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INSTRUCTIONS

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- 2. Answer the test online at eCortex.ca. To pass, a grade of at least 70% (11 out of 15) is required.
- 3. Complete the required feedback for this lesson online at eCortex.ca.

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Communicating with and supporting caregivers

by Sarah-Lynn Dunlop, BA, MEd, RPhT



Learning objectives

Upon successful completion of this lesson, you will be able to do the following:

- 1. Understand the demands on caregivers and caregiver stress.
- 2. Recognize the role of the pharmacy technician in supporting caregivers and the pharmacy team.
- 3. Identify strategies for ensuring effective communication with caregivers.
- 4. Identify appropriate resources that can provide support for caregivers.

Introduction

Approximately one-quarter of Canadians act as caregivers to family, friends or neighbours, allowing more than two million Canadians to continue living in their homes. (1) While providing care for a loved one may often be reward-

ing and fulfilling, it can also present the caregiver with a variety of challenges. Patients with long-term and/or complex conditions may have a variety of healthcare professionals involved in providing care. These professionals may manage different aspects of the

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Condition	Information	Symptoms
Autism Spectrum Disorder (ASD)	1 in 68 children diagnosed with ASD. ⁽²⁾ Symptoms can range from mild to severe.	Problems with communication and social interactions such as: ⁽²⁾ • inability to engage in social reciprocal relationships • need for highly structured and dependable routine • failure to respond to own name • inability to make eye contact • cognitive disabilities • sensory problems • behavioural problems (self-injury, aggression) Tend to experience challenges with: ⁽²⁾ • toileting • sleeping Tend to experience several concurrent conditions (co-morbidities): ⁽²⁾ • autoimmune conditions • seizure disorders • asthma, allergies, eczema • respiratory infections • ear infections • gastritis
Dementia	402,000 Canadians 65 years of age and older are living with dementia. (3) Caused by neurodegeneration (loss of brain cells and important neural connections). (5)	Symptoms include:(3) • memory loss • changes in behaviour • problems with judgement and reasoning • changes in mood • changes in communication abilities Alzheimer's disease is the most common cause of dementia. It is a progressive, irreversible disease characterized by the formation of "plaques" and "tangles" throughout the brain, which cause brain cells to degenerate and die. In addition to memory loss, patients often experience:(5) • confusion • decline in ability to think • decline in ability to understand and follow conversations • decline in ability to perform simple tasks • decline in ability to look after themselves • decline in ability to communicate
Multiple Sclerosis (MS)	1 in 385 Canadians has MS. ⁽⁶⁾ MS is an autoimmune disease of the central nervous system in which the body attacks myelin (a fatty substance coating axons of neurons that speeds up transmission of nervous impulses).	Symptoms of MS are often unpredictable, varying from person to person and time to time in the same individual. Patients may experience periods of symptoms (referred to as relapses, attacks, episodes, flare-ups or exacerbations) followed by periods of recovery or remission. Symptoms can include: • lack of coordination • cognitive impairment • depression • bipolar affective disorder • extreme fatigue • sensory impairment
Parkinson's Disease	Affects 1 in 500 Canadians. ⁽⁴⁾ Neurodegenerative disease in which cells that produce dopamine die. ⁽⁶⁾ Dopamine is a neurotransmitter involved in motor control.	Patients experience motor & non-motor symptoms. Motor symptoms: ⁽⁸⁾ • tremor • slowness & stiffness • difficulty starting, controlling or stopping movement • impaired balance • rigid muscles Non-motor symptoms: ⁽⁸⁾ • depression • anxiety • cognitive changes • difficulty swallowing • fatigue • soft speech • sleep disturbances

patient's health and medical conditions. Pharmacists and pharmacy technicians are the most accessible health professionals across Canada, requiring them to be able to effectively communicate with patients and caregivers. It is imperative that pharmacy technicians have an understanding of common long-term and/or complex conditions, as well as the demands these conditions place on caregivers, and be prepared to provide assistance and resources within their scope of practice. Table 1 lists a few long-term and/or complex conditions with which caregivers may require support.

Caregiver Challenges and Stressors

Caring for loved ones with long-term and/ or complex conditions presents many rewards to the caregiver, as well as significant challenges to both the patient and the caregiver, from the impact of the condition itself to managing co-existing conditions. While many caregivers are happy to provide care for a loved one and feel rewarded by such an experience, others feel obligated to provide care and are intimidated by the expectations. (9) This can be associated with feelings of being overwhelmed, stressed and even resentful. (9) Caregivers looking after a loved one with a long-term and/or complex condition may also be experiencing denial, fear, anger, grief and high levels of stress. (9) Pharmacy technicians must recognize the important role of caregivers, as well as the substantial stress related to taking care of a loved one with a long-term and/or complex condition and the need for caregiver support.

Caring for a loved one with a long-term and/or complex condition requires the caregiver to balance all of the tasks required to provide care along with the responsibilities of their own normal daily life. Providing care may involve preparing meals, cleaning, managing finances, and providing personal care, as well as emotional support. (10-12) In addition, caregivers may find themselves suddenly responsible for making medical decisions (e.g., deciding on treatment, goals of care, or end-oflife options), managing, preparing and administering medications, monitoring the patient's health status, balancing medical appointments, arranging/providing transportation and communicating with a variety of healthcare professionals, which can all provoke added stress.(13)

TABLE 2 - Signs and Symptoms of Caregiver Stress ⁽¹¹⁻¹³⁾		
Condition	Information	
Social withdrawal	Reduced interest in participating in activities previously enjoyed Lack of interest in staying in touch with friends	
Anxiety	Worrying about what will happen	
Depression	Feelings of sadness and hopelessness most of the time	
Exhaustion	Not enough energy to complete daily tasks	
Sleeplessness	Inability to fall asleep Waking up throughout night Stressful dreams	
Emotional reactions	Often irritable Crying at minor upsets	
Lack of concentration	Difficulty focusing and completing tasks	
Health problems	Weight gain or loss More frequent illnesses (cold, flu) Development of chronic health problems (back problems, high blood pressure)	

Signs of caregiver stress

All of these demands can have various consequences for the caregiver, affecting their own physical, psychological and financial health. "Caregiver stress" can include exhaustion, lack of sleep, social withdrawal, lack of concentration, anxiety, depression and increased health problems. (11,13)

Table 2 summarizes signs and symptoms of caregiver stress. Caregivers may experience changes in sleep (difficulty falling asleep and/or staying asleep, restless sleep), fatigue, changes in appetite causing weight loss or weight gain, and headaches. (11-14) Caregivers are also at risk of developing chronic conditions, including back pain or high blood pressure, and are more susceptible to illnesses such as the common cold or influenza.(11,13,14) Caregivers may feel helpless, worried, anxious, and overwhelmed when faced with the demands and stress of taking care of a loved one. (10) Caregivers may not recognize these as symptoms that result from the stress of being a caregiver, as they are more focused on the health of the individual for whom they are providing care and many caregivers do not self-identify as a caregiver. (9,12) As front-line healthcare professionals, pharmacy technicians should watch for these signs when communicating with caregivers and be aware of risk factors for caregiver stress or burnout. Table 3 identifies some risk factors that contribute to caregiver stress or burnout.

TABLE 3 - Risk factors for caregiver stress(15)

- Living with patient (giving care 24/7)
- Financial strain
- Limited formal or informal support network
- · Lack of coping skills
- Gender roles
- Age (young caregivers and older caregivers)
- Severity of patient's condition

Financial challenges

Caregivers may also face financial challenges while caring for a loved one, through added costs of providing care and loss of potential income. Many caregivers spend \$100-\$300 per month on expenses directly related to providing care. (16) Expenses can include the cost of providing transportation to appointments, rehabilitation, specialized equipment, medications that are not covered, and help with daily activities (e.g., hiring assistance with cleaning, meal preparation, etc).(16) Caregivers are also more likely to face financial challenges due to lost income: 26% of caregivers take a leave of absence from work; 15% reduce their hours at work; 6% guit their jobs; and 10% turn down job opportunities.(16)

Role of the Pharmacy Technician

Caregivers looking after loved ones with long-term and/or complex conditions present pharmacy technicians with opportunities to effectively practise several of their professional competencies, including patient care, health promotion, communication and edu-



TABLE 4 - Examples of open-ended questions to promote effective communication with caregivers⁽¹⁹⁾

Asking closed-ended questions will often lead to yes or no answers and may influence the caregiver's response. They may answer yes or no to a question because they think that is the "correct" response. Try using open-ended questions to encourage the patient or caregiver to engage in open and honest discussion.

Instead of:	Try this:
Does the patient have any drug allergies?	Tell me about any drug allergies the patient has. What type of reactions did he/she experience?
Is the patient taking other medications/ Are you taking other medications?	Tell me about any over-the-counter or natural health products the patient (or yourself) take.
Have you taken this medication before?	What questions or concerns do you have about this medication?
Do you want to speak to the pharmacist? Do you have any questions?	What concerns do you have that need to be discussed with myself or the pharmacist?
Are you administering/taking the medications as prescribed?	How are you administering this medication?
Are you having challenges administering the medication?	Tell me about any challenges you have administering the medication.

TABLE 5 - Questions to help identify specific medication issues

- Is the patient refusing to take the medication?
- Is the patient experiencing any difficulty swallowing the medication?
- Is the patient experiencing any adverse reactions to the medication?

TABLE 6 - Questions to help identify issues with caregiver well-being

- How are you feeling?
- How have you been managing to balance providing care and maintaining your own daily life?
- Can you tell me about any recent changes in your own health?

cation. Caregivers are often hesitant to admit when they are struggling or to ask for help.⁽⁹⁾ When caregivers come to the pharmacy, in addition to gathering important health updates on the patient, pharmacy technicians can check in on how the caregiver is managing. Developing an open and positive relationship with caregivers can help support better health outcomes for the patient, as well as for the caregiver.⁽¹⁵⁾

Check for adherence

Pharmacy technicians should watch for adherence issues with medications. Refills requested too early or too late can be signs that the caregiver is experiencing difficulty managing or administering medications. Difficulties may include the patient not wanting to take a medication because they find the medication has an unpleasant taste or is difficult to swallow, the patient is experienc-

ing adverse reactions, or is taking too many medications. Adherence issues may also be an indication that the medication is too expensive and the patient is having a hard time affording it.

Pharmacy technicians can alert the pharmacist to any adherence issues and work together to provide solutions. If patients are experiencing difficulty swallowing certain medications, pharmacy technicians can provide information on which medications can be crushed, chewed or sprinkled on food to help increase adherence and improve patient outcomes. When medications have an unpleasant taste, technicians may be able to suggest ways to mask the taste or refer to the pharmacist to select an alternate dosage form. Pharmacy technicians must always ensure that any therapeutic decisions are made by the pharmacist. Patients with adherence issues related

to adverse reactions should be referred to the pharmacist for further assessment. If the patient is non-adherent because they are taking many medications or the caregiver is finding managing the patient's medications to be overwhelming or confusing, pharmacy technicians can provide education about compliance packaging options, complete a best possible medication history, and schedule a medication review with the pharmacist.

Pharmacy technicians can also explain the importance of, and assist in, creating and maintaining an accurate and up-to-date list of medications the patient is taking in case of hospital, specialist or other healthcare practitioner visits. This should include when and how the patient is taking each medication to ensure that other healthcare professionals have an accurate medication history.

Communicate effectively with caregivers

To open the lines of communication and identify medication problems, pharmacy technicians can ask open-ended and closed-ended probing questions in a non-judgmental manner. Open-ended questions, which encourage the caregiver to share information, should be used to start the conversation. Table 4 provides examples of open-ended questions to promote effective communication with caregivers.

Open-ended questions can then be followed up with more specific, closed-ended ("yes/no") questions to help gather more detailed information. (19) Table 5 lists questions pharmacy technicians can ask to help identify specific issues with medications and medication management.

Pharmacy technicians should watch for over-the-counter (OTC) items the caregiver is purchasing and ask whether these are for the patient or the caregiver. OTC items for the patient may require a referral to the pharmacist to determine if there is the potential for an interaction with the patient's condition or prescription medications. OTC items for the caregiver may be an indicator of the caregiver's own health.

Pharmacy technicians can start a dialogue with caregivers about their overall health and how they are managing, screening for those who may require pharmacist intervention (especially when the caregiver also has prescription medications) and those who may benefit from additional support.

Table 6 lists questions pharmacy technicians



BOX 1 - Caregiver Resources on Specific Medical Conditions

These resources provide helpful information about specific conditions that may require caregiver support.

- ALS Society of Canada https://www.als.ca/
- Alzheimer Society of Canada http://alzheimer.ca/en/Home
- Autism Canada. https://autismcanada.org/
- Centre for ADHD Awareness. http://caddac.ca/adhd/
- Canadian ADHD Resource Alliance (CADDRA) https://www.caddra.ca/
- Canadian Cancer Society https://www.cancer.ca/en/?region=on
- MS Society of Canada. https://mssociety.ca/
- Parkinson Canada https://www.parkinson.ca/
- Schizophrenia Society of Canada http://www.schizophrenia.ca/

BOX 2 - National Resources to Support Caregivers

- Alzheimer Society of Canada https://alzheimer.ca/en/Home/Living-with-dementia/Caring-for-someone
- Bayshore Health Care, Family and Caregiver Resources https://www.bayshore.ca/home-care/family-caregiver-resources/
- Canadian Cancer Society www.cancer.ca/en/cancer-information/cancer-journey/if-you-re-a-caregiver/?region=on
- Canadian Mental Health Association Caregiver Support and Mental Health https://cmha.ca/documents/caregiver-support-and-mental-health
- Carers Canada https://www.carerscanada.ca/
- Government of Canada, Benefits for Caregivers https://www.canada.ca/en/financialconsumer-agency/services/caring-someone-ill/benefits-tax-credits-caregivers.html
- Government of Canada, Self-care for Caregivers https://www.canada.ca/en/public-health/services/reports-publications/respondingstressful-events/self-care-caregivers.html
- Parkinson Canada https://www.parkinson.ca/about-parkinsons/caregiving/?highlight=caregivers%20
- Respite Care in Canada https://www.seniorszen.com/blog/2012/02/03/respite-care-canada
- Teva Caregivers Resource https://www.tevacaregivers.com

can ask the caregiver about their own well-being.

Pharmacy technicians should recognize that the stress placed on caregivers can create barriers to effective communication. Caregivers under stress may display frustration, irritability, or even anger when communicating, and may appear rushed because of multiple demands on their time. (17,18) Keep in mind that high levels of stress can make it difficult for caregivers to understand and remember information. Communication is only effective when all parties involved receive and understand the intended message. To ensure effective communication, pharmacy technicians should employ the following practices: (19)

- Use clear, simple, specific language
- Verify caregiver understanding by asking the caregiver to repeat back what you said
- Use open-ended questions to start dialogue when gathering information from the caregiver
- Follow up with specific closed-ended

questions to gather more detailed information

- Pay attention to the caregiver's nonverbal communication
- Be aware of your own nonverbal communication (e.g., look caregiver squarely in face, maintain eye contact, as well as open, relaxed posture)
- Actively listen to the caregiver
- Summarize your interpretation of what the caregiver has said to ensure you have received the intended message

Provide resources to help caregivers

Caregivers may experience increased stress when there is a lack of resources available to them. Pharmacy technicians can help ensure the pharmacy has information on resources available to help caregivers. This may include information on provincial/territorial drug programs to assist with medication costs, as well as community, provincial/territorial or national resources that can provide support to patients and caregivers of

patients with long-term and/or complex conditions. Box 1 lists some resources that may be helpful to caregivers caring for loved ones with specific medical conditions.

In addition to providing information and resources directly related to the patient and their condition, pharmacy technicians can also provide access to resources dedicated to supporting the caregiver. Caregivers may not recognize their own need for support, the importance of support, or be aware of available resources. Pharmacy technicians can remind caregivers of the importance of self-care and provide tips for caregivers on taking care of themselves (Table 7). Maintaining social support networks is important to supporting caregivers. In addition, many society or association websites for specific medical conditions also provide support networks for caregivers, offering tips for caring for a loved one with the specific condition, as well as forums for caregivers to share and connect through their own experiences. It is important that caregivers also understand the value of giving themselves a break. Respite care is short-term care that offers the opportunity for caregivers to take breaks in order to care for themselves and help decrease the risk of caregiver stress, burnout or fatigue. Respite care can be accessed through local and/or provincial/territorial agencies, many of which offer respite care for one day or several days. Pharmacy technicians can ensure information regarding local respite care agencies is available and easily accessible for caregivers. Box 2 lists national resources that may be helpful to caregivers.

Provide other education/training

Pharmacy technicians can also provide hands-on training to caregivers on the correct use of various devices (blood glucose meters, valved-holding chambers, home blood pressure monitors) and reassess their technique periodically to reassure caregivers that their technique is optimal.

Conclusion

Caregivers dealing with patients with longterm and/or complex conditions may face a variety of challenges, requiring patience and understanding of the condition. As many patients may be unable to fully communicate with their healthcare teams, caregivers will often take on this responsibility. Pharmacy technicians armed with an understanding of



TABLE 7 - Self-Care Tips for Caregivers^(12, 14)

It is important for caregivers to take care of themselves physically, psychologically and emotionally. Pharmacy technicians can share the following tips with caregivers to promote optimal caregiver health. Remember, if caregivers are not well, they will not be able to care for their loved one.

- Minimize isolation
- Stay socially engaged
- Spend time with family and friends
- Make time to do the things you enjoy
- Maintain a healthy lifestyle
- Eat nutritious food
- · Drink plenty of water
- Avoid excessive intake of caffeine and alcohol
- Engage in regular physical activity
- Go for a walk
- Do some yoga
- Get enough sleep
- Know and respect your limits
- Ask for help
- Take a break
- Join a support group with other caregivers

the condition, caregiver stress and effective communication skills, as well as resources to help support the caregiver, can play an important role on the healthcare team, offering support and education to caregivers. This will support positive outcomes for the patient, as well as the caregiver.

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QUESTIONS

1. Children with Autism Spectrum Disorder tend to experience:

- a) Increased incidence of autoimmune conditions
- b) Increased incidence of respiratory infections
- c) Increased levels of hyperactivity and impulsivity
- d) A & B

2. Which of the following is caused by the loss of brain cells due to the formation of plaques and tangles throughout the brain?

- a) ADHD
- b) Alzheimer's Disease
- c) Autism Spectrum Disorder
- d) Multiple Sclerosis

Pharmacy technicians can provide support to individuals caring for patients with chronic conditions by doing all of the following EXCEPT:

- a) Providing education about compliance packaging
- b) Performing a medication review
- c) Recognizing signs of caregiver stress
- d) Watching for OTC purchases

Please select the best answer for each question and answer online at eCortex.ca for instant results.

- Pharmacy technicians can ensure effective communication by doing all of the following EXCEPT:
- a) Actively listening to the caregiver
- b) Asking only yes or no questions
- c) Paying attention to nonverbal communication
- d) Using clear, simple, specific language
- 5. Which of the following is a sign of caregiver stress?
- a) Increased incidence of colds and flu
- b) Lack of coordination
- c) Optic neuritis
- d) Sensory impairment

6. Which of the following is NOT a strategy to help caregivers engage in self-care?

- a) Engage in regular physical activity
- b) Join a support group with other caregivers
- c) Minimize social gatherings
- d) Take a break

7. Which of the following statements is TRUE?

 a) Caregivers are at risk of developing chronic conditions, such as high blood pressure

- b) Caregivers often to do not recognize the signs and symptoms of caregiver stress
- c) Caregivers often face financial challenges directly associated with providing care
- d) A & C
- e) A, B & C
- 8. What percentage of caregivers take a leave of absence from work in order to provide care for a loved one with a chronic condition?
- a) 6% b) 10% c) 15% d) 26%
- 9. Which of the following is an example of an open-ended question?
- a) Are you administering this medication as prescribed?
- b) Do you have any questions?
- c) Has the patient taken this medication before?
- d) How are you administering this medication?

10. Which of the following statements is TRUE?

 a) Close-ended (yes/no) questions should NEVER be used when gathering information from a caregiver



- b) Communication is effective when you feel you have effectively delivered your message
- c) Open-ended questions should be used to start a conversation
- d) All of the above
- Adherence issues can indicate that a caregiver is experiencing difficulty managing or administering the patient's medications.
- a) True
- b) False

12. Factors that contribute to adherence issues may include:

- a) Difficulty swallowing medications
- b) Medications that are not covered
- c) Adverse drug reactions
- d) A & C only
- e) A, B & C

13. Which of the following statements is TRUE?

- a) Caregivers often experience increased health problems themselves
- b) Caregivers may find managing medications overwhelming or confusing

- c) Caregivers will have to balance caring for their loved one with their normal daily lives
- d) All of the above
- 14. Mary, a 40-year old married mother of two, has recently started caring for her ailing mother who has been diagnosed with Alzheimer's disease. Upon her mother's diagnosis, Mary has moved her mother into her home, so they can both adjust before her condition worsens. Mary and her husband both have stable and secure, high-paying jobs and are in good health. Mary has been receiving help from her close friends, who have been helping transport Mary's children to their various activities and have even brought over some meals while Mary adjusts to her role as a caregiver. What risk factors to caregiver stress, fatigue, or burnout does Mary have?
- a) Age
- b) Lack of support
- c) Living with patient
- d) Mary does not have any risk factors

- 15. One year after Mary's mother has been diagnosed with Alzheimer's disease and has moved in with Mary and her family, Mary's mother's condition has deteriorated considerably, placing significant demands on Mary. Lately Mary has been feeling angry, stressed and even a little resentful. Upon recognizing this in Mary on her latest visit to your pharmacy, which of the following should you discuss with Mary?
- a) Suggest that Mary ensure her social calendar is cleared. Spending too much time out with friends is only adding to her list of duties as a caregiver. If she spends less time socializing, she will have more time to take of her duties as a caregiver.
- Suggest that Mary send her mother to a nursing home to eliminate her stress and offer Mary a list of local nursing homes.
- c) Suggest Mary look into respite care to provide Mary with short breaks, allowing her
 to take some time to look after herself.
 Offer Mary a list of local agencies providing
 respite care.
- d) All of the above would be beneficial to Mary and should be discussed.

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