Older Adult Mental Health Teams. See the FAQ below for more detailed information about why specialized senior teams and clinics are considered a critical pathway for new referrals.
  - Discharge Planners (acute care settings)
  - Primary Care Providers (including general practitioners and nurse practitioners)
  - Mental Health Service Providers

  - Primary Care Networks
  - Division of Family Practice
- Aboriginal Health Authority, Nation, or Band
- Family Caregivers of British Columbia (FCBC)
- Community service agencies (see Connection to Community Services for information on how to grow and strengthen those relationships)
- Self-referrals from caregivers who have learned about an FFCS program through newsletters, or advertisements in the community, or online
- Internal referral: for FFCS programs embedded in a larger agency
- Family members, friends, or other caregivers
- Private sector: pharmacists, estate planning lawyers, private practice social workers and counsellors, etc.

A note from the FFCS frontlines:

"Referrals that are made by health professionals on behalf of a consenting caregiver are very effective because they connect caregivers who are too overwhelmed or too busy to make a call. By acknowledging the value of this extra step and the referrer's efforts, we create an ongoing warm invitation for health professionals to make referrals on behalf of caregivers."

Program 'Champions'

Over time, you may find that some referrers become 'champions' for your program. Champions understand the program's value and advocate for it by regularly referring caregivers. They often emerge from the Health Authority because they hear directly back from patients about how valuable the program is and begin to see the positive results for caregivers. They become motivated to refer other caregivers for support services as well.

Messages from HA Champions:

> **"I spoke with two caregivers that I met with this week who raved about you and the healing and validation you were able to provide. Awesome!"**
>
> ~ *Champion Referrer (Geriatric Specialty Services)*

> **"I was with Ms. Nelson and she told me how helpful and wonderful you are. I just want to thank you. Your program makes a real difference from where I'm standing."**
>
> ~ *Champion Referrer (Case Manager)*

Frequently Asked Questions about Building Relationships with the Local Health Authority:

Where should I focus my relationship-building efforts within my local Health Authority?

Though almost all areas of a Health Authority would benefit from awareness about the FFCS programs, there are two critical areas for programs to develop and strengthen connections, and to develop robust referral pathways:

1. Specialized seniors teams and clinics (also known as Geriatric Specialty Services, Specialized Seniors Clinics, Geriatric Assessment Programs, Seniors Outpatient Clinics, or Older Adult Mental Health Teams).

2. Home and Community Care (also referred to as Community Health Services in some health regions).

These two areas in each Health Authority serve the most caregivers and have the highest engagement levels with the most caregivers. They conduct clinical assessments and watch for caregiver stress and burnout.

Specialized Seniors Teams or Clinics

In each Health Authority in BC, there is a specialized seniors team or clinic. The names of these teams differ between regions. They may be referred to as the Geriatric Specialty Services, Specialized Seniors Clinic, Geriatric Assessment Program, Seniors Outpatient Clinic, Older Adult Mental Health Team, etc. These teams are comprised of gerontologists, nurses, social workers, and psychiatrists, who specialize in complex health challenges with seniors. Caregivers supporting complex and challenging situations are often referred to these specialty teams by a family doctor or nurse practitioner.

<u>It is important to note these specialty teams and services do not interact directly with the public. When connecting with them for the first time it may require some research and phone inquiries to your HA.</u>

How do we begin to build a good relationship with our Health Authority?

We can initiate and build fruitful relationships with Home and Community Care and the Specialized Seniors Teams through a series of strategies:

- Ensure your referral process is clear, simple, efficient, and tested.
- Ensure your referral descriptions highlight why making a referral on behalf of a caregiver is more effective than suggesting the caregiver reach out themselves.
- Provide clear advertising and promotion of the program, which also highlights the simple steps to make a referral.
- Contact the team leads for both Home and Community Care and the regional Specialized Seniors Team/Clinics to share information about the program, emphasizing the program's benefits for caregivers.
- Regularly drop off program promotional materials for distribution at the Home and Community Care office and the Specialized Seniors' Team office.
- Ask if you can present the FFCS program at a staff meeting.

- Offer warm acknowledgement in response to referrals: *"Thank you for referring Jose to the Family and Friend Caregiver Support Program. We appreciate your support of family caregivers."*
- Advertise your program in *Pathways* and *Fetch*. In BC, these online databases are a health practitioner's 'go-to' resource for information about community services.

FFCS Pro Tip

Stories are powerful and caregivers often want to share their journey and experiences. Find ways to share these stories with health care professionals to demonstrate the valuable and practical ways that caregivers have benefited from your support services.

How do I strengthen our connection with the Health Authority when our efforts have not resulted in consistent referrals?

- If you produce a caregiver resource guide, newsletter, or any other materials, offer to email them to the team leads whenever they are updated. This is a great opportunity for ongoing points of connection.
- Position your services as helpful to the Health Authority, supporting both the caregiver's capacity and positive engagement with the healthcare system.
- Show responsiveness and welcome feedback from healthcare professionals about the FFCS program and what support they see as most valuable for caregivers.
- Reach out specifically to the team lead and ask if they have any feedback to increase connection and boost consistent referrals.

Referral Success Stories

The following example illustrates how one FFCS program found a way to connect more robustly with their Health Authority's Home and Community Care team:

Responsiveness is a Key Relationship-Builder

Though we often dropped off our pamphlets and newsletters, we noticed that we were not getting any referrals from Home and Community Care. Our CSC asked the Home and Community Care manager if we could present our program at one of their upcoming staff meetings. We were told that time was very limited but that we could have 10 minutes to introduce the services and include a short Q&A.

The meeting included several case managers, a behaviourist, the team lead, two front-line home support workers, and an administrator. After giving a brief introduction to the program, we decided to ask those attending what issues they were seeing on the front lines with caregivers. We were interested in their perspective on caregiving and how our services could be more responsive to the issues they frequently saw.

This is when our relationship began to shift. The staff expressed frustration about various issues in their dealings with caregivers. We kept an open and curious mindset and learned that they experienced too many caregivers who were unprepared when facing their own medical emergencies. Home and Community Care felt that there was too much expectation on their services to respond when their capacity was already challenged.

Acknowledging this issue at the meeting, we committed to working with caregivers on their emergency plans during their one-to-one meetings. As this work began to take shape in one-to-one support sessions, not only did this help relieve some caregiver stress and anxiety about not having an emergency plan in place, it also enhanced our relationship between Home and Community Care. They saw us as responsive allies, and we soon started to get more referrals from the case managers.

Champions within the Health Authority

The following letter exemplifies how key staff within the HA can take a leadership role in advancing support for FFCS programs. This message was sent by a nurse from the Geriatric Specialty Services to her colleagues, as well as to the Home and Community Care staff; to introduce FFCS services and boost internal support for referrals.

A Caregiver Support Coordinator meets with loved ones who are in a caregiving role, whether they are living with their loved one or not. She understands the emotions that take a toll when one is worried about a loved one and is able to provide the support needed to help caregivers take care of themselves through the process of caregiving. The more support offered to a caregiver the better, otherwise caregivers are at even higher risk of developing medical and mental health issues of their own.

As a caregiver for my aunt for several years, I cried every day and felt alone. My aunt refused every service and began accusing me of all kinds of things, as is often the case. This kind of service would have been great to have been linked up to, and it wasn't available at the time. It took a significant toll on me and I will always remember the impact, which is why I try very hard to link caregivers up to this service.

A Caregiver Support Coordinator meets with people both individually in person and on the phone, and in groups. The one thing we as staff can do to ensure caregivers get support is by letting people know of this free and confidential service.

Referring works best when a staff person gets permission from the caregiver and emails the program directly. This takes the burden off of the overwhelmed caregiver's to do list. Caregivers have overwhelmingly reported how helpful it is to receive a call, knowing the referral has already taken place.

I have brought several pamphlets, cards, and a newsletter to your desk that I hope staff can familiarize themselves with.

Shelley Iberg, B.C.R., M.A.,R.C.C.
Geriatric Specialty Services, Island Health

ADDENDUM I: SUPPORT GROUP MEETING GUIDELINES TEMPLATE

Welcome to the ______Insert Program Name______Support Group

We strive to offer a friendly, confidential, inclusive, and non-judgmental atmosphere, to meet other caregivers with similar experiences.

We ask that you agree to the following group guidelines:

- Confidentiality is based on mutual trust and respect. This is a shared responsibility. Please do not disclose to anyone outside the group, information that may identify another group member: *'What is shared in this room, stays in this room.'*
- We support you to hold the primary responsibility for your own well-being during the meeting. If at any time you need to leave or take a break, you are welcome to step away from the meeting.
- Everyone's presence is appreciated. Everyone will be given the opportunity to share and no one is required to speak during the meeting.
- We don't give advice unless we are asked. Please do not tell another member of the group what they should or should not be thinking, feeling, or doing.
- Each participant is given time to speak without interruptions. Please do not ask questions or seek more information when another caregiver is speaking in the meeting. What each person chooses to share is appreciated and sufficient.
- Please remember that your experience may not be the same as others. Expressing excessively negative or critical opinions about specific healthcare facilities or healthcare services and workers can be hurtful to other caregivers.
- Understand that any knowledge shared by caregivers in meetings is based on personal experience and should be confirmed as needed with your case manager, doctor, or other professional.

A few practical matters:

- We may have a waitlist for our support groups. If you know someone who may benefit from caregiver support, please refer them to the facilitator. Our support groups are not open drop-ins.

- Our facilitators are not medical professionals. If you are looking for therapy or another treatment option, we can help refer you to those services.
- If the person you are caring for dies, the loss of the caregiving role is an important part of the grieving process. We can help you find bereavement support through hospice and you are welcome to continue attending our support group meetings for three months.
- Meetings may need to be cancelled from time to time due to illness and/or facilitator availability. We endeavour to give you as much notice as possible if the schedule is changing.
- Facilitators use first names and don't provide personal contact information to other support group members without permission.
- Each participant attends at their own risk, understanding that viruses can be transmitted during indoor group meetings.

A few good questions to ask yourself when attending any support group meeting:

- Can I support and uphold the guidelines?
- Am I learning helpful ways to support my loved one and cope with my concerns?
- Do I enjoy the group? Do I see a benefit from being part of the group?
- Do I feel better after attending meetings?
- Do I have any concerns about confidentiality? Do I feel like my privacy is being respected?
- Do I feel safe and comfortable sharing my experiences and thoughts with the group?

ADDENDUM II: COMMON REFERRAL FORM TEMPLATE

The intention of this common referral form is to ensure that all FFCS programs are collecting standardized information from people or agencies referring to them. The form includes the minimum amount of information that should be collected for all referrals. Programs can ask additional questions if desired. The design of this form is intended to be low-barrier for caregivers, and simple for professional agencies and clinics to complete.

***

Family & Friend Caregiver Support Program: Referral Form

Thank you for supporting family caregivers. Please ensure that the person you are referring has consented to receive this referral.

Date of referral: ______/_________/__________ (dd/mm/yyyy)

Referral From:

- ☐ Home and Community Care (e.g., Case Manager, Social Worker, Home Support Worker, etc.)
- ☐ Mental Health Services (Health Authority Based)
- ☐ Primary Health Practitioner (e.g., Family Physician, Nurse Practitioner, etc.)
- ☐ Community-Based Agency
- ☐ Family Member and/or Caregiver
- ☐ Self-Referral
- ☐ Other, please specify: ________________

Referring Person/Agency Information

*First Name: _________________________ *Last Name: __________________________

Email: ____

*Phone number: ____

Caregiver Information (if different than above)

*First Name: ___________________________ *Last Name: ____________________________

Email: ____

*Phone number: ____

Caregiver geographical area (if applicable): ____

Additional Information

Additional referral details: ____

ADDENDUM III: A SAMPLE MODEL FOR SERVICE DELIVERY LEVELS

The Cowichan Family Caregivers Support Society (CFCSS) has been providing free caregiver support services since 2000 and now includes a team of front-line service staff. This Service Delivery Model may not apply to every program, however, it illustrates how a staff can prioritize consistent connection and build trust with caregivers over extended periods. The Cowichan Family Caregivers Support Society (CFCSS) developed the following Service Delivery Level Model in 2022.

Cowichan Family Caregivers Support Society Service Delivery Model

Level 1

The caregiver is accessing 1-2 program elements, experiencing consistent points of contact, and averaging one substantive connection every 6-8 weeks.

Level 2a (common)

The caregiver is accessing 2 program elements, experiencing consistent points of contact, and averaging one substantive connection every 4-5 weeks.

Level 2b (common)

The caregiver is accessing 2-3 program elements, experiencing consistent points of contact, attending support group meetings twice a month, and averaging one substantive connection every 4-6 weeks.

Level 3

The caregiver is accessing 3-5 program elements, experiencing consistent points of contact, and averaging 2+ substantive connections every 4 weeks.

Level 3b

The caregiver is accessing 3-5 program elements, experiencing consistent points of contact, attending support group meetings twice a month, and averaging 2+ substantive connections every 4 weeks.

Three Examples of the Services Delivery Levels in Action

Level 1

Caregiving Scenario: The caregiver is in her mid-30s and works part-time in the healthcare sector. She had been caring for her mom, in her home, for 1.5 years and was experiencing caregiver stress and burnout by the time we received the referral. A home care nurse referred the caregiver. The mother died six months into service delivery, and the client completed services soon afterward.

Service Delivery Summary: The caregiver received six months of support services that included: **9 points of contact by email, 5 phone support meetings.**

- Service streams included: one-to-one support and information/referral.
- Email points of contact included a caregiver newsletter and resource materials.

A caregiver's message...

> **"I really appreciated knowing that I had a 'lifeline' with your emails, and the chats we had through the time I spent looking after my mom. It gave me a sense of support in the background if I ever needed it. And the few times we spoke on the phone were so helpful for me to know that I'm doing okay with the care I'm giving and the care I needed to care for myself. Thank you for this. If I need some further support, I can now reach out to hospice. Thanks for all you do to help caregivers!"**

Level 2(b)

Caregiving Scenario: The caregiver is in his late 70's and is retired. He was the primary caregiver to his spouse. His spouse has now been placed in long-term care, and he is still supporting her. The Geriatric Specialty Services team at Island Health referred the caregiver.

Service Delivery Summary: The caregiver received six months of support services that included: **52 points of contact by email, 15 support group meetings, 11 in-person meetings, 7 phone support meetings**.

- Service streams included: one-to-one support, healthcare system navigation and support group meetings.
- Email points of contact included caregiver newsletters and resource materials.

A caregiver's message…

> **"I am so pleased; I felt the first time we met I knew that I was going to get a lot out of this process! I look forward to going to the support group meetings. Hard stuff comes up, but I know it will dissipate. It is really nice connecting with others in the group and being able to receive one-to-one support when I need it."**

Level 3

Caregiving Scenario: The caregiver is in her mid-60s and is self-employed. She was the primary caregiver to her spouse and began accessing services in the earlier stages of her spouse's cancer diagnosis. The caregiver was referred by a community member who was aware of our services. The file was closed after her spouse died.

Service Delivery Summary: The caregiver received two years and eight months of support services that included: **110 points of contact by email, 14 phone support meetings, 14 in-person meetings.**

- Service streams included one-to-one support, information/referral, healthcare system navigation, advocacy, Circles of Support program.
- Email points of contact included caregiver newsletters and resource materials.

A caregiver's message…

> "Your steadfastness and presence (even digitally) since almost the beginning (of my caregiving journey) has meant more than you will ever know. People ask me about donating to cancer agencies or cancer research. I say the Cowichan Family Caregivers Society has done more for me/ us emotionally than anything over the last three years."

Service Delivery Model Definitions

- **Program elements**: refer to the different services caregivers can access during their involvement.
- **Substantive connection**: refers to emotional support and/or systems navigation that requires staff time that is personalized and focused. Usually in a one-to-one support session format: delivered in-person, by phone, email, or virtually.
- **Email and phone 'points of contact':** can include logistical and administration emails ('check-in' messages, setting up appointments, support group reminders, 1-1 meeting reminders, resources, information, etc.), and substantive connections.

ADDENDUM IV: ONE-TO-ONE SUPPORT AT DIFFERENT PHASES OF THE CAREGIVING JOURNEY

Many factors influence a person's experience of their caregiving role. This can include the entry point into their caregiving role, the duration of the caregiving role, the intensity of the caregiving responsibilities, the trajectory of care recipient needs (acute, long-term, unknown, linear, fluctuating), the relationship between caregiver and care recipient, and the physical proximity with the care recipient.

Over time, caregivers can experience changes in their own perception and orientation to their caregiver role. The five key phases in the caregiving journey include caregiver emergence, entrenchment, reorientation, loss of the caregiver role, and caregiver transition to care recipient. A caregiver may experience one or multiple phases, and key support themes often arise during each phase. One-to-one support is beneficial for caregivers in all phases of the caregiving journey.

Caregiver Emergence

This is a time when a person is becoming more aware of their role as a caregiver and working to integrate their new or emerging caregiving responsibilities. This new role is developing alongside their already established family role (i.e. spouse, adult child, sibling, cousin, friend).

During the emergent phase of caregiving, there can be different responses to the term 'caregiver.' Many people accept the term 'caregiver' because it affirms their experience and gives them helpful language to convey and express their reality. In this case, using the word 'caregiver' is empowering and beneficial.

However, the term caregiver can also create pressure and expectations, and some people may be uncomfortable being referred to as a caregiver. For some, their role in the family already includes the commitment to caregiving. As a result, they are reluctant to differentiate between their long-standing role and the caregiving role (for example, "I'm not a caregiver, I'm her husband, and this is what husbands do").

When a person expresses resistance to the term 'caregiver,' we support them where they are at. We only refer to the person as a caregiver once they use it themselves. We can explore the tension about the term 'caregiver' as a process of self-discovery. Over time, most people will adopt the term 'caregiver' themselves, especially as their role becomes more entrenched and their primary role (spouse, adult child, etc.) is eclipsed by the caregiving role.

Common themes during caregiver emergence:

- Varied emotional responses to the new role (fear, reluctance, acceptance, embrace, affirmation, etc.)
- Resistance to the use of the term 'caregiver'
- Integrating the emerging role with existing work and home obligations
- Emerging roles activate painful memories or challenging life experiences (prior loss/grief, past trauma, previous caregiving responsibilities, previous involvement with healthcare systems, etc.)
- Starting to work with extended family about healthcare plans, including navigating the healthcare system
- Advanced care planning and personal planning discussions
- Concern or worry about the future, including caregiver entrenchment
- The decision to commit to, or exit the caregiving role

Typical program support during caregiver emergence: *low to moderate*

- One-to-one emotional support
- Healthcare system navigation
- Connection to community services
- Knowledge and skill enhancement
- Support group, if assessed to be helpful

Caregiver Entrenchment

This is a time when the caregiver is in a pattern of consistent and sustained effort and responsibility while providing support in the home. Others cannot easily replace their critical role.

In the home can include various settings:

- The care recipient lives in their own home and receives support.
- The care recipient resides in the family home with the caregiver.

- The care recipient lives in seniors’ independent living with support.
- The care recipient resides in assisted living.

It is important to note that while caregiver entrenchment generally refers to a time when the care recipient is living at home, an important exception exists. Some entrenched caregivers provide daily and essential caregiving for a loved one in a long-term or hospital/critical care setting.

Common themes during caregiver entrenchment:

- Regular and significant caregiving responsibilities with a focus on stabilization, health, and safety, often requiring caregiver vigilance
- Acute care interactions: episodic and/or alarming medical events
- Acceptance and/or expansion of home and community care services including: home support, Adult Day Programs (ADP’s), residential respite, social work, and specialty teams
- Frustrations with limits to support provided by the healthcare system and/or other family members
- Social and physical isolation of caregiver
- Planning/anticipating upcoming transitions
- Advanced Care Planning (ACP) and personal planning
- Need for boundary awareness and self-care
- Caregiver exhaustion, burnout, guilt, compassion fatigue
- Personal growth themes
- Anticipatory grief
- Suicidal ideation (thoughts or ideas about suicide)
- Worry about what will happen if the caregiver were to get sick or die
- Desire to leave/flee the caregiving role
- Enmeshment in the caregiving role (when the caregiver and care recipient’s emotional states and personal boundaries are blurred)
- Increased complexity in medical caregiving tasks

- Physical injuries due to caregiving
- Mistreatment and/or neglect of the care recipient
- Mistreatment and/or neglect of the caregiver
- Strengthening social supports
- Changes in intimacy/sexual health (in relationships where there is sexual intimacy)
- Caregiver's experiences of psychological distress and or physical distress
- Decision to recommit or exit the caregiving role

Typical program support during caregiver entrenchment: *moderate to high*

- One-to-one emotional support
- Support groups
- Circles of support
- Healthcare system navigation
- Connection to community services
- Knowledge and skill enhancement

Caregivers who are 'entrenched' in their role, will often receive the most significant benefits and outcomes from one-to-one support. The entrenched caregiver is deeply involved in many aspects of care and is more likely to question whether they can sustain their efforts. One-to-one support expands and enhances a caregiver's circle of support and can provide the resources a caregiver needs to do the work more sustainably.

Caregiving Reorientation from Entrenchment

This is a time when there is a significant change to the caregiver's entrenched role.

Examples of this can include:

- The care recipient goes into permanent residential care
- The caregiver's health condition changes, requiring that they do less

Common themes during caregiver reorientation from entrenchment:

- Practical restructuring of the caregiving role
- Deliberating and navigating new support levels
- Caregiver relief
- Caregiver guilt
- Anticipatory grief (feelings of grief from knowing your loved one will die)
- Reclaiming self-care
- Overcoming caregiver social and physical isolation
- Implementing advanced care planning
- New relationships for the caregiver
- Continuation of daily care for basic needs (less common)
- Transforming the caregiving role substantially and/or leaving the caregiving role

Typical program support during caregiver reorientation from entrenchment:
low to moderate

- One-to-one emotional support
- Support groups
- Healthcare system navigation
- Referrals to community services

After reorientation, the level of support needed by a caregiver is substantially reduced and service levels are reassessed and lowered appropriately.

Loss of the Caregiver Role

This is when a person is no longer in a caregiving role due to the care recipient's death.

Common themes during the loss of caregiver role:

- Bereavement
- Loss and grief

- Regret
- Relief and expansion
- Grief over the loss of the caregiving role
- Reclaiming self-care
- Overcoming caregiver social and physical isolation
- Reclaiming/finding a new identity
- Estate administration
- Reflecting and finding meaning

Typical program support during loss of the caregiver role: *support services phased out to completion*

- Phased out of one-to-one support
- Phased out of support group
- Connection to community services

A supported transition from the caregiver support services is offered. The caregiver transitions to other programs/supports as required.

Caregiver Transition to Care Recipient

This is a time when the caregiver experiences a significant decline due to aging, chronic illness, and/or a debilitating disability and needs caregiving support themselves. Depending on the situation, a rapid or gradual transition is required as they transition from caregiver to care recipient.

Common themes for caregiver transition to care recipient:

- Support for the caregiver's development of a gradual or immediate transition plan for the caregiving role
- Grief over the loss of the caregiving role
- Reclaiming self-care
- Caregiver's disclosure of health concerns to family and their Health Authority

Typical program support during caregiver transition to care recipient: *support services phased out to completion*

- Phased out of one-to-one support
- Phased out of support groups
- Referrals to community or agency resources

A supported transition from the caregiver support services is offered. The caregiver transitions to other programs/supports as required.

ADDENDUM V: RECOMMENDED TRAINING

Caregiver Support Group Facilitator Training

Family Caregivers of BC offers group facilitator training, check their website for next scheduled session.

Asist: Applied Suicide Intervention Skills

The Centre for Suicide Prevention's two-day interactive workshop will train you to intervene with an individual who is thinking about suicide

Crisis, Compassion, and Boundary Setting

Vancouver Island Crisis Society's has a three hour research-driven, trauma-informed workshop on areas such as The Crisis Oriented Client, Self-Reflection, Mindful Practice, Self Care, and much more.

San'yas Indigenous Cultural Safety Training

San'yas offers an anti-racism, Indigenous cultural safety training program, please see their website for training options and information.

Centre for Collaboration, Motivation, and Innovation (CCMI)

CCMI offers training in areas such as: Strategies for Well-being, Communicating with Compassion and Clarity, Trauma-Informed Care, Motivational Interviewing, and Brief Action Planning.

Homelessness Services Association of BC (HSABC)

HSABC offers a wide range of training in-person, online, and recorded library. To access their training offerings, non-profit agencies must join HSABC's annual membership program ($285 per year, April 1-March 31). Once a non-profit joins, all the staff can get access.

Visit https://hsa-bc.ca/cgi/page.cgi/join.html to see if your agency is already a member of HSABC. If it is, then you can create a user account under your agency's account.

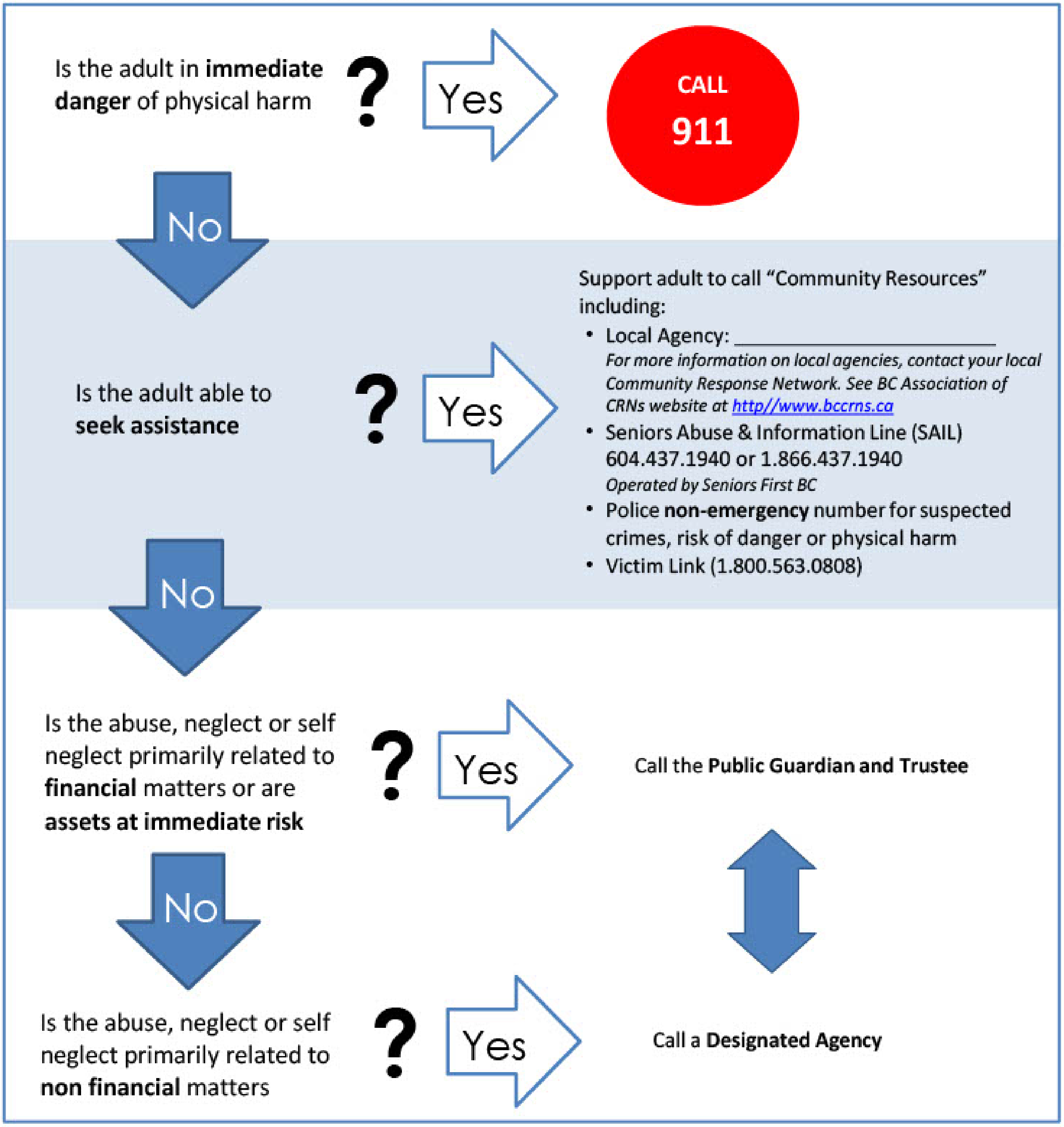
If you cannot find your agency in the link above, then visit https://hsa-bc.ca/membership-overview.html to register your agency and pay membership fee.

ADDENDUM VI: DECISION TREE

How to assist an adult who is abused, neglected or self neglecting

A Decision Tree for effective referrals of adults in B.C.
who may be vulnerable and/or incapable

For introductory videos on how to use this Decision Tree and the roles of the police, designated agencies and the Public Guardian and Trustee (PGT), visit https://www.youtube.com/@pgtbc.



Is the adult in **immediate danger** of physical harm ? Yes → CALL 911

No ↓

Is the adult able to **seek assistance** ? Yes →

Support adult to call "Community Resources" including:

- Local Agency: ____________________
  For more information on local agencies, contact your local Community Response Network. See BC Association of CRNs website at http//www.bccrns.ca
- Seniors Abuse & Information Line (SAIL) 604.437.1940 or 1.866.437.1940
  Operated by Seniors First BC
- Police **non-emergency** number for suspected crimes, risk of danger or physical harm
- Victim Link (1.800.563.0808)

No ↓

Is the abuse, neglect or self neglect primarily related to **financial** matters or are **assets at immediate risk** ? Yes → Call the **Public Guardian and Trustee**

No ↓

Is the abuse, neglect or self neglect primarily related to **non financial** matters ? Yes → Call a **Designated Agency**

Page 1 of 2

Police	Designated Agency: Regional Health Authorities and Community Living BC (CLBC)	Public Guardian and Trustee (PGT)
For a video on role of the Police, visit https://youtu.be/86uokvZVF6w	For a video on the role of Designated Agencies, visit https://youtu.be/fJL8Sz8Lqlk	For a video on role of the PGT, visit https://youtu.be/PZtCunZqEvM
Governing Legislation:	**Governing Legislation:**	**Governing Legislation:**
Criminal Code RSC 1985 c. C-46	Adult Guardianship Act RSBC 1996 c. 6	Public Guardian and Trustee Act RSBC 1996 c.383
Why would you call?	**Why would you call?**	**Why would you call?**
You suspect a crime has occurred, might occur or someone is exhibiting behavior indicating a lack of wellbeing and unpredictability.	You are concerned that an adult is being abused, neglected or is self neglecting and is unable to seek support and assistance on their own due to: • physical restraint, • a physical handicap limiting ability to seek help, or • an illness, disease, injury or other condition affecting ability to make decisions about the abuse or neglect The adult may live in their own home, the home of a relative, a care facility, or any other place except correctional centres.	You have reason to believe that an adult is not capable of managing their financial and legal affairs and there is imminent risk to their assets. Concerns may include: • the adult appears to be under duress and going along with decisions they do not agree with • there may be financial mismanagement of an adult's financial affairs • the adult may not be able to look after their financial affairs and needs someone to make financial decisions • someone with authority to manage the adult's financial affairs may not be fulfilling their duties and responsibilities
Where should you call?	**Where should you call?**	**Where should you call?**
• Emergency - Call 911 if you suspect o Immediate risk to a person's physical safety, or o A crime is occurring • Local Police non-emergency Tel: ____________________	View https://www.trustee.bc.ca/Documents/designated-agency-responders/Designated_Agencies_Contacts.pdf for links to all Designated Agencies, or visit your Health Authority website (search abuse and neglect) • Local Health Authority Tel: ________________ • Local Community Living BC (CLBC) Tel: ________________	Visit https://www.trustee.bc.ca/services/services-to-adults/Pages/assessment-and-investigation-services.aspx for PGT referral form. Contact Information: • Toll free Tel: 1.877.511.4111 • Local Tel: 604.660.4507 • Toll free Fax: 1.855.660.9479 • Local Fax: 604.660.9479 • Email: AIS-PDS@trustee.bc.ca
What can you expect?	**What can you expect?**	**What can you expect?**
You will be asked to provide information about the nature of your concern, the adult you feel is a victim and any possible suspect(s). You can expect that some basic information about yourself will also be requested.	You will be asked to provide information about the adult and the nature of your concern.	You will be asked to provide information about the nature of your concern, personal information about the adult and any decision maker.
Actions may include:	**Actions may include:**	**Actions may include:**
• Attending the location • Dispatching special units where available • Visiting adult, gathering information and evidence which may indicate a criminal offence such as: o assault, sexual assault, o failure to provide necessities of life o theft, theft by power of attorney o fraud, forgery, extortion • Liaising with Designated Agency and/or Public Guardian and Trustee as required • Assessing for adult's wellbeing • Considering peace bonds, no contact orders • Referring to community resources • Considering/recommending charges	• Interviewing adult and others • Requesting information • Offering support and assistance (includes referral to community resources) • Liaising with Public Guardian and Trustee and/or police as required • Reporting suspected crimes to police • Exercising emergency powers to enter and remove adult to a safe place • Obtaining a restraining order • Obtaining a court order for support and assistance	• Gathering additional information • Requesting account information from financial institutions and current decision makers (attorney, representative, trustee, committee) • Liaising with Designated Agency, community services, or police, as appropriate • If urgent risk to assets, exercising protective powers such as: o stopping withdrawals or sale of assets o redirecting income for the adult's health or safety • Looking for an appropriate decision maker. If none, and a decision maker is needed, consider obtaining authority as Committee of Estate, or in exceptional circumstances, Committee of Person.

Developed in partnership by the Public Guardian and Trustee, RCMP BC "E" Division, Crime Prevention Services, and Fraser Health Authority
For inquiries contact the PGT at ais-pds@trustee.bc.ca. Readers are referred to their organization's accompanying training materials and organizational policies for making reports to the police, designated agencies, or the PGT.

ADDENDUM VII: FFCS COMMUNICATIONS AND MARKETING TEMPLATES

Family and Friend Caregiver Support Communications and Marketing Materials Toolkit

Funded by the Government of BC and
managed by United Way British Columbia

United Way
British Columbia

Working with communities in
BC's North, Interior, Lower Mainland,
Central & Northern Vancouver Island

Introduction

Brand overview

This toolkit has been developed to provide a fresh, consistent, and professional appearance for communication materials for agencies offering Family and Friend Caregiver Support across the province.

The intent is to give you a series of building blocks to create your own custom communication pieces. This includes templates within Microsoft Word and Canva. You can use these templates as-is or feel free to develop your own using the guidelines found here in this toolkit.

How to use this toolkit

This toolkit will provide you with the correct fonts, colours, and shapes to use in developing your own custom communications and marketing materials.

We have provided you with a section on best practices for communicating with seniors as well as some guidance on how to use the templates in Word or Canva. Please note that these instructions require an understanding of how to use these apps and will only be giving guidance and not detailed instructions.

We are currently testing these templates and are open to any helpful comments, requests, or support that you need to create these marketing pieces.

Where to find templates and resources

- All templates and photography for Word and Canva and the toolkit can be found on CORE BC.
- The links to the Canva templates are also on page 9 of this toolkit.
- Approved stock photography and program photography can be found here.
- You can download the approved font (Roboto) here

Colours:

There are two main colours in the Family and Friend Caregiver Support brand. A dark turquoiseand blue. Feel free to use white and black as well.

You can use any tint of these colours just keep in mind that high contrast is essential for readability with seniors. We recommend that a light tint of 10% or 20% is best if using black text. If using white text, we recommend using only the 100% dark blue as a background.

dark turquoise:

RGB: 3/82/89
CMYK: 92/52/53/31
Hex: #035259

blue:

RGB: 111/203/211
CMYK: 53/0/18/0
Hex: #6fcbd3

Fonts:

The typeface or font to use is Roboto. You will need to have this font installed on your device and the font can be downloaded for free here:

https://fonts.google.com/specimen/Roboto

Roboto
ABCDEFGHIJKLMNOPQRSTUVWXYZ
abcdefghijklmnopqrstuvwxyz
1234567890

Roboto BLACK
ABCDEFGHIJKLMNOPQRSTUVWXYZ
abcdefghijklmnopqrstuvwxyz
1234567890

You can use whatever size or weight you wish but you should never go below 12pt. in size to optimize for senior's readability.

There is no specific size or weight to use for headings, subheads, or body text. Do what you think is appropriate.

Building Blocks: Shapes and Images:

Boxes

The Family and Friend Caregiver Support brand uses solid boxes to organize content. You are welcome to use these boxes any way you like but be sure to employ high contrast if using text over a colour box.

Use white text for high contrast

Use white text for high contrast

Images

When possible, use photography from your program. If you do use photos from your program, you must have signed consent from every person in the picture in order to use it in any public facing materials. Any stock photography that we have provided does not require a signed form and are free to use.

You can find a standard consent form on CORE BC.

We have supplied a set of approved photos for use. You can access the photos here.

Comments on Design for Seniors:

Here are some helpful tips when creating communication pieces targeted at seniors:

- **Font size must be larger than normal** for ease of readability. We recommend 12-14pt type for general text.
- **Space out the lines of text**. Be sure not to have your lines too tight together. 1.25 - 1.5 line spacing is good.
- **High contrast between text and background colour**. Try to have black text on a white background as often as possible. If using a coloured background, keep it very light for black text or very dark for white text.
- **Simplify the design elements**. Do not clutter or add a lot of elements to try to make the page look pretty or exciting.
- **Keep the message concise and to the point**. Making a clear message helps seniors understand what you are communicating to them.

Templates:

Templates for brochures, flyers, posters, and social media have been created in Microsoft Word and Canva as a starting point for you to create your communication materials. These can be used as-is by just adding your logo or you can modify as little or as much as you like as long as you stick to these brand guidelines.

These templates have been designed to work if printed professionally or within your workplace.

Who is a family caregiver?

A family caregiver is someone who gives care and support to an adult family member or friend.

Family caregivers are the unsung heroes in our community. They look after our most vulnerable community members and provide over 80% of eldercare, often at a significant cost to themselves. With support, they can relieve the health care system. Without help then can become ill or burned out. It makes great sense to support caregivers and their struggles touch our hearts.

Do you know someone who may benefit from direct support for their caregiving efforts?

Ask the caregiver's permission and then send their contact information to our organization at

[insert contact info here]

We will follow up to arrange support.

[logo here]

Contact Us

(123) 456-7890

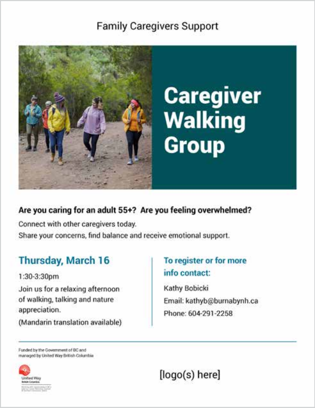
Program Name
Address Line
Address Line
Other Contact Info
Website

Family Caregivers Support

Are you providing care for a family member or friend? We can help.

[logo(s) here]

tri-fold brochure
2-sided & 11" x 8.5"



Family Caregivers Support

Caregiver Walking Group

Are you caring for an adult 55+? Are you feeling overwhelmed?

Connect with other caregivers today.
Share your concerns, find balance and receive emotional support.

Thursday, March 16

1:30-3:30pm

Join us for a relaxing afternoon of walking, talking and nature appreciation.

(Mandarin translation available)

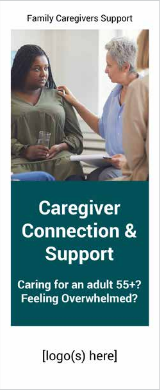
To register or for more info contact:

Kathy Bobicki
Email: kathyb@burnabynh.ca
Phone: 604-291-2258

Funded by the Government of BC and managed by United Way British Columbia

[logo(s) here]

flyer
1-side & 8.5 x 11"



Family Caregivers Support

Caregiver Connection & Support

Caring for an adult 55+? Feeling Overwhelmed?

[logo(s) here]

rack card
2-sided & 3.5 x 8.5"

Family Caregivers Support

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Kathy Bobicki
Email: kathyb@burnabynh.ca
Phone: 604-291-2258

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[logo(s) here]

poster
1-side & 8.5 x 11"

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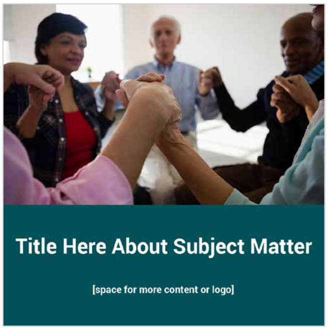
Phone: 604-291-2258

Funded by the Government of BC and managed by United Way British Columbia

[logo(s) here]

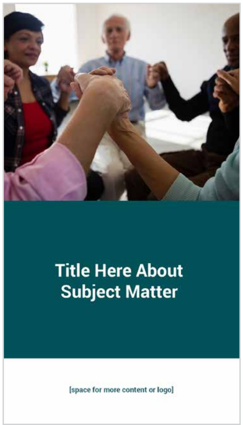
poster
1-side & 11 x 17"



Title Here About Subject Matter

[space for more content or logo]

facebook and
instagram square



Title Here About Subject Matter

[space for more content or logo]

facebook and
instagram story

Title Here About Subject Matter

[space for more content or logo]

twitter image
post

MS Word Templates:

Microsoft Word Templates

The following templates have been created for your use and can be found here:

- Tri-fold brochure
- Letter-sized flyer
- Letter-sized poster
- Tabloid-sized poster
- Rack card (3.5″ x 8.5″)

Please use the following page as a guide as to how these templates have been constructed and how to work with them. These guidelines are not tutorials on how to use Word and to use these templates requires some competency in MS Word. That being said, please forward any issues or questions you have with the templates as we are building a FAQ and testing them at this stage.

Need help or want to leave feedback?

You can provide feedback and questions on these resources on CORE BC or by emailing healthyaging@uwbc.ca

How to use the MS Word Templates:

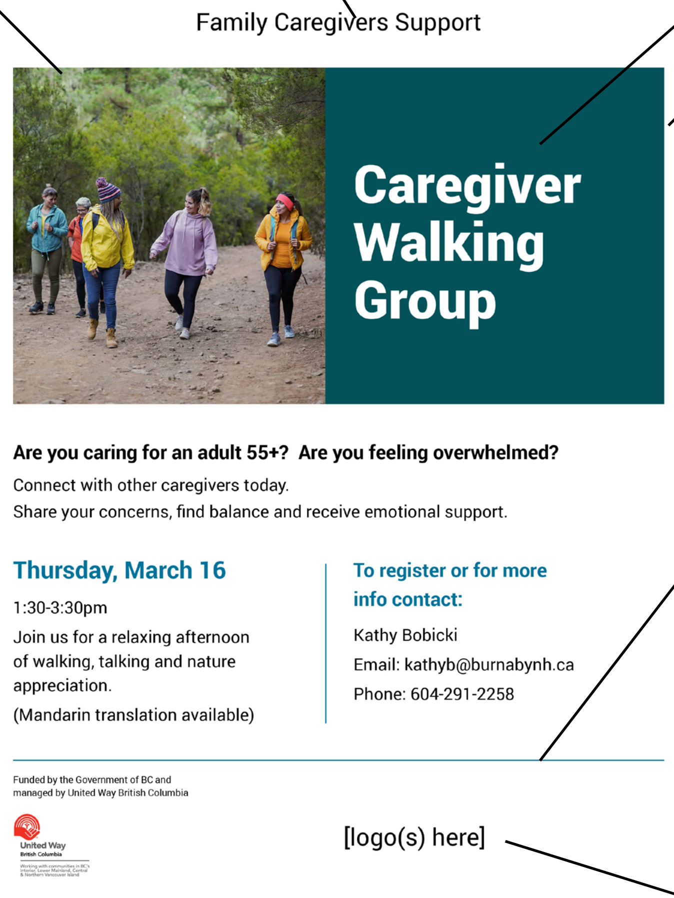
We're using the flyer as an example but this information applies to all templates.

Overall: All text is created using text boxes and layered over shapes. All of this can be custom edited to whatever you wish but you should have a good level of knowledge working with Word.

Image can be used as-is or your own custom image is possible.This is constructed by filling a shape. To change the picture, go to **format shape** > **fill.**

We recommend that this stays here for context but can be moved or deleted entirely.

Edit as you see fit. Be sure to use high contrast when text is set on a coloured background.



Family Caregivers Support

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Kathy Bobicki
Email: kathyb@burnabynh.ca
Phone: 604-291-2258

Funded by the Government of BC and managed by United Way British Columbia

United Way
British Columbia
Working with communities in BC's Interior, Lower Mainland, Central & Northern Vancouver Island

[logo(s) here]

Boxes can be moved and resized for customized content.

All text is editable and customizable.

Thin separator lines are helpful to organize content and make it easier for seniors to understand content easily.

This can be moved if necessary but must be included.

Place your logo here by right clicking and selecting **"Change Picture"** then **"From File"**. Adjust as needed.

Canva Templates

The following templates have been created for your use and can be downloaded using the links below.

VERY IMPORTANT: Make a copy so that you do not overwrite our templates.

- On the template you wish to use, hover over the top right corner and click (...) and then select "Copy to another team".

- Go back to your Canva account and make changes to your copy.
- Tri-fold brochure
- Letter-sized flyer
- Letter-sized poster
- Tabloid-sized poster
- Rack card (3.5" x 8.5")
- Facebook and Instagram square template
- Facebook and Instagram story template
- Twitter image template

Please use the following page as a guide as to how these templates have been constructed and how to work with them. These guidelines are not tutorials on how to use Canva and to use these templates requires some competency in Canva. That being said, please forward any issues or questions you have with the templates as we are building a FAQ and testing them at this stage.

Need help or want to leave feedback?

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How to use the Canva Templates:

We're using the flyer as an example but this information applies to all templates.

Overall: All text is created using text boxes and layered over shapes. All of this can be custom edited to whatever you wish but you should have a basic level of knowledge working with Canva.

Image can be used as-is or your own custom image is possible.

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United Way British Columbia

Your logo here [delete this box)

Boxes can be moved and resized for customized content.

All text is editable and customizable.

This can be moved if necessary but must be included.

Delete this and place your logo here.

Feedback

Need help or want to leave feedback?

You can provide feedback and questions on these resources on CORE BC or by emailing healthyaging@uwbc.ca