



# Saint Elizabeth

*Well beyond health care*

## Caregiver Compass

Tips and tools to help you manage your caregiving responsibilities



*Caregiving is about people, families and their relationships*



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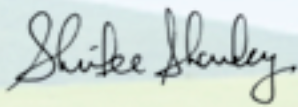
## A PERSONAL MESSAGE

# The caregiver journey

Something happens when you are caring for another person. You discover strength you never knew you had; you find light in the darkest of places; and you develop human connections beyond what you thought possible. I am constantly moved by the stories shared at Saint Elizabeth. The highs take your breath away; and so do the lows. The demands and emotions involved test a caregiver's will. So often, the difficulty comes from understanding where to begin when overwhelmed by the stack of decisions and documents that seem to collect.

With this in mind, we have created the *Caregiver Compass*. It is a starting point for caregivers, providing basic and practical information on caring for a loved one who needs support due to aging, disabling medical conditions, chronic injury and long-term illness. There is guidance on learning how to accept help and create a caregiver team; on handling health, home, legal and financial demands; on maintaining your own wellbeing; and more. As a health care provider caring for individuals and families in their homes for over a century, we wanted to craft a resource that spoke to the challenges we see families and friends face when juggling the mental, physical and emotional dynamics of caregiving.

We hope the *Caregiver Compass* will provide support and direction when you need it most.



**Shirlee Sharkey**

*President and CEO, Saint Elizabeth*

## WHO IS A CAREGIVER?

Caregivers provide care and assistance for spouses, parents, children and other family members or friends who need support. A caregiver may support someone because of age, medical conditions, injury, long term illness or disability. Caregiving responsibilities typically involve support from family, friends, professional health care providers, community organizations and government resources.

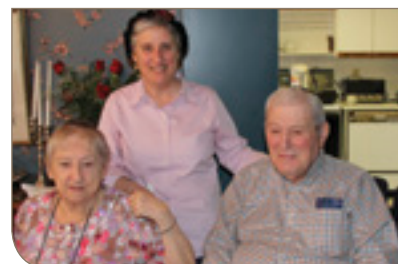
### Who is a caregiver?

You may not see yourself as a caregiver, but rather as someone simply supporting a person who needs you. Providing support is especially natural if you are helping someone who means a lot to you. Seeing yourself in the role of caregiver acknowledges the important work you're doing.

Most people will become a caregiver at some point in their lives – adults both young and older are caring for their children, spouses, parents, relatives, friends and neighbours. Many people become caregivers without warning or preparation. The intensity and length of caregiving varies.

What kind of caregiver are you? Consider these caregiving scenarios:

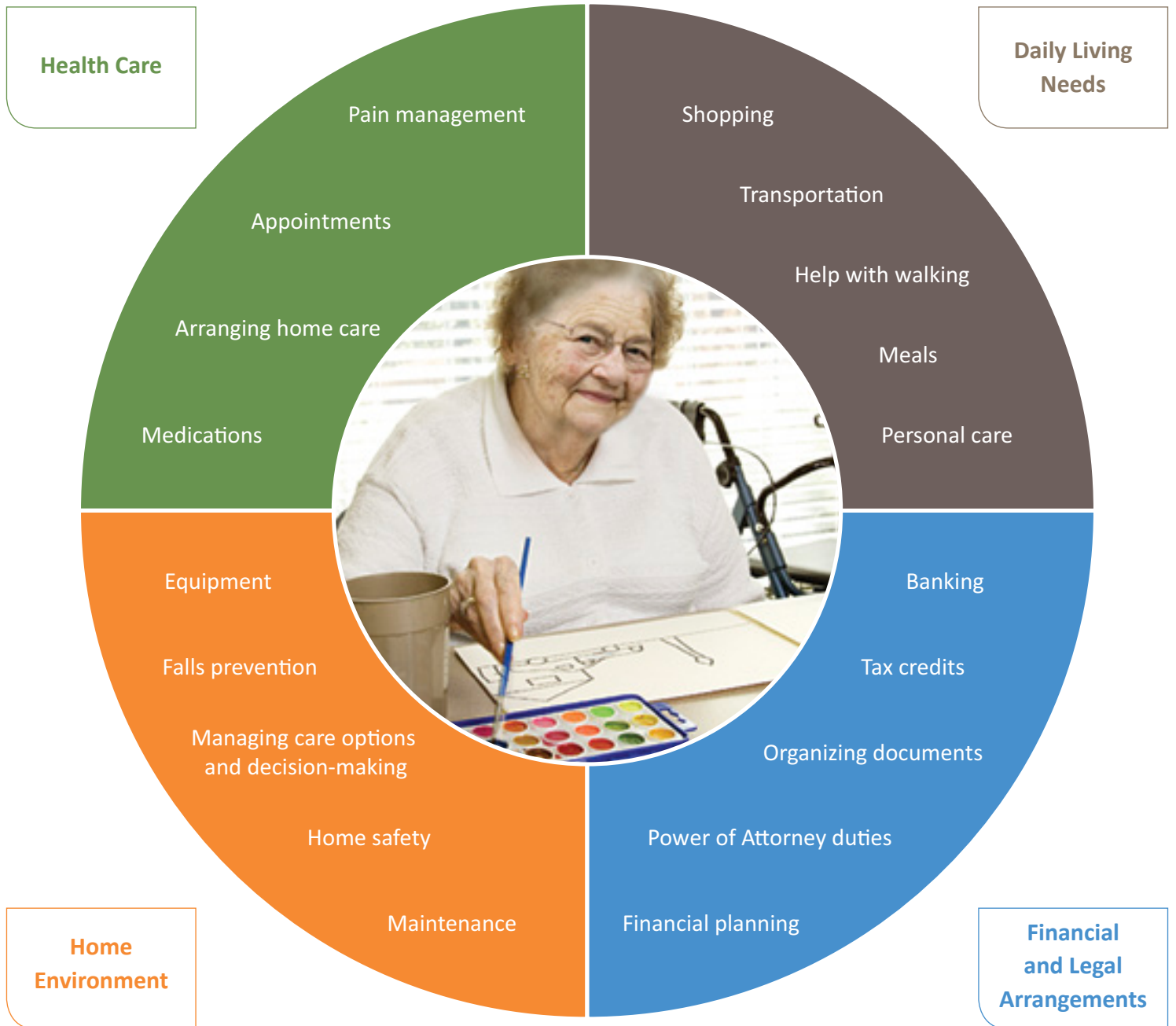
- “My husband needs a lot of help since his accident. Our family and friends are worried that I’m burning out – but I feel like it’s okay to lose sleep and put myself last right now until he recovers.”
- “I’ve been taking care of my mother for 4 years while she battles cancer. My kids encourage me to spend some time taking care of myself, but I am not sure how much time I have left to spend with my mom. I don’t want to spend any time away from her.”
- “My friend is going through cancer treatments and I’m helping out by preparing meals and driving her children to activities.”
- “I took care of my mother for sixteen years when she was living with Alzheimer’s disease. It was hard. I think one of the things I struggled most with was the change in our relationship and our roles. She had always taken care of me, but suddenly I was making her meals, giving her a bath and changing her. I felt guilty for thinking it wasn’t fair. I didn’t know who I could speak to about it.”
- “Our son was born with a health condition that demands special care. I have quit my full time job to look after his needs.”



Many caregivers find themselves part of the “sandwich” generation, caring for BOTH their parents and their children.

*Family caregivers are the invisible backbone of the health care system. Research shows that between 70 and 80 percent of the care given in the community to older adults is provided by family and friends.<sup>i</sup>*

# CAREGIVING RESPONSIBILITIES



“I have helped my wife for many years with her rheumatoid arthritis. She is in a wheelchair and I take her to all her appointments and to her swim class – it’s the only outing she has.”

## WHEN DOES A PERSON NEED HELP AT HOME?

### Recognizing the need for additional support

Areas to observe	Signs to watch for
<b>Personal appearance</b>	<ul style="list-style-type: none"><li>• Poor hygiene, hair untidy or greasy</li><li>• Dressing poorly or inappropriately</li><li>• Bruises and other signs of trauma, falls or abuse</li></ul>
<b>Housekeeping</b>	<ul style="list-style-type: none"><li>• Dirty and cluttered home, laundry piling up</li><li>• Home maintenance and repairs neglected</li></ul>
<b>Eating</b>	<ul style="list-style-type: none"><li>• Significant or unexplained weight loss or gain</li><li>• Problems preparing food</li><li>• Fridge in disarray or empty, food with long past expiry dates or spoiled</li></ul>
<b>Medication mix-ups</b>	<ul style="list-style-type: none"><li>• Medications expired, unfilled or not being taken</li><li>• Confusion about when and why medications should be taken</li></ul>
<b>Memory problems</b>	<ul style="list-style-type: none"><li>• Leaving stove or lights on</li><li>• Unopened or unpaid bills</li><li>• Forgotten appointments</li><li>• Calling repeatedly or forgetting to call</li><li>• Repeating questions and conversations within a short time</li></ul>

Adapted from: Roberts, Shirley. *Doris Inc.: A Business Approach to Caring for Your Elderly Parents*. John Wiley & Sons Canada, Ltd. 2012. p. 63. Print. Included with permission from the publisher.

## BE PROACTIVE: PREPARING TO BECOME A CAREGIVER

*An estimated 4 to 5 million Canadians are providing care for a family member – that's 1 in 5 Canadians.<sup>ii</sup>*

Caregiving often comes on unexpectedly and/or suddenly. What can you do to start preparing for the future? A number of big decisions will need to be made surrounding home, work, finances, and places of care. Places of care may include:

- the care recipient's home
- a caregiver's home
- an alternate setting (such as adult day centres, see page 26 – Other care options); or
- a combination of the above

Often these conversations don't take place until an urgent need or crisis occurs.



## RESPECTING THE CARE RECIPIENT'S CHOICES

Involve the person in decisions about their care and have conversations about their wishes – before an urgent need or crisis occurs. **The ability to make choices** and direct their own care is important to care recipients. Respect their wishes and, when possible, their right to live with choices they are comfortable with.

## CAREGIVING CONVERSATIONS: COMMUNICATION TOOL

Talking to your care recipient and family members about caregiving is sometimes hard to do. Receiving care may be seen as a loss of independence. Here are some examples of words or phrases you can use to help you **listen** and **talk** about caregiving.

### Family Communication

Issue or topic	Caring for a senior	Caring for an adult	Caring for a child
<b>Long-distance caregiving</b>	“Although I may live hundreds of kilometers away, Mom’s comfort and safety are still very important to me. Can we talk about what I can do from a distance to help care for Mom?”  “It’s important that we all stay connected. Why don’t we set up regular times to talk on Skype so that we can see how Joan is doing?”  “I didn’t notice Dad repeating himself so often the last time I was here. Do you remember when it started?”		
<b>Sharing caregiving roles and responsibilities</b>	“I know we all love Mom so much and we want to ensure she is safe and comfortable as she gets older. There are many responsibilities to caring for her – let’s figure out how we can all share in the tasks since we all have different abilities.”	“There are so many things we can do to care for Lisa. I have made a list of the key things that I think need to be taken care of. Can you let me know if there is anything to add, and what you might be able to take on?”	
<b>When family members are unable or unwilling to provide support</b>	“I understand providing traditional help is difficult for you. Let’s talk about what is important to you and how you think you can help in different ways.”		

*Everyone makes mistakes. Forgive yourself.*

## Home Environment

Issue or topic	Caring for a senior	Caring for an adult	Caring for a child
<b>Current home environment</b>	<p><b>Note:</b> Help the senior in your life focus on the potential changes in their home environment as a new phase of life and a new experience, not the end of their independence.</p> <p>“Where do you want to live as you get older? Have you thought about staying at home, or other locations? I have a friend at work who is planning for the future and it made me wonder about your plans.”</p> <p>“If you decide to stay here, are there neighbours who can help? Do you have all the facilities or services you may need nearby?”</p> <p>“What types of things might you need to continue living in your house and taking care of it?”</p> <p>“Tell me what crosses your mind when you think about moving somewhere else?”</p>	<p>“Have you thought about where you want to live as your condition changes?”</p>	<p>“As you get older we may have to start considering changing your bedroom or bathroom. It would be great if you could help us decide what changes we might need to make. What types of things are important to you?”</p>
<b>Accepting more care</b>	<p>“Have you thought about what is important to you related to care that could help you at this time in your life?”</p> <p>“Are there specific things that you would like help with?”</p> <p>“How can we help make that happen?”</p> <p>“We should find out the cost of some of the care options we have discussed and see what is possible.”</p>		<p>“As you get older and your needs change we are going to need more care for you. What are some things that are important to you as this happens?”</p>
<b>Moving and/or downsizing</b>	<p>“Do you think you are going to be able to maintain this house by yourself in the next few years?”</p> <p>“My goal is to help you maintain your independence and freedom; and sometimes a move actually increases people’s freedom. I was talking to a friend of mine – her mother told her what relief it finally was to move into a retirement home and not have to worry about their big home.”</p> <p>“Let’s start with looking at one room at a time. Tell me what things are most important to you, and what we might be able to give to a relative or friend.”</p> <p>“How do you like your new location? Is there anything you are worried about now that you are living in (<i>e.g., long-term care home, assisted living facility</i>)?”</p>		<p>“Moving and change can always be scary. What can we do to make this move as easy as possible for you?”</p> <p>“As we get older and retire, we may need to downsize or change where we are living. Have you thought about where you want to live? Is there someone in our family, other than Dad and I, who you would want to live close to?”</p>

Issue or topic	Caring for a senior	Caring for an adult	Caring for a child
<p><b>Communicating with health care providers</b></p>	<p>“How comfortable are you talking to your (<i>nurse, doctor</i>) and asking questions about your condition?”</p> <p>“It’s a good idea to have someone come with you to doctor’s appointments to help you ask questions and write down the answers. Who would you like to help with this?”</p>	<p>“I understand it can be stressful and overwhelming to talk to a health care provider about a condition. How do you feel about talking to them?”</p> <p>“If you feel this way it would be a good idea to have someone come with you to doctor’s appointments, to help you ask questions and write down the answers. Who would you like to help with this?”</p>	<p>“Even though you are young it is important for you to describe how you are feeling to your (<i>doctor, therapist</i>) and be a part of the decisions that need to be made about your health. Can I help you make a list of questions for your appointment tomorrow?”</p> <p>“How are you feeling about what we have to discuss with the doctor? I am always here to help you if you don’t understand something.”</p>
<p><b>Medication safety</b></p>	<p>“Managing many medications can be very time consuming and sometimes even dangerous. Have you ever heard of a blister pack and how this might make managing your medications easier?”</p> <p>“Keeping track of all your medications can be confusing. Have you ever tried keeping a list of your current medications?”</p> <p>“Did you know that you can review your list of medications with the pharmacist for additional safety?”</p> <p>“It can sometimes be hard to read medication labels. Did you know that if you have trouble with your vision, you can request that medication labels be printed in large type?”</p> <p>“Have you ever wondered what to do with your unused and expired medications? It can be dangerous to keep them. Did you know that you can bring unused medications back to your pharmacy?”</p>	<p>“It must be hard to be a kid and have to worry about your medications. When you go to camp I am going to have a counsellor worry about what time you have to take them. How do you feel about that?”</p> <p>“I know you feel better after taking your medicine but it is really important that you keep taking it as long as your doctor tells you to.”</p> <p>“It is really important to keep track of your medicine. Write down the day and time each time you take it. I can help you make a chart of when you take your medicines and you can fill the chart in.”</p> <p>“Medications can cause reactions, or side effects. Did you know that you can ask your doctor what reactions can happen when you use your medicine? You can watch for these changes and then tell an adult if you start to feel any of them.”</p>	

Issue or topic	Caring for a senior	Caring for an adult	Caring for a child
<p><b>Advance care planning</b></p>	<p>“What kind of care would you want – or not want – to receive if you were not capable of deciding for yourself?”</p> <p>“Who would you want to make decisions for you if you were not capable? You can choose one or more people to be your ‘substitute decision makers’, but it’s important to make sure they clearly understand their job and your care wishes.”</p> <p>“I know it’s a very difficult topic to discuss but we want to ensure your wishes are respected and we plan for what you want at the end stages of your life. Have you thought about what you would want done in the event you require CPR (Cardiopulmonary resuscitation)?”</p>		<p>In many cases, parents give consent or permission for treatment on behalf of their child. Older children or youth may give their own consent for treatments or procedures, depending on their maturity and understanding of the situation.</p> <p>It is important that you are open with your child about what is happening and let him or her make decisions when appropriate.</p> <p>Speak to a member of your child’s health care team if you are not sure when to involve your child in decision-making.</p>
<p><b>End-of-life wishes</b></p>	<p>“What are the most important things that you want your family, friends, and/or doctors to understand about your wishes for end-of-life care?”</p> <p>“I was thinking about what happened to _____, and it made me realize...”</p> <p>“Even though you’re okay right now, I’m worried that _____. Let’s talk about it so that we can be prepared.”</p> <p>“Are there important milestones you’d like to meet if possible?” (<i>e.g., your daughter’s wedding, birth of a grandchild, a birthday or anniversary.</i>)</p>		<p>Consider reading books that deal with illness and death which are age and developmentally appropriate.</p> <p>Think about how your child usually communicates and likes to receive information. Does your child like to hear lots of detail or just the basics?</p> <p>Asking questions like “Do you understand what is happening?” or “Do you have any questions about what is happening?” allows children the opportunity to share their fears, ask questions or express their wishes, including at end-of-life.</p> <p>If you are unsure about how to discuss this with your child or would like some support in doing so, speak to a member of your child’s health care team.</p>

## Daily Living Needs

Issue or topic	Caring for a senior	Caring for an adult	Caring for a child
<b>Safety</b>	<p>“Are you worried about your comfort and safety? Can you tell me about some things that could be done to make things easier for you?”</p> <p>“Is there anything in your house that makes you worry that you might fall or hurt yourself?”</p> <p>“I would never want you to accidentally fall and hurt yourself. Could we take a look around your house and remove any avoidable hazards?”</p>		<p>“Your safety and comfort are so important to me. I know you want to grow up and try new things and I am so excited about that but we need to find a comfortable balance for both of us.”</p>
<b>Toileting</b>	<p><b>Note:</b> Try to be very matter-of-fact when talking about toileting needs.</p> <p>“Tony, is this a good spot to keep the bedpan?”</p> <p>“Does your catheter bag need to be emptied?”</p> <p>“Do you think you will require the bedpan/commode before your shower today?”</p> <p>“Do you remember when your last bowel movement was?”</p>		
<b>Bathing</b>	<p>“Are my visits each Monday a good time to help you bathe?”</p> <p>“I am here to help you manage on your own. I will only help you with the areas you find difficult to do by yourself.”</p>		<p>“I understand it is difficult to have someone help you bathe. Is there anything I can do to make you feel more comfortable?”</p>



## Financial and Legal Arrangements

Issue or topic	Caring for a senior	Caring for an adult	Caring for a child
<b>Sharing of banking information</b>	<p><b>Note:</b> Focus on being proactive and achieving peace of mind.</p> <p>“It would bring me a lot of peace of mind if I knew I had the information I needed in case of an emergency.”</p>		
<b>Organizing documents such as wills, powers of attorney, advance directives</b>	<p>“Dad, you taught me to be responsible my whole life. Let’s work together to ensure you have all your necessary documents organized.”</p> <p><b>Note:</b> Be proactive and respect the care recipient’s wishes.</p> <p>“You have always showed me so much love and respect that I want to make sure your wishes are respected and accounted for in the correct documents. Could I take a look at your will with you?”</p>	<p>“I was just talking to my parents about their wills, POA’s and advanced directives and it made me think about you. Do you have these documents organized?”</p>	<p>Depending on age, these may be important areas to explore with your child.</p> <p>Speak to a member of your child’s health care team if you are unsure about how to handle these topics.</p>
<b>Investments, life insurance, accountants and investment advisors</b>	<p>“I was just discussing my plans for retirement with my financial advisor and it got me thinking about your finances. How do you feel about talking over the details of your financial plan just in case something happened to you? I have heard some bad stories about families who had trouble finding important information during a crisis.”</p>		

### TOP TIPS



- When possible, involve the person you are caring for in discussions and decisions regarding their care. You may have to introduce and revisit a subject several times.
- Talk to the person who needs care in a way that you would want to be spoken to.
- Prepare lists of questions to ask health care providers.
- It’s okay to respectfully question and discuss care recommendations if you disagree or are concerned about them.
- Be patient. Take things one step at a time. Don’t try to predict how everything will unfold, and be flexible as things change over time.

## CREATING A CAREGIVER TEAM

“You simply cannot do this alone.”

Caregiving is a “team effort” with multiple caregivers taking on different roles and responsibilities. It is helpful when there is a **Primary Caregiver** who coordinates the responsibilities of the team.

### Learning to say “Yes”

It is okay to ask for support. Family members and friends are often very happy to help with caregiving responsibilities but you need to remain positive and be specific about how they can help.

Tip: List several areas where you need help. If it’s appropriate, call or email all of your potential supports to let them choose what they can help with.

“Recently, my father had an operation to repair an artificial heart valve. Their neighbours were a great help but I also had to use all my vacation time to help out.”



## CAREGIVING CHECKLIST:

Here is a checklist you can use to help you keep track of caregiving responsibilities

Caregiving Responsibilities	Who Can Help	
	Name	Phone Number
<b>Home</b>		
<ul style="list-style-type: none"> <li>• Home maintenance (e.g., painting, light repairs)</li> </ul>		
<ul style="list-style-type: none"> <li>• Laundry (e.g., washing, ironing, shopping for supplies)</li> </ul>		
<ul style="list-style-type: none"> <li>• Groceries and meal planning</li> </ul>	e.g., friends, grocery delivery service	
<ul style="list-style-type: none"> <li>• House cleaning</li> </ul>		
<ul style="list-style-type: none"> <li>• Grass cutting, snow removal, and/or gardening</li> </ul>	e.g., neighbourhood teenager	
<ul style="list-style-type: none"> <li>• Safety checks (e.g., daily confirmation that the person is safe)</li> </ul>		
<ul style="list-style-type: none"> <li>• Pet care (e.g., walking, grooming, feeding, vet appointments)</li> </ul>	e.g., neighbourhood friend	
<b>Daily Living Needs</b>		
<ul style="list-style-type: none"> <li>• Transportation to and from appointments</li> </ul>	e.g., family member	
<ul style="list-style-type: none"> <li>• Bathing and showering</li> </ul>	e.g., home care service	
<ul style="list-style-type: none"> <li>• Meal preparation</li> </ul>		
<ul style="list-style-type: none"> <li>• Home safety and adaptations (e.g., removing fall hazards, checking smoke detectors, installing bathtub grip bars)</li> </ul>		
<ul style="list-style-type: none"> <li>• Social interaction and companionship</li> </ul>		
<b>Health Care</b>		
<ul style="list-style-type: none"> <li>• Arranging doctor / care provider appointments</li> </ul>		
<ul style="list-style-type: none"> <li>• Communicating with health care providers (asking questions, taking notes) and explaining this information to the care recipient</li> </ul>		
<ul style="list-style-type: none"> <li>• Medications (e.g., placing orders, picking up, monitoring use)</li> </ul>		
<ul style="list-style-type: none"> <li>• Exercise</li> </ul>		

## CAREGIVING CHECKLIST:

Here is a checklist you can use to help you keep track of caregiving responsibilities

Caregiving Responsibilities	Who Can Help	
	Name	Phone Number
<b>Financial</b>		
<ul style="list-style-type: none"> <li>• Paying bills</li> </ul>		
<ul style="list-style-type: none"> <li>• Accessing benefits (e.g., Registered Disability Savings Plan, federal Caregiver Tax Credit, Compassionate Care Benefits)</li> </ul>		
<ul style="list-style-type: none"> <li>• Banking (e.g., knowing the location of all banking and investment accounts, credit cards, lines of credit and any outstanding loans)</li> </ul>		
<ul style="list-style-type: none"> <li>• Financial planning (e.g., managing investments)</li> </ul>		
<ul style="list-style-type: none"> <li>• Paying taxes</li> </ul>		
<ul style="list-style-type: none"> <li>• Sale of assets (e.g., home, vehicle)</li> </ul>		
<ul style="list-style-type: none"> <li>• Assisting with paying for medical equipment or services</li> </ul>		
<b>Legal</b>		
<ul style="list-style-type: none"> <li>• Organizing important documents for access by primary caregiver and a back-up or substitute decision maker</li> </ul>		
<ul style="list-style-type: none"> <li>• Will (e.g., up to date and securely stored)</li> </ul>		
<ul style="list-style-type: none"> <li>• Power of Attorney (e.g., up to date and securely stored)</li> </ul>		



- **Divide responsibilities** into those that can be met by family members or friends, and those that need support from health care providers or paid service providers (e.g., property maintenance).
- Make sure **each family member has input** in decision making and arranging for care.
- Do your best to ensure caregiving roles fit needs and preferences of family members and the care recipient.
- **Keep caregiving roles flexible.** Know that needs and roles may change over time.
- **Implement a buddy system.** Everyone involved in caregiving should have a partner to check in with to avoid becoming burned out or overwhelmed.
- **Ask for help.** Be specific about what kind of help you need.

## WHAT SUPPORT SERVICES ARE AVAILABLE?

This section provides tips and strategies to help you understand your options, and identify what types of services are available to you.

### Financial planning and management services

Caregiving roles may span several years, and the level of care required can escalate. One way to minimize the challenges associated with financial stress or time away from work is to take steps now.

- Speak to your bank about what financial planning programs are available. Or, contact an independent financial management firm who can select the most suitable products specific to your needs (e.g., retirement savings plans, high interest accounts, life insurance, employee benefits, and tax services).
- Learn about the federal government's Compassionate Care Benefit (CCB) program. Employment Insurance benefits and job protection are provided to eligible family members for up to six weeks while they take time away from work. Visit [www.servicecanada.gc.ca](http://www.servicecanada.gc.ca) for information.
- Create an emergency fund in case you need to pay for unexpected caregiving costs, reduce your working hours or take an unpaid leave of absence from work.
- Remember, you are not alone. Reach out to family, friends, co-workers and community associations when you need help.

### Home and community care services

#### *What is home and community care?*

Home and community care is a term that includes a wide range of health and social services delivered to people of all ages in the home or other community setting. One of the goals is to provide family caregivers with the support they need.

Home and community care is ideal when a person prefers to stay at home but needs ongoing care that can't be easily or effectively provided solely by family and friends.

Health care professionals with specialized experience in areas like seniors care, rehabilitation therapies and personal support services are available to support you in your home. Home and community care can be customized to fit your needs.

#### **Benefits of home care include:**

- Ability to remain at home in a comfortable environment, with a greater sense of independence
- Reassurance
- Security
- Interaction with the care provider and having the time to sit and talk



## What types of services are available?

- Access to equipment and supplies
- Adult day programs
- Assessment for driving
- Cancer care
- Chronic disease management
- Dementia and Alzheimer's care
- Friendly visiting
- Help with walking and exercise
- Mental health
- Nursing care
- Nutrition counseling
- Occupational therapy and home adaptations
- Palliative and end-of-life care
- Personal care (e.g., help with bathing, dressing and feeding)
- Physiotherapy
- Respite
- Social work
- Speech therapy
- Transportation to appointments
- Wound care

## Your home and community care team

*Registered Nurses (RN), Registered Practical Nurses (RPN), Licensed Practical Nurses (LPN):*

Nurses provide services such as pre- and post-natal care, child and family care, mental health and crisis intervention, home chemotherapy, respiratory care, wound and ostomy care, diabetes management, seniors care and palliative care.

*Personal Support Workers (PSW):*

PSWs assist people with daily personal care needs including bathing, toileting, dressing, mobility and feeding.

*Registered Therapists:*

Includes occupational therapists, physiotherapists, dietitians, social workers and speech language pathologists.

*Crisis Workers:*

Programs may include intervention and support for teens, adults and seniors who are experiencing mental health challenges.

## How can caregivers arrange for these services?

Many home care services are available to you through your provincial health care plan, and anyone can make a referral (including you). Your doctor and/or local health authority can provide you with information about services in your area.

Call our Ask Elizabeth support line to learn how to access services and government programs that are available to you:

**1-855-Ask-Eliz (275-3549)**





- It's important to get support. Plan ahead so you know what services are available and how to access them when you need to.
- A wide range of health care services are available in your home.
- Ask friends and neighbours for help.
- Home and community care can be customized to your needs. It's about the relationships between professionals, individuals and their families.

## ADVOCATING FOR THE CARE RECIPIENT

Caregivers are often advocates for those they love and care about, stepping up on their behalf to ensure they get the best possible care. There are a variety of ways you as a caregiver can be an advocate, depending on what you feel comfortable with.

### Understanding the health condition

Caregivers provide care to people with a broad range of health conditions (examples include Multiple Sclerosis, diabetes, heart disease, cancer, dementia and Alzheimer's disease, and chronic obstructive pulmonary disease – COPD). The more information you have about the condition, research and treatment options, the better prepared you will be to provide care now and in the future.

### Organizing health information

- Keep notes and records of the person's health history including allergies and other health problems.
- Keep a current list of medications and dosages, including any over-the-counter medications like acetaminophen, vitamins, supplements and topical creams. Lists any side effects and reactions. Your pharmacy can provide you with a printed list of all prescription medications.
- Review the medication list with your pharmacist, who can explain dosage directions, identify any drugs that should not be taken together, and identify any potential side effects.
- Regularly check all medications, including over the counter medications, and discard the ones that have expired.
- Report any adverse reactions to all medications, including over the counter medications or supplements, to the health care provider right away.

### Communicating with health care providers

- It can be helpful for the care recipient to have another set of ears to take in information from doctors or other care providers. Ask the person you care for if he/she is comfortable with you accompanying them to their appointments.
- If you go to medical appointments, offer your support while acknowledging the person you are caring for is still in charge. Prepare your questions ahead of time and write down detailed answers.



## Caring for people with complex needs

- Request specific accommodations for children at school and gently remind teachers about a child's needs.
- Make the care environment 'normal' for other family members or children.
- Regularly assess the care recipient's ability to use the stairs, bathroom, and their ability to get in and out of bed.
- Involve the care recipient in all decisions about home modifications.



- Know your healthcare team and their roles. Also learn about additional health care providers who may be helpful in the future.
- Keep a current list of all medications.
- Keep all health, medication, and legal information including medical directives or powers of attorney up-to-date and easily accessible in case of emergency.

## HOME SAFETY

If the person you are caring for is at home, there are tools you can access and equipment you can use to help prevent injuries. Be sure you involve the person you are caring for in any changes you make to the home.


Consider the following tips:

<b>General Safety and Precautions</b>		<b>Kitchen</b>	
<input type="checkbox"/>	Ensure smoke detectors are installed and working properly	<input type="checkbox"/>	Rearrange cabinets so the items needed most often are within easy reach
<input type="checkbox"/>	Plan and discuss evacuation procedures in case of fire	<input type="checkbox"/>	If the care recipient has dementia or Alzheimer's, cover stove burners and remove knobs, install natural gas shut-off valves, and put locks on oven doors
<input type="checkbox"/>	Keep emergency phone numbers handy	<input type="checkbox"/>	Consider unplugging or putting away appliances like blenders, food processors, and toasters
<input type="checkbox"/>	Inform neighbours of any safety features such as double locks, or changes in the care recipient's health, in case of emergency	<input type="checkbox"/>	Have a fire extinguisher that is easily accessible
<input type="checkbox"/>	Keep cleaning supplies, chemicals, and sharp objects in a locked cabinet	<input type="checkbox"/>	Use a kettle with automatic shut-off
<b>Falls Prevention</b>		<input type="checkbox"/>	Lower hot water temperature to less than 49 degrees Celsius (120 degrees Fahrenheit)
<input type="checkbox"/>	Install sturdy banisters on both sides of the stairs	<b>Bedroom</b>	
<input type="checkbox"/>	Use sturdy, non-slip rugs without rips or tears	<input type="checkbox"/>	Install bedrails to provide extra support when getting into or out of bed
<input type="checkbox"/>	Salt driveways and walkways in the winter	<input type="checkbox"/>	Use incontinence pads and mattress covers to protect the mattress
<input type="checkbox"/>	Install bright lights in hallways and bathrooms	<input type="checkbox"/>	Install night lights
<input type="checkbox"/>	Clear pathways of any extension cords or other tripping hazards	<input type="checkbox"/>	Consider removing the bed frame if the bed is too high
<input type="checkbox"/>	Remove mats or tape them to the floor		
<b>Furniture</b>			
<input type="checkbox"/>	Check that chairs have armrests which are the correct height		
<input type="checkbox"/>	Consider raising the height of seats (where possible) to make it easier to sit down or stand up		

If the care recipient needs special or more expensive equipment (such as an adjustable bed or electric wheelchair), speak with your doctor, your health care team, or community organizations about how to borrow, rent or buy specialty devices.

### Mobility aids

- Specialty lift chairs are designed to tilt forward to help someone who has trouble getting in or out of a chair.
- Electric or manual wheelchairs may be bought second-hand, or borrowed through community organizations or health care programs.
- Canes, walkers and walking aids are available in many forms, come in a variety of heights and with various grip styles.



- Make use of assistive devices such as grab bars in the bathtub, shower seats, raised toilet seats, or walkers.
- Salt driveways and walkways in the winter.
- Rearrange cabinets so the items needed most often are within easy reach.
- Set water heater temperature to less than 49 degrees Celsius (120 degrees Fahrenheit).
- Make sure smoke detectors are working and keep a fire extinguisher in the kitchen.

## CARING FOR THE CAREGIVER: MAINTAINING YOUR WELLBEING

Being a caregiver can be very rewarding, deepen relationships, and be filled with unexpected moments of laughter. It can also be very demanding, especially if you have a young family and a busy job. The caregiver role also comes with a wide range of emotions, so it is important for you to take care of yourself.

*“It’s okay to want a break.”*

*“I’m 32. After giving birth last year to our second child my wife was diagnosed with breast cancer. Our parents live in another province. I work hard to care for all of us but I’m having a hard time talking about it.”*

### Manage your expectations

Caregivers may experience a **range of emotions**:

- |               |   |                              |
|---------------|---|------------------------------|
| • Anger       | • Fulfillment                                   | • Guilt                      |
| • Anxiety     | • Greater appreciation for health and wellbeing | • Isolation                  |
| • Fear        |   | • Joy                        |
| • Frustration | • Grief   | • Strengthened relationships |

## Signs of caregiver burnout (compassion fatigue)

Burnout refers to feeling unable to continue to provide the best care, not because you are not trying or don't want to, but because you are emotionally or physically spent. Do you:

- Feel pulled in many directions?
- Feel trapped?
- Feel unable to meet the expectations and needs of the person you care for?
- Feel exhausted?
- Have an inability to eat or sleep well?
- Experience strong emotions or mood swings?
- Have difficulty concentrating?
- Feel isolated from your family and friends?

Speak to your health care professional if you are experiencing any of the above.

Levels of distress are higher for caregivers who provided more than 21 hours per week of care, and for those who are caring for people with depression, cognitive deficits, or behavioural problems. [CIHI, 2010]

## Finding support

**Ask for help** from family and friends, including guidance on which caregiving tasks can wait and what is a priority. See the Caregiving Checklist on page 16.

**Stay connected to your own life.** Take the time to care for yourself every day, no matter what. This is not selfish. You need to be in good physical and emotional health to be a good caregiver.

**Get some rest and do the things that you enjoy.** It may be something as simple as curling up in your favourite chair with a good book, meeting a friend for coffee or going for a bike ride. Whatever the activity, the point is to remember to stay involved in your life.

Have a backup or secondary caregiver you can call on when you need to take a **temporary break or vacation** from caregiving responsibilities.

**Arrange for home and community care services.** See page 19 for the types of care available in your home.

**Learn to say “Yes”** and accept help.

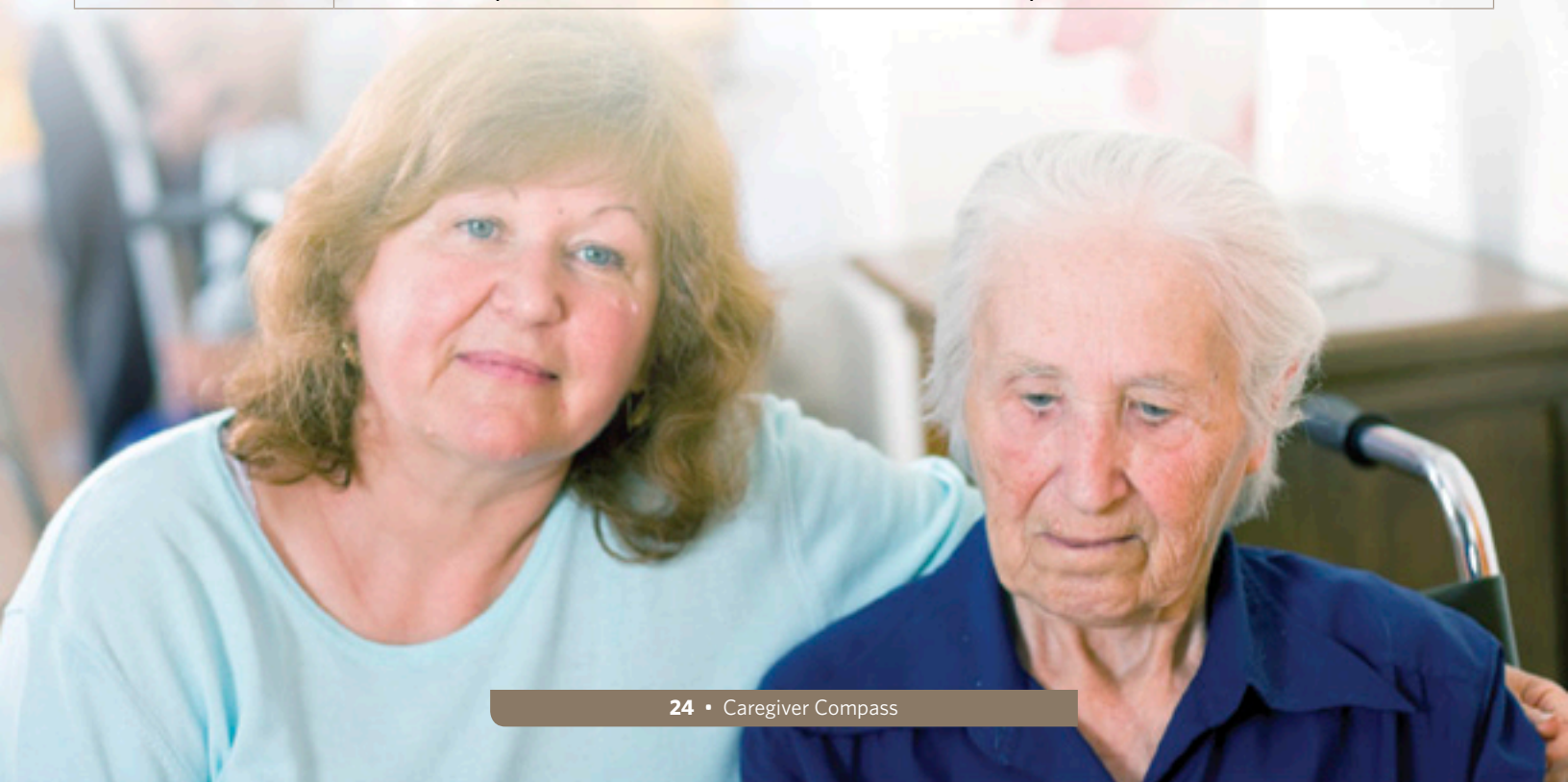
## Research Study: Keys to Caregiver Support

Caregivers often need help coping with the demands and stresses associated with their efforts. A recent Saint Elizabeth research study was unique because it included family caregivers at all stages of research. The research identified several promising practices to better serve the needs of caregivers.



## Questions to ask: Choosing caregiver support programs or services

Responding to the unique care situation	1. Can the program or service be customized to meet our needs?
	2. Will the service provider learn about and respect my relationship with the person who needs care?
	3. Does the service/program include strategies to address family dynamics and roles?
	4. Are there programs specific for male or female caregivers?
	5. Does the program or service recognize cultural influences and diversity?
Caregiver involvement and interests	6. Are there opportunities to network with other caregivers?
	7. Will I be connected to community services?
	8. Does the program have online interactive components available?
	9. Will the program help me apply my knowledge and skills through coaching or mentoring?
The emotional context of care	10. Is there a focus on caring for the caregiver?
	11. Does the program recognize that caregivers experience different emotional stages?
	12. Does the program build caregivers' confidence in their role?
	13. Are caregivers encouraged to reflect on their positive experiences?
Providing relevant information	14. Will I learn how to navigate the health care system?
	15. Will I learn practical strategies for caregiving?
	16. Is the information provided appropriate to the stage I am at in the caregiving journey (e.g., short-term vs. long-term caring)?
Caregiver participation	17. Will I receive help arranging respite care (caregiving breaks)?
	18. Is help with transportation available?
	19. Is the program convenient and flexible?
	20. Does it provide a welcome and comfortable atmosphere?



## ORGANIZING FINANCIAL AND LEGAL INFORMATION

While caregiving can be very fulfilling, caregivers can also feel the impact of the financial, emotional, social, and physical costs of their role. These costs, which might also include making changes to your job – or leaving the workforce altogether – have an estimated market value of between \$24 and \$31 billion.<sup>iii</sup>

Create a list of important documents and note their locations. This list should include the following:

Type of document	Examples	Location
<b>Identification</b>	<ul style="list-style-type: none"> <li>• Birth certificate</li> <li>• Marriage certificate</li> <li>• Passport</li> <li>• Social Insurance Number</li> </ul>	
<b>Bank account information</b>	<ul style="list-style-type: none"> <li>• Bank accounts</li> <li>• Mortgages</li> <li>• Credit cards, lines of credit</li> <li>• Loans</li> </ul>	
<b>Investments</b>	<ul style="list-style-type: none"> <li>• RRSPs</li> <li>• Pension plans</li> <li>• Mutual funds</li> <li>• Stocks</li> <li>• Bonds</li> <li>• RESPs</li> </ul>	
<b>Legal</b>	<ul style="list-style-type: none"> <li>• Wills</li> <li>• Power of Attorney documents</li> <li>• Advance directives (instructions for future medical care)</li> <li>• Any documents pertaining to pre-planned funeral arrangements or death in the home</li> </ul>	
<b>Key assets or income</b>	<ul style="list-style-type: none"> <li>• Vehicle ownership</li> <li>• Property ownership</li> <li>• Income sources</li> <li>• Recent tax returns</li> <li>• Insurance policies</li> <li>• Post office box key</li> <li>• Safe deposit box key</li> </ul>	
<b>Contact information</b>	<ul style="list-style-type: none"> <li>• Lawyers</li> <li>• Financial planners</li> <li>• Accountants</li> </ul>	



- Don't rely on memory for the location of important documents. Know where they are before you need them. Make sure a trusted friend, family member or substitute decision maker knows where these documents are kept.
- The person you care for might be reluctant to share personal financial and legal information with you. Explain that you are concerned about finding important information and documents in case of an emergency, and you want to ensure their wishes are met.

## MORE CARE OPTIONS

*“My husband is quite frail and has dementia. His prognosis is not very good and I am trying to take care of him, but I am overwhelmed by the decisions we need to make.”*

### Hospice palliative care

Hospice palliative care is a **type of care** provided to patients and families who are dealing with a life threatening illness. Hospice palliative care is often called palliative care, hospice care or end-of-life care (Canadian Virtual Hospice, 2009). The goal of palliative care is to reduce suffering and improve quality of life.

### Quality palliative care:

- focuses on the concerns of patients and their families
- provides relief for pain and other physical symptoms such as loss of appetite, shortness of breath or fatigue
- examines the whole person by considering the emotional and spiritual concerns of patients and families while respecting their social and cultural needs
- ensures that care is respectful and supportive of patient dignity
- is provided by an interprofessional team of caregivers including volunteers, social workers and spiritual leaders in addition to medical and nursing professionals (Canadian Virtual Hospice, 2009)

If you are not sure where to find palliative care services, talk to your doctor or nurses who are providing care right now.

*“My father is 87 and suffering from advanced pancreatic cancer. My wife and I are trying to keep him comfortable at home, and we're providing most of his support other than medical care.”*



## Residential and long-term care

Residential care may become necessary in the following situations:

- You don't have the skills or the ability to provide the level of care required
- The person you are caring for needs 24-hour care
- You are unable to find or pay for other supports that could keep the person you are caring for at home
- The health and safety of the person you are caring for is at risk
- Your own health may be at risk if you continue your current level of caregiving responsibilities

Make the decision a collaborative one by including the person you are caring for and other interested parties in the process. To learn more:

- Check local directories for community services for seniors
- Ask health care providers for suggestions
- Seek recommendations from friends and colleagues
- Look in the Yellow Pages under headings such as "homes for elderly", "nursing homes", "rest homes", "retirement homes"



## References

<sup>i</sup>Health Council of Canada (April 2012). *Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada?*; IRPP Study #23 (November 2011). Janice Keefe, *Supporting Caregivers and Caregiving in an Aging Canada*.

<sup>ii</sup>Canadian Caregiver Coalition (August 2008), *Caregiver Facts*. Accessed April 17, 2012. <http://www.ccc-ccan.ca/media.php?mid=124>

<sup>iii</sup>IRPP Study #23 (November 2011). Janice Keefe, *Supporting Caregivers and Caregiving in an Aging Canada*.

## ABOUT SAINT ELIZABETH

Saint Elizabeth has been a trusted name in Canadian health care for more than a century and is a leader in responding to client, family and system needs. As an award-winning not-for-profit and charitable organization, Saint Elizabeth is known for its track record of social innovation and breakthrough clinical practices. Our team of more than 6,500 nurses, rehab therapists, personal support workers and crisis intervention staff deliver over five million health care visits annually.



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