

# CLINICAL NOTES

I N N O V A T I V E H E A L T H C A R E S O L U T I O N S

## Chronic health conditions: Understanding their impact on Canadians

*By the Health Council of Canada*

More than nine million Canadians, or one-third of youth and adults in Canada, have one or more chronic health conditions—long-term problems such as arthritis, diabetes, cancer, and heart disease. These conditions affect well-being and quality of life and represent a significant, and growing, health care and economic burden for Canada.

### Everybody's business

Preventing and managing chronic health conditions is everybody's business. To a great extent, chronic health conditions are rooted in the way we live. A handful of avoidable risk factors—things that we can change, such as

being overweight, physical inactivity, poor eating habits, and smoking—feed our current epidemic. Sustained programs and supportive policies that enable people to reduce these and other risk factors are smart investments.

For those who already have chronic illness, access to high-quality health care can help patients prevent complications, reduce the future need for expensive health services, and secure a better quality of life. Ultimately, the nature and pace of efforts to provide better health promotion, disease prevention, and chronic illness care will be determined by the Canadian public and their influence with elected officials at all levels of government.

For meaningful progress to occur, interested Canadians, including frontline health care professionals, need to be engaged in identifying priorities, problems, and potential solutions.

### A case for action

Canadians are quite healthy by international standards, but chronic health conditions are on the rise. Though these health problems are more common among vulnerable populations, chronic conditions cut across all ages, incomes and circumstances. Because most seniors have chronic health conditions, the social and economic burden of these conditions will deepen

*continued on page 2*

## Aging vision: How visual aids can help older adults

*By Linda Petty, OT Reg (Ont), BSc (OT)*

As people age, they'll likely find that their vision is not as sharp or effective as it used to be. In fact, many seniors find they need new lighting in areas where they read or play cards, or start limiting their driving at night, as a result of changing vision. And at least 25 per cent of seniors develop age-related eye diseases, such as macular degeneration, cataracts and glaucoma. As well, those with diabetes can experience cataracts or glaucoma as well as blurred vision. Diabetic retinopathy is also common, developing in 90 per cent of those who have been insulin dependent for over 20 years.

Health care professionals who work with

seniors need to understand both "normal" aging vision and common eye conditions in order to understand how they affect older people in their daily function. As there are gaps in service and communication between rehabilitation services and eye care professionals, those involved with seniors also need to understand available services and aids to ensure that their clients receive the best possible care. With support, education, and modifications to the home environment, these clients can live independently and safely in the community.

*continued on page 4*

<b>INSIDE</b>	
<b>Helping clients through life events: A guide for professionals</b>	<b>6</b>
<b>Psychological aspects of ALS: Understanding clients' needs</b>	<b>8</b>
<b>Abuse of older adults: Detecting and managing mistreatment</b>	<b>10</b>
<b>Enhancing social support: Helping youth with chronic conditions</b>	<b>12</b>

## Chronic health *continued from cover*

as our population ages.

We can change that future—if we act now. Though there is a hereditary link to some conditions, many chronic health conditions and complications from them are rooted in the way we live. Public policies and health care programs that are designed to promote healthy lifestyles and improve the environments in which we live, work and play can help to prevent disease and reduce the burden it brings to our families and communities.

The case for action is based on these facts:

- Chronic health conditions are on the rise and now affect at least one in three Canadians—more than nine million people. One-third of these people have multiple long-term health problems.
- Chronic health conditions threaten the length and quality of Canadians' lives.
- Chronic health conditions represent a significant, and growing, health care and economic burden for Canada.
- A handful of avoidable risks, also increasingly common, cause most of the burden of chronic disease.

*Chronic health conditions are on the rise and now affect at least one in three Canadians—more than nine million people.* One-third of these people have multiple long-term health problems. While the prevalence of some chronic health conditions remains stable or has declined, for other conditions rates are rising. For example, in 2005, almost 5 per cent of the population aged 12 and older (1.3 million Canadians) had diabetes compared to about 3 per cent (722,000 people) a decade ago. Similarly, almost 15 per cent of us (4.1 million people) had high blood pressure in 2005, compared to almost 9 per cent (2.1 million people) in the 1990s. Nine million Canadians—about one in three youth and adults ages 12 and up—report that they have been diagnosed by a health care professional as having at least one of seven high-prevalence, high-impact chronic health conditions: arthritis, diabetes, cancer, chronic obstructive pulmonary disease, heart disease, high blood pressure, and mood disorders. These select chronic health conditions are much more common among lower-income Canadians, women, and seniors.

More than one-third of people with

chronic health conditions also report that they have multiple long-term health problems, and certain conditions tend to cluster. For example, more than half of people with arthritis or high blood pressure, and three-quarters of people with heart disease or diabetes, have other select conditions. Health care services must be tailored to address these patterns of multiple chronic health conditions when patients seek care.

*Chronic health conditions threaten the length and quality of Canadians' lives.* Chronic health conditions can have profound effects on people's sense of well-being and their ability to continue their everyday activities at home, work and play. Not surprisingly, health status declines and disability increases as people develop more long-term health problems.

We found that more than one-third of people with one chronic health condition report moderate or severe disability (36 per cent) and half of those with two or more conditions report moderate or severe disability (51 per cent). Those with none of the select conditions report the highest quality of life and are most likely to report no or mild disability.

Some chronic health conditions, such as heart disease and cancer, tend to cut lives short while others, such as mood disorders, are more likely to reduce a person's quality of life. If our goal is, as the authors of one Canadian study put it, to add "years to life and life to years," we should look broadly across our population and target efforts to improve both life expectancy and quality of life.

*Chronic health conditions represent a significant, and growing, health care and economic burden for Canada.* People with chronic health conditions are higher users of health care services than those without long-term health problems and the more conditions people have, the more health care they use. Compared to Canadians with none of the select chronic health conditions, those with three or more chronic conditions

- use twice as many consultations with a family doctor, 1.5 times as many consultations with specialists and other doctors, and

four times as many consultations with nurses (these are health care consultations outside of the nights that patients stayed in hospitals)

- are 11 times more likely to receive home care services
- are four times more likely to stay overnight in hospitals
- spend three times more nights in hospitals

*A handful of avoidable risks, also increasingly common, cause most of the burden of chronic disease.* A number of chronic diseases share common risk factors, which explains why so many people have multiple long-term health problems. Tobacco, alcohol, high blood pressure, high cholesterol, and obesity are the major culprits, and the World Health Organization (WHO) estimates that at least one-third of the total "burden of disease" in developed countries is caused by these five risk factors.

In recent decades, Canada has seen a surge in risk factors among young and old, fueling concerns that today's adults could be the first generation in history to develop health problems such as heart disease and stroke at younger ages than the generations before them. Obesity among North American children is leading to early onset

of chronic disease and greater likelihood that more years will be spent in ill health.

As well, rates of chronic disease and their risk factors are high and vary somewhat across Canada's regions. For example

- nearly 60 per cent of adults and more than one in four children in Canada are either overweight or obese, and obesity has risen in every province over the past 20 years.
- close to half of Canadians (40 per cent to 55 per cent across the provinces and territories) are not active enough to maintain good health.

Communities that have higher rates of chronic disease should be able to achieve lower rates, as others have done. A study showing that people in Atlantic Canada have the most risk factors for heart disease, while western provinces have the least, also found that almost half of the regional differences in deaths related to heart disease could be explained by regional differences in risk factors (e.g., smoking, obesity, diabetes, and high blood pressure), social determinants of health

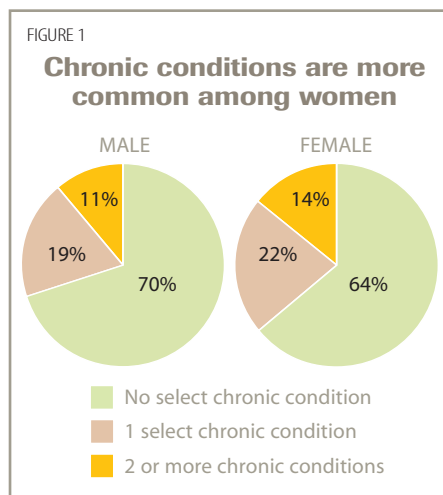
More than one-third of people with chronic health conditions also report ... multiple long-term health problems....

(e.g., education levels and unemployment rate), and community characteristics (e.g., population density and ethnic makeup).

Physical and social environments are among the other factors that may help account for differences in health status in different parts of Canada. For example, there is an inverse relationship between obesity and the size of the community where people live. Adults living in Canadian cities have lower obesity rates (20 per cent) than the national average (24 per cent) and much lower than those living outside of urban areas (29 per cent). This may in part be due to people's ability and willingness to walk more in densely-populated cities where they can rely less on motor vehicles. And diabetes rates in Toronto are higher in "inner suburb" neighbourhoods where more people rely on cars and have to travel farther to grocery stores.

*Preventive action now can secure a healthier future for Canadians and a more sustainable future for our health care system.* There is tremendous opportunity to reduce the burden of chronic disease. According to the WHO, 90 per cent of type 2 diabetes, 80 per cent of coronary heart disease, and one-third of cancers globally could be avoided if we all ate a healthier diet (less salt, sugar, and fats; more fruits and vegetables), got more physically active, and stopped smoking.

After synthesizing evidence from international research, the WHO concluded that industrialized countries stand to gain another five years of healthy life expectancy if they can do better at preventing chronic illness. For many of the risk factors for chronic disease, negative impacts can be reversed quickly, most benefits will accrue within a decade, and even modest changes in risk factor levels can bring about large improvements in people's health.



Studies in Canada have estimated how reducing risk factors can prevent chronic disease, lower the demand for health care, and save money. For example, if everyone lowered their daily consumption of salt by less than one teaspoon (1,840 mg of sodium/day), this could result in a 30 per cent decrease in cases of high blood pressure in Canada, or one million fewer Canadians with this condition. Direct cost savings—from reduced need for physician visits, laboratory tests, and medication—are estimated at \$430 million per year.

### Reducing consequences

There is much that public policy and health care can do to stop the continuing rise in chronic health conditions in Canada and to lessen the devastating consequences of chronic diseases among people who have them. Sustained, well-executed, and targeted social marketing campaigns can be a cost-effective way of improving consumers' knowledge about nutrition, their attitudes about food, and the things they eat. These interventions are particularly effective when targeted for people who are at high risk for developing chronic disease.

ActNow BC, a province-wide initiative in

British Columbia, is founded on the evidence that public policy can create a healthier future and reduce our use of health care. In 2004, the BC Provincial Health Officer projected the additional health care costs for people with diabetes, and estimated how much those costs could theoretically be reduced if the incidence of diabetes declined by 25 per cent or 50 per cent over 10 years. Potential outcomes were modelled after a widely reported study on nutritional and physical activity change, and potential savings to the health care system were estimated at \$100 million to \$200 million annually. This and other research demonstrating the cost-effectiveness of programs that help people make lifestyle changes to reduce their risk of diabetes influenced the BC government's decision to implement ActNow BC ([www.actnowbc.ca](http://www.actnowbc.ca)).

### Sustained and co-ordinated strategies

By increasing healthier lifestyles among the population, a successful program could possibly achieve an even greater payoff in terms of quality of life as well as health care cost savings. The way health care is organized and delivered can also help to delay or prevent the onset of chronic health conditions and reduce the risk of complications from them.

Sustained and coordinated strategies to help Canadians stay healthy can and do work. These investments pay dividends in very human terms and in real cost savings to society.

*Adapted from Why Health Care Renewal Matters: Learning from Canadians with Chronic Health Conditions, a report published by the Health Council of Canada. The full report is available at [www.healthcouncilcanada.ca](http://www.healthcouncilcanada.ca).*

*The Health Council of Canada monitors and reports on the progress of health care renewal.*

## Free subscription!

Published since 1999, *Clinical Notes* continues to advance professional education for therapists across North America by featuring informative articles written by your health care peers.

As part of our continuing commitment to meet the needs of our subscribers, we will be publishing new issues in electronic format only, available to download from our website.

If you would like to continue your subscription, please provide us with a valid e-mail address. To sign up for automatic e-mail notification of when a new issue is available and to download the new issue, please visit

[www.shoppershomehealthcare.ca/clinicalnotes](http://www.shoppershomehealthcare.ca/clinicalnotes)

## The aging eye

As the eye ages, the muscles in the iris, which control the size of the pupil, weaken and do not respond to light as well. This results in a smaller pupil than needed in poor light. Also, aging individuals lose more rods than cones, with one autopsy study showing almost one-third of the rods in the macula had been lost. The weakened muscle control impacts on dark adaptation, and the diminished number of rods may also be a factor. As well, the light-sensitive pigment in the rods regenerates more slowly in older eyes. As such, seniors need to adapt their habits as well as the home environment to accommodate this poorer dark adaptation and reduced sight.

## Common eye disorders

Aging adults are also prone to a number of eye-related disorders:

- **Age-related macular degeneration (AMD).** This eye condition is increasing rapidly in prevalence with an estimated 2.1 million Canadians experiencing blindness and irreversible vision loss due to AMD. And 78,000 new cases are diagnosed each year. AMD now affects more people than the number of Canadians affected by glaucoma or cataracts combined.

The cause and cure for AMD is still being studied; however, researchers know that it results in damage to the retina in the central area, or macula. Images become distorted or wavy, or blank or black spots obscure central vision, resulting in the

inability to read, drive, recognize faces, etc., while leaving varying amounts of peripheral vision.

There are two types of AMD: dry and wet. Generally, **dry AMD** progresses quite slowly, with the build up of drusen, small deposits in the deep layers of the retina, and disrupting the layers above it, eventually damaging the layer of photoreceptor cells. At present, there is no treatment. Seniors need to learn to monitor their own vision, using an Amsler Grid, or a straight line of a door/window frame, to determine any sudden distortions or changes in their vision, as up to 43 per cent of people with late stage dry AMD progressed to wet AMD within five years, according to the age-related eye disease study (AREDS).

**Wet AMD** is characterized by the proliferation of new, abnormal retinal blood vessels which bleed and displace the macula and cause rapid loss of central vision. Seniors can go from having functional vision to being unable to read, drive and perform everyday tasks in the space of three months or less, despite medical intervention. Various treatments are now available for wet AMD that can stop the deterioration and even improve visual function. However, treatment is only available from an ophthalmologist and needs to be re-administered periodically, depending on the disease's progression.

- **Cataracts.** Cataracts are an opacity occurring in the normally transparent lens, causing reduced visual acuity. Cataracts occur in six per cent of seniors and frequently

in conjunction with other eye conditions, such as glaucoma and age-related macular degeneration. While cataracts are operable, ophthalmologists usually do not operate during the early stages, resulting in a time period of at least several months to over a year in which the person may have cloudy vision and reduced acuity. Cataract surgery sometimes does not result in the complete restoration of visual function.

- **Diabetic retinopathy.** Abnormal and fluctuating blood sugars impact the blood vessels of the retina, especially over longer periods of time. Ninety per cent of individuals with insulin-dependent diabetes for longer than 20 years experience retinal hemorrhages. The fluctuations in diabetic control can result in fluctuating vision over the course of a day, and periodic retinal hemorrhages can result in scotomas, or black spots blocking the vision. Laser surgery can be used to remove exudates; however, repeated bleeding results in long-term vision loss due to scarring and scotomas. These can limit the client's reading, driving and mobility.

- **Glaucoma.** This disease affects approximately seven per cent of seniors, with increased intraocular pressure. The pressure results in damage to the retinal nerve fibers at the optic nerve head, which results in visual field defects. Glaucoma is treated with medications or surgery to control intraocular pressure; however, it can progress to severe vision loss or blindness in some cases.

## Unmet needs

After seniors access the Medicare funded services of ophthalmology and optometry, and possibly ADP-funded high-tech aids, many are not eligible for support through home care, including for occupational therapy, physical therapy and homemaking services, unless they have additional medical needs.

The Canadian National Institute for the Blind (CNIB) can help, but it receives only 29 per cent of its budget through government funding; the rest is dependent on donations, so staffing availability can be

limited. Furthermore, while CNIB staff are trained specifically in vision loss rehabilitation, this is usually through a two-year college program and does not include all aspects of rehabilitation medicine.

According to a 2004 report on the needs of those with age-related macular degeneration, for people with vision loss ...

- admission to nursing homes is three years earlier.
- number of falls is twice as high.
- incidence of depression is three times as high.

- occurrence of hip fracture is four times as high.

- number of deaths is twice as high.

These statistics demonstrate the real risks to seniors of vision loss. Providing the additional resources of occupational and physical therapy and homemaking in falls prevention, enhancing community participation and help in homemaking/personal care needs would aid in alleviating the admission to nursing homes and physical/emotional injuries incurred by seniors with vision loss.

## Services and intervention

There are at least three levels of health care providers and support who can assist older adults with vision problems; however, seniors may not be receiving all the support available due to a lack of cross referrals or information. As noted in the descriptions of the eye conditions above, significant change and fluctuation in functional vision can occur in all of these conditions. As such, seniors may require more support and additional equipment at various times and may not be aware of what is available, or who to turn to for help.

Ideally, seniors with the above eye conditions will have access to all of the following levels of service, depending on their needs and the progression of their eye condition:

### Primary medical intervention

- Ophthalmologists diagnose eye conditions and provide whatever medical treatment is available.
- Residual problems result in visual impairment and require referral to other services.

### Secondary intervention

- Optometrists measure acuity levels, etc., and provide corrective glasses or contact lenses. If these are not adequate for functional needs, the client may need additional optometric assessment by an optometrist specialized in low tech aids or by a Canadian National Institute for the Blind (CNIB) low vision specialist.
- Low technology vision aids: magnifiers, telescopes, glasses mounted or hand held, for near, mid and distance use. (In Ontario, these can be funded up to 75 per cent by Assistive Devices Program.)
- High technology vision aids: screen magnification and reading, optical character recognition, Closed circuit televisions (CCTV) for everyday reading and writing needs. Books on CD are available from the CNIB library, and are played on specialized "DAISY" playback machines.

### Tertiary intervention

- Orientation and mobility training, which is usually provided by a CNIB orientation and mobility (O&M) trainer.
- Accommodation within the home environ-

ment, usually provided by a CNIB rehabilitation worker, however, limited in scope and number of visits.

### Safety tips

Fortunately, seniors with vision problems can take a number of steps to improve their quality of life:

- Increasing light can improve function. Use task lighting, especially in places where seeing detail is needed.
- Nightlights are inexpensive and can help prevent falls, especially for older people who make night-time trips to the bathroom. When clients are in unfamiliar surroundings, such as staying at a friend's place or at a hotel, leave a bathroom light on, or travel with a night-light.
- Avoid glare and contra lighting by controlling the overhead lighting, regulating sunlight with blinds and curtains, and by placing TVs or other objects people want to see so that the window lighting won't be directly on them or behind them.
- Where possible, increase contrast by altering background colours. Examples include using place mats on desk surfaces to help seniors easily find objects on them.
- Bring items closer for magnification, or enlarge them (e.g., get a larger TV screen, or move the seating closer).
- Keep paths and stairways clear of objects, including slippers. Loose rugs are particularly problematic; get rid of them or secure them with carpet tape.
- Make sure eye glasses are clean and up to date. Seniors benefit from having annual eye check ups with their optometrist or ophthalmologist.
- Seniors need to realize the urgency of any signs of sudden vision loss and go to their eye doctor or local emergency department immediately.
- Protect eyes during the day by wearing sunglasses and a hat with a brim when the sun is shining.

Furthermore, vision loss can also affect driving ability. Seniors with declining or reduced vision can heed the following steps:

- Clean the vehicle's windshield, inside and

## Home aids and equipment

Aging adults can find support at home through various aids and equipment. Many items adapted for low vision needs are now readily available, such as talking watches and large print telephones and calculators, at local electronics stores or home health care stores.

As well, the CNIB has a centralized store for low vision/blindness aids (see [www.cnib.ca](http://www.cnib.ca)).

out, at least weekly. A grimy windshield scatters light and intensifies glare.

- Clean the headlights. Even a thin layer of grime reduces the light they cast by about 90 per cent. Also, make sure the headlights are properly aligned.
- Adjust the rearview mirror manually, if needed, to eliminate the reflected glare of headlights.
- Avoid looking directly at approaching vehicles at night. Instead, direct your eyes 20 degrees to the right to the white line on the right side of the road and use your peripheral vision to see ahead for those few moments.
- Reduce your speed at night and increase the distance between you and the vehicle ahead of you. You should be able to stop inside the area illuminated by your headlights.

Without proper support, seniors with vision loss are at risk in the community. Frontline professionals who work with these clients should understand the risks these clients face in order to help older people improve their daily function. Fortunately, with education, support and the right home modifications, aging adults with vision loss can live safely and independently.

References are available from the author. E-mail [linda.petty@utoronto.ca](mailto:linda.petty@utoronto.ca).

Linda Petty, OT Reg (Ont), BSc (OT), is a clinical specialist with the Adaptive Technology Resource Centre at the University of Toronto. For more information, visit <http://atrc.utoronto.ca> or call 416-946-3225 for the Vision Technology Service.

# Helping clients through life events: A guide for professionals

Focusing on the family is an integral component of practice. While most nurses and other health care professionals already have relevant knowledge and skills to care for families, they are interested in enhancing their expertise in this area. *Supporting and strengthening families through expected and unexpected life events*, a guideline developed by the Registered Nurses' Association of Ontario, promotes evidence-based practice and facilitates education, reflection and reaffirmation of the importance of caring for families in practice.

The intent of the guideline is to further build upon, improve and deepen nurses' knowledge and skills towards meeting the needs of families. The overall goal is to assist nurses and other professionals in promoting

family health through interventions and supports provided during expected as well as unexpected life events. Expected life events may include birth, school, adolescence, aging, and death, while unexpected life events may include trauma/accidents, chronic illness, developmental delay and disability. The guideline also includes recommendations for connecting professionals with families, in order to be able to assist families during these events.

## An integral role

The family plays an integral role in promoting and maintaining health of family members, as well as providing physical and emotional support. This guideline was developed to increase nurses' awareness of the role and

needs of the family and to facilitate the development of partnerships with the family and health care team.

Focusing on the family is an integral component of practice, as health and illness behaviours are learned within the context of the family. Families are affected when one or more members experience related health issues. The family is a significant factor in the health and well-being of individuals, and promotion, maintenance and restoration of families are important to society's survival.

## A value-laden concept

The concept of family is value-laden, and has varied over time in response to changes in predominant ideologies, values and social trends. Family definitions tend to be described according to structural criteria (what they look like) or functional criteria (what they do).

An example of a structural definition is as follows: "A now-married couple (with or without never-married sons and/or daughters of either or both spouses), a couple living common-law (with or without never-married sons and/or daughters of either or both partners), or a lone parent of any marital status, with at least one never-married son or daughter in the same dwelling."

A functional definition of the family by the Vanier Institute of the Family is as follows: "Family is defined as any combination of two or more persons who are bound together over time by ties of mutual consent, birth, and/or adoption/placement and who together, assume responsibilities for variable combinations (for such things as) physical maintenance and care of group members."

## Significant change

Over the past three decades there have been significant changes in the family environment, such as smaller families, increased diversity and more complex family relationships. Individuals construct their own definition of family regardless of how a researcher or policy-maker defines it. Therefore, for the purpose of this guideline, the family is defined as "being unique and whomever the individual identifies as being family."

## Guiding the family assessment

Following are a few questions that professionals can ask families during an assessment:

1. Who of your family and friends would you like us to share information with and who not? (identifies alliances, resources and conflictual relationships)
2. How can we be most helpful to you and your family or friends during the hospitalization? (clarifies expectations, increased collaboration)
3. What has been most/least helpful to you in past hospitalizations or health visits? (identifies past strengths, problems to avoid and successes to repeat)
4. What is the greatest challenge facing your family right now? (indicates actual/potential suffering, roles, and beliefs)
5. What do you need to best prepare you/your family member for discharge? (assists with early discharge planning)
6. Who do you believe is suffering the most in your family at this time? (identifies which family member requires the greatest support and intervention)
7. What is the one question you would most like to have answered right now? (explores the most pressing issue or concern)
8. How have I been most helpful to you in this family meeting? How could I improve? (demonstrates a willingness to learn from families and work collaboratively)

As well, here are five broad questions that can be explored with families during an assessment:

1. What is the family working on or dealing with?
2. How is the family going about it?
3. What does the family want or what is it working toward?
4. What resources is the family using and what other resources could be mobilized?
5. What aspects of the broader context of family life might explain the family's present health behaviour or situation?

Families have strengths and require support as they undergo expected and unexpected life events. Throughout the life cycle, expected changes are experienced by all families. Developmental changes in a family, such as transition to parenthood, being middle-aged parents, retirement and death, come in stages during which a period of disequilibrium occurs and adjustments are made.

## Tasks through the lifespan

An important nursing role is to assist families and their individual members move toward completion of individual and family developmental tasks throughout the lifespan. When unexpected life events occur and a family member is at home or hospitalized with health care needs, the family experiences numerous complex demands.

Recent trends within the health care system have resulted in an increased need for awareness of the significance of the family when providing caregiving. Restructuring of health care systems and the resulting budget cuts to health care organizations have resulted in the expectation for families to assist in caregiving when a family member is hospitalized. The increasing proportion of older people with disabilities and chronic illness, as well as technological advancements that enable medical treatments that were once only done in the hospital to be performed at home, have also dramatically changed the nature of home care. These trends have resulted in an increased reliance on family and friends to meet the needs of the frail, ill or disabled.

Women form the majority of home care personnel, such as visiting nurses, therapists and personal support workers. Females also provide the majority of the caregiving of older family members with wives and daughters predominating. This persistent differential representation of women providing both paid and unpaid care in the home means that shifts in the delivery of health care from institution to the household tend to affect women to a greater degree than men.

Following are a summary of eight recommendations to help nurses and other professionals assist families during life events:

### 1. Develop an empowering partnership with families by

- recognizing the family's assessment of the situation as essential

- acknowledging and respecting the important role of family in health care situations
- determining the desired degree of family involvement
- negotiating the roles of both nurse and family within the partnership.

### 2. Assess family in the context of the event(s) to identify whether assistance is required by the nurse to strengthen and support the family.

While a family assessment should include information in the following areas, it should be tailored to address the uniqueness of each family through examining

- family perception of the event
- family structure
- environmental conditions
- family strengths

### 3. Identify resources and supports to assist families to address the life event, whether this is expected or unexpected.

Resources should be identified within the following three categories:

- intrafamilial
- interfamilial
- extrafamilial

### 4. Educate nurses, families, policy-makers and the public to respond to expected or unexpected life events within the family.

### 5. Sustain a caring workplace environment conducive to family-centred practice by

- ensuring that nursing staff are oriented to the values and assessment of family-centred care
- ensuring that nurses have the knowledge, skill and judgement to implement family-centred care
- providing ongoing opportunities for professional development for nursing staff

### 6. Support the implementation of interdisciplinary, family-centred practice in the workplace by

- ensuring appropriate resources (e.g., time, staffing)
- developing and implementing family-centred practices and policies
- creating and maintaining environments that are conducive to family-centred care
- developing programs that promote work-life balance for employees

### 7. Advocate for changes in public policy by

- lobbying for public discussion on family caregiving and the development of a public position on what level of caregiving is reasonable to expect from families
- lobbying for public education about the value and legitimacy of the role of family caregivers and how multiple family members respond to life events
- lobbying for a full range of adequate and effective programs for family members who are involved in caregiving and other life events within the family
- lobbying for consistency in funding, availability and delivery of respite care programs and other supports for families across Ontario
- lobbying for the funding of research projects that examine family as the providers and recipients of care and the application of lessons learned from this research into public policy and program development
- lobbying for mechanisms within organizations for families to dialogue with one another in an open forum

### 8. Nursing best practice guidelines can only be successfully implemented if there are adequate planning, resources, organizational and administrative support, as well as appropriate facilitation.

Organizations may wish to develop a plan for implementation that includes

- an assessment of organizational readiness and barriers to education
- involvement of all members (whether in a direct or indirect supportive function) who will contribute to the implementation process
- dedication of a qualified individual to provide the support needed for the education and implementation process
- ongoing opportunities for discussion and education to reinforce the importance of best practices
- opportunities for reflection on personal and organizational experience in implementing guidelines

*References are available in the original source document.*

*Excerpted with permission from Supporting and strengthening families through expected and unexpected life events, a nursing best practice guideline produced by the Registered Nurses' Association of Ontario. The full document can be found at [www.rnao.org](http://www.rnao.org).*

# Psychological aspects of ALS: Understanding clients' needs

By Pippa Wysong

At the recent 18th International Symposium on ALS/MND, researchers described various behavioural and psychological changes seen in amyotrophic lateral sclerosis (ALS) patients ranging from having a discordance between emotions and what individuals may outwardly express, to a lack of awareness of any behavioural or personality changes.

## Identifying levels of insight

How much insight patients have regarding personality changes they might experience after developing their disease was the subject of a talk given by Jonathan Katz from the Forbes Norris ALS/MDA Research Center at the California Pacific Medical Center, San Francisco. He presented details of a study comparing the levels of insight between two different groups of ALS patients: those with frontotemporal dementia (FTD) and those without.

It's common for changes such as increased irritability to occur in ALS patients, but some individuals may not be aware of such changes. Getting an idea of how much insight people have of themselves is useful because it can tie in with how well patients comply with treatments and why there might be discordance between what a patient says about himself and what their caregivers say. It could also help indicate whether FTD or other problems are present.

## Exploring changes

A retrospective study was done on 15 patients to determine whether they had personality change since the onset of ALS, and whether they had insight to these changes. The patients had all been referred for neuropsychological assessments and completed a self-rating form of the Frontal Systems Behaviour Scale (FrSBE). A total of four patients had ALS FTD, and 11 had ALS with no FTD.

The FrSBE helps rate whether behaviour changes are associated with damage to the frontal-subcortical part of the brain. It is commonly used on patients with various neurode-

generative disorders and determines levels of apathy, disinhibition, and executive function.

Caregivers were also given questionnaires to determine their observations as to whether the patient under their care had undergone behaviour or personality changes since the onset of ALS. Comparing caregiver and patient observations can indicate whether patients had insight into changes in their behaviour.

"If the patient was not aware of the personality changes since disease onset compared to what the caregiver was saying, we'd say the patient didn't have insight into those changes," Katz says.

## Comparing ratings

Ratings from caregivers and ALS patients were compared, as were overall findings between patients with FTD and those without FTD. Subjects were asked to rate what patients were like prior to ALS diagnosis, as well as at the time they were answering the questionnaires.

When it came to the 11 ALS patients with no FTD, ratings between patients and caregivers were similar. When asked what patients were like prior to diagnosis, there was no difference between the caregiver and patient assessments. At the time the questionnaires were filled out, both patients and caregivers noted an increase in apathy, plus other minor behaviour changes—but there was agreement. For this group, "we conclude there are no significant differences between patient and family behavioural ratings," he says.

The story was somewhat different with the ALS patients who had FTD. For the time prior to developing ALS, patients and caregivers provided similar ratings and both groups noted slight changes in executive dysfunction, such as poor decision making and difficulty with complex analysis.

But after the disease had progressed, caregiver and patient ratings differed. At the time the questionnaire was administered, the four patients reported only mild changes, while care-

givers reported significant changes. "This would suggest that these patients do not have insight into the changes in their personality," Katz says.

## Examining awareness

While the study had only a small number of patients, it demonstrated that the four ALS patients with FTD were unaware of the extent of change since their disease onset. "This is very similar to the literature on FTD outside of the ALS population," he says.

While a lack of insight is a known feature of FTD, patients who have good insight but complain of apathy or poor concentration may have other conditions that also may occur in ALS, such as respiratory-related cognitive changes, apathy related to disability, anxiety, depression, fatigue, or medication effects.

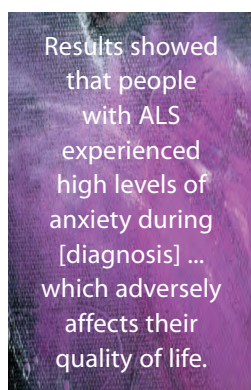
Another area reported on was patients' perceptions of how much control they have over their disease. Dr. A. Chio from the University of Torino presented a study evaluating 77 patients (39 men, 38 women) with ALS for what psychologists call "health locus of control" (HLC).

The concept behind HLC is whether people believe they have any level of control of their disease themselves (called internal control), or whether they perceive the course of the disease is influenced more strongly by external factors that they have little or no control over.

In the study, subjects underwent detailed psychological evaluation, looking not only at HLC but levels of depression, anxiety and other factors that could affect well-being and attitudes.

In brief, researchers found that most of the ALS patients had an external HLC and felt that others, such as medical staff, had greater control over their disease course. Patients who had an internal HLC tended to have higher education levels and also had higher function and lower disability scores. By age, it was found younger patients were more likely to have an internal HLC, while older patients had an external HLC. People with an internal HLC also tended to have a more positive outlook about the disease.

Other University of Torino researchers looked at anxiety, depression and quality of life (QOL) among patients and caregivers. A study was presented describing findings from 75 ALS



patients and their caregivers who were assessed for anxiety and depression during the time patients were first getting their diagnosis of ALS, and again during follow-up visits.

Results showed that people with ALS experienced high levels of anxiety during the diagnostic phase of the disease and that this adversely affects their quality of life, as well as that of their caregivers. Anxiety was present at much higher levels than researchers had anticipated and is something that needs to be aggressively treated during the early phase of their disease. Key factors that affected patients' QOL were level of anxiety, depression, religiosity and the caregivers QOL and well-being, researchers say.

### Expressing emotions

Another problem a percentage of ALS patients may suffer from is pseudobulbar affect (PBA), a condition where patients outwardly, and involuntarily, express emotions that are not the same as what they feel.

Details of this condition and a description of a newly developed test to evaluate it were

presented by Jennifer Murphy from the University of California at San Francisco (UCSF). "There are many terms for pseudobulbar affect. It has been described as emotional dyscontrol, pathological laughing and crying and PBA. More recently, the term IEED, meaning involuntary emotional expression disorder, has started being used," she says.

PBA has been reported in a number of neurological conditions, and is believed to occur in upwards of 50 per cent of ALS patients. Many ALS patients with PBA stop socializing for fear that they will uncontrollably laugh or cry at inappropriate times. They are unable to control these outbursts and are highly embarrassed by the condition.

Researchers at UCSF developed a new questionnaire called the PBAQ with the goal of creating a tool that can assess PBA more thoroughly than existing tools. The idea was to develop something that could provide "a qualitative picture of what the patient is experiencing. It's an 18-item questionnaire. It has two components: one for the patient to rate, and one for the caregiver to rate. The purpose

behind that was to get at insight," Murphy says.

### Assessing clients

A total of 40 patients underwent assessments with the PBAQ, as well as with another assessment, the CNS-LS (an assessment tool already used in practice). Findings from both sets of assessments were compared. It was found that the UCSF PBAQ detected PBA in 45 per cent of the patients, compared to 33 per cent by the CNS-LS questionnaire. Unlike the CNS-LS, the new questionnaire also asks about levels of anger and irritability among patients, something that is also useful to know about, Murphy says.

"With this questionnaire, we hope to obtain a better characterization of each patient's PBA syndrome," she says. There are effective treatments for PBA, and such a tool can help more patients get appropriate treatment.

*Adapted with permission from the winter 2008 edition of Research News Special Report, a publication from the Amyotrophic Lateral Sclerosis Society of Canada.*

*Pippa Wysong is a medical writer.*

## Linda's corner

*Linda Norton, Rehabilitation Education Co-ordinator at Shoppers Home Health Care, answers your seating and mobility-related questions.*

**Q** As part of a restraints minimization program, I want to remind staff how important it is to release the restraint (where we have not been able to eliminate it) and reposition the client. How often do clients need to be repositioned to prevent pressure ulcers?

**A** There may be legislative requirements in the province in which you work as well as specific facility policies that may provide guidance. Unfortunately, the literature regarding how frequently a client needs to be repositioned is not conclusive.

What is known is that small changes in posture can impact pressure distribution over the buttocks, and the more frequently a person moves, the better. I would aim to have clients repositioned every 20 minutes and then adjust the timing based on the client's skin integrity and tolerance. If the client is developing skin redness, pressure, friction and shear are not being managed adequately and the treatment plan will require revision.



Contact Linda via phone **416-232-1706** or e-mail **lnorton@shoppersdrugmart.ca**

**Q** I have a client who wants a power wheelchair. I believe she could be taught to use this device safely, but the team I work with on the unit does not support this idea and will not allow her to try one. Any thoughts?

**A** Introducing power mobility to a client who may or may not be safe can be a challenge. Concerns often centre around the safety of the client, or of other clients or staff on the unit.

For these reasons, it is important to establish team consensus regarding how and when power mobility devices will be introduced to clients, how safety is determined, and how and when power mobility devices will be removed if a client is unsafe.

This discussion is easier to have when establishing a policy rather than centred on a specific client. Setting a policy may help team members be more objective as to what is appropriate in specific circumstances. And once a policy has been set with team agreement, you can use it to gain support for the power mobility assessment process for specific clients.

# Abuse of older adults: Detecting and managing mistreatment

By Health Canada

Abuse of older adults is also called elder abuse or abuse of seniors. One of the simplest definitions is “mistreatment of older people by those in a position of trust, power or responsibility for their care.” Neglect is commonly associated with abuse.

## Forms of abuse

Different forms of abuse are most commonly grouped into four categories:

- Physical abuse involves inflicting physical discomfort, pain or injury. It includes behaviours such as slapping, hitting, punching, beating, burning, sexual assault and rough handling.
- Psychological abuse diminishes the identity, dignity and self-worth of the older person. Examples are name calling, yelling, insulting, threatening, imitating, swearing, ignoring, isolating, excluding from meaningful events and deprivation of rights.
- Financial abuse, also known as material or property abuse, involves the misuse of money or property. Examples include stealing money or possessions, forging a signature on pension cheques or legal documents, misusing a power of attorney, and forcing or tricking an older adult into selling or giving away his or her property.
- Neglect is the failure of a caregiver to meet the needs of an older adult who is unable to meet those needs alone. It includes behaviours such as denial of food, water, medication, medical treatment, therapy, nursing services, health aids, clothing and visitors.

Specialists in the field of abuse of older adults also recognize other forms, including medical, systemic, sexual, civic and human rights abuse. An abused older adult may experience more than one type at any given time.

## Prevalence

Findings differ regarding the number of abused older adults, and regarding who is abused and who abuses. Studies vary in the definitions of the age group and the behaviours labelled as

abuse. These inconsistencies make it impossible to compare findings across provinces or among social agencies in any one region.

Available information on prevalence is likely understated because abused older adults are reluctant to identify themselves. They often take no action against their abusers. They may be embarrassed, unsure that any good will result, unwilling to risk rejection by loved ones, or afraid of having to leave their home.

The Canadian study most often quoted on prevalence of abuse of older adults is a 1990 national telephone survey of 2,000 older adults in private dwellings. The findings are comparable to those found in other countries:

- Approximately four per cent of older adults living in private homes reported experiencing abuse or neglect.
- The most prevalent mistreatment reported was material abuse, most often involving widowed older adults living alone and perpetrated by a distant relative or a non-relative rather than by a close family member.
- Chronic verbal aggression, a component of psychological abuse, ranked as the second most prevalent form of abuse. Victims were usually abused by their spouse.
- Physical abuse ranked third. Again, in the majority of cases the abusers were spouses of the victims.

## Interpersonal dynamics

In the past, the most popular explanation for abuse of older adults was that it was provoked by stress on the person providing long-term care for the older adult. Recent research shows that the dynamics between dependent individuals and their caregivers are much more complex.

The most common explanations of abuse of older adults focus on the following:

- A web of dependent relationships, physical, emotional and financial, between the victim and abuser. Research findings are

inconsistent. Not all dependent seniors are abused. Some studies even suggest that abusers are more likely than non-abusers to be dependent on their victims.

- Traits of the abusive caregiver. An impressive amount of research has linked mental health problems and social characteristics of caregivers to abuse. One example is that abusers are more likely than non-abusers to have alcohol or other substance abuse problems.
- Situational stress. Caregiver stress related to long-term care of an older adult sometimes leads to abuse. The failure of stress-reducing interventions (e.g., home care assistance, respite care) to reduce abuse has led to less emphasis on the singular importance of caregiver stress.
- Transgenerational family violence—children from a long history of family violence “getting back at” a parent. The limited research on this theory suggests that it explains child abuse much more than senior abuse.
- Social isolation. Isolation has not been established as a cause of abuse, but abused older adults are more likely to have fewer contacts with friends and family members than are non-abused older adults.
- Pervasive societal power imbalances. Individual experience is inseparably linked to social forces and institutional practices that may support power imbalances in families (e.g., ageism or sexism).

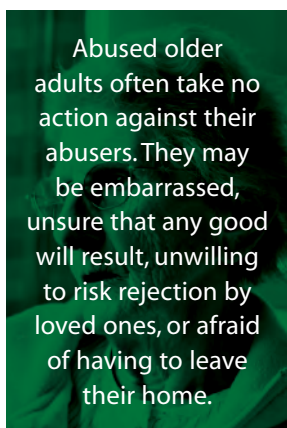
Several of these models may be required to explain abuse of older adults. Service providers and professionals need to explore all of these possible explanations to determine what intervention is most likely to succeed.

## Many roles

The persons at greatest risk for being abused or for abusing, and the conditions which put them at risk, vary with the types of abuse.

## The abused older adult

Few consistent differences have been found between abused and non-abused older adults. The age, gender, marital status, ethnicity and income level of older adults who are abused do not differ significantly from those who are not abused. Consistent differences



that do exist include the following:

- Older adults who live with someone are more likely to be abused than those who live alone.
- Older adults who live with grown offspring or other caregivers are more likely to be abused than those who live with a spouse.

### The abuser

- Males are more likely to be perpetrators of physical abuse. Women are more likely to be perpetrators of neglect and financial abuse.
- A large-scale study in the United States found that family members were suspected in two-thirds of reported abuse cases, most often adult children and then spouses. Except for the financial category, abuse by non-family members is rare in private dwellings.
- Abusers have been characterized in various studies as having other problems, including financial difficulties, recurring mental health problems, limited social supports, substance (alcohol) abuse, police arrests and poor employment records.
- To prevent repeat offences in cases of serious abuse, changing the living arrangements is usually more effective than giving caregiving assistance to the abuser.

### Detection and management

Potential indicators of abuse have been documented on the basis of the behaviours and appearance of both victims and perpetrators in known abuse cases. Recently, more attention is being paid to characteristics of caregivers. New, simple screens of caregivers are now available for identifying situations of high risk for abuse of older adults.

However, decisions about how and when to intervene are still among the most difficult that service providers face. Ethical dilemmas are common. Knowledge about successful interventions is growing but is slow to reach the practice level. Interventions are shifting to approaches that are more respectful of the rights of older persons to make their own choices. These approaches are based on increased understanding of help-seeking behaviours and the power of social support. Each intervention must be unique to the situation and to the mental competency of both the abused and abuser.

Existing domestic violence programs need to consider special approaches for older adults because

- older adults tend to be more isolated than

women or children

- neglect is generally not part of domestic violence programs
- unlike the situation for children, societal norms do not give responsibility for the care of older adults to any particular individual or agency

### A team approach

Awareness is growing among various disciplines about the critical role each can play, as well as the importance of a team approach, in the detection, assessment and treatment of abuse of older adults.

Treatment teams often include the client, a nurse, physician, social worker, geriatrician, and psychiatrist or mental health worker. Other team members may include the client's dentist, lawyer and bank manager, a representative from a housing placement service and a human rights advocate. Older professionals are valuable members on the treatment team.

Community committees focus on activities such as

- an assessment of the need for professional education, protocols, policies and procedures
- education and awareness programs for professionals and the public
- consistent tools for detection and protocols for what to do and who to contact if abuse is suspected
- standard record-keeping and tracking of referrals
- additional opportunities to enhance social support networks for all seniors, and
- processes for reviewing and changing programs

Involving seniors and seniors' organizations in local initiatives is critical for success. A Canadian network of seniors' organizations has identified 10 broad areas requiring action: justice, isolation, attitudes, empowerment, education and training, support services, housing, cultural sensitivity, research and responsibilities of governments.

Professionals and service providers need more training about abuse of seniors and increased awareness of available local community supports.

### Legislation

Mandatory reporting of abuse of older adults

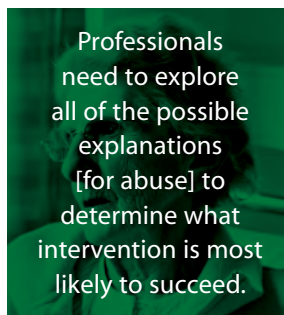
in the United States has not proved successful in reducing abuse because the resources to act on reports have not been provided.

In Canada, many believe that laws intended for the general public are adequate for cases of abuse of older adults (i.e., family law and laws dealing with physical assault, financial abuse, neglect, mental cruelty, consumer protection and housing).

New Canadian laws for adult guardianship and adult protection support models in which consumer and service providers make treatment decisions together.

As legislation changes, continuous monitoring is needed to guarantee

that decisions do not rely on the same solution for all cases. Also, the approaches supported by the law must not be so expensive that they disappear in times of funding cuts (e.g., specific advocacy services).



### Research

Research provides information that guides decisions about interventions, staffing needs and legislation. Multidisciplinary research is needed to advance knowledge in the following key areas:

- standardization of definitions and measures
- trends in prevalence and incidence of abuse
- prevalence and incidence studies in institutions and home care services
- the nature of financial abuse and neglect
- other research methodologies (e.g., first person accounts to develop knowledge about how abuse happens, continues and ends)
- the staffing and training implications of prevalence trends
- refinement of available screening and assessment instruments
- evaluation of existing intervention programs (e.g. practices, costs, outcomes of treatment programs)
- the effects of recent changes in community support systems
- evaluation of education of primary health care providers and other service providers and professionals
- monitoring and evaluation of legislative changes.

*Adapted from "Abuse and neglect of older adults," a fact sheet produced by Health Canada.*

# Enhancing social support: Helping youth with chronic conditions

By Janette McDougall, PhD, and Colleen Willoughby

Social support is considered to be one of the most important factors affecting how people adjust to adversity. Studies indicate that children and youth with chronic physical health conditions have smaller social networks and are more socially isolated than other children.

Moreover, research has shown that low social support is associated with poorer adjustment for children and youth with chronic conditions. However, studies suggest that if social support is perceived as positive, it can be associated with perceptions of happiness and success in life for these children and youth.

## Social interaction

Past research indicates that heightened psychological and behavioural adjustment problems for children and youth with chronic conditions are related to low social support from both close friends and classmates, with low classmate support having a particularly strong impact. Research indicates that students with chronic conditions are half as likely than students without chronic conditions to experience a sense of belonging, feel safe or accepted at school, or view other students as kind.

## Support for youth

Researchers suggest that initiatives to promote social support for youth should target change on multiple levels (personal, interpersonal and environmental) and in multiple environments (home, school and community). Social support not only involves the needs, abilities and perceptions of the recipient but the abilities and attitudes of the providers of support.

## Practical implications

### Personal level

- **Identify and support children and youth at**

**risk.** Early assessments of children with chronic conditions that evaluate their social skills, friendship patterns, activity limitations, recreational participation, and concerns about the effects of their condition on peer relations could be carried out by educational and/or health professionals. The potential benefits of social skills development in helping children with chronic conditions to access and maintain social support have been consistently stressed in the literature. It would be helpful for these types of identification and intervention efforts to start in the preschool years and reoccur around important transitions, such as entering high school.

### Interpersonal level

- **Encourage positive peer relationships at school.** School initiatives might be developed to increase interpersonal contact and encourage supportive relationships among students with and without chronic conditions, both within and outside the classroom. Such initiatives might include partnering children with mentors; setting up buddy relationships or support groups; providing opportunities for social interactions at lunch, and before and after school; providing assignments that involve small groups of students outside class; creating learning centres that encourage interaction; and involving all students, even those with significant needs, in providing support to others in order to develop a sense of competence.

### Environmental level

- **Promote socially welcoming and supportive schools.** Initiatives and policies could be put in place to promote socially welcoming and supportive schools, such as having monthly school themes (e.g., respect); “decategorizing”

groups (i.e., de-emphasizing differences between students); encouraging understanding for all students; providing inservices for teachers to increase their understanding of various chronic conditions; and ensuring availability of health support personnel.

- **Facilitate opportunities to participate beyond school.** Families and professionals could facilitate opportunities for children and youth with chronic conditions to interact with peers at home, in the community, and at school. It is important for parents to support and encourage autonomy so that these children and youth can benefit from both peer and family support.
- **Advocate for effective programs and policies.** Family, professional and student advocacy can help to ensure school and community initiatives and programs are in place and are truly helpful.

## Positive life outcomes

Social support can be associated with positive life outcomes for children and youth with chronic conditions. Ways to enhance their social support include

- identify and support children and youth at risk
- encourage positive peer relationships at school
- promote socially welcoming and supportive schools
- facilitate opportunities to participate beyond school
- advocate for effective programs and policies

*Adapted from Facts to Go, Volume 3, Issue 3, produced by Thames Valley Children's Centre (TVCC). To read the full document, including references, visit [www.tvcc.on.ca](http://www.tvcc.on.ca).*

*The authors are with TVCC in London, ON.*

Shoppers Home Health Care is focused on helping Canadians stay active, healthy and independent. From daily living convenience products to sales, service and rentals of mobility, durable medical equipment and respiratory care equipment, health professionals can rely on the finest products and services for health recovery and maintenance. Visit our website at [www.shoppersdrugmart.ca](http://www.shoppersdrugmart.ca) to find a SHHC location nearest you or call **1-800-746-7737 (SHOPPERS)**.

**SHOPPERS**  
**HomeHealthCare®**

*Healthcare solutions for better living*

Publisher's note: The views expressed in *Clinical Notes* are those of the authors and do not necessarily reflect the opinions of the publisher or Shoppers Home Health Care.