Saint Elizabeth

Well beyond health care

Caregiver Compass

Tips and tools to help you manage your caregiving responsibilities

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Welcome

Something happens when you are caring for another person. You discover strength you never knew you had; you find light in the darkest of places; and you develop human connections you never thought possible.

With this in mind, we created the Caregiver Compass. As a health care provider caring for individuals and families in their homes for over a century, we wanted to craft a free and easy to access resource that speaks to the challenges we see families and friends face when juggling the mental, physical and emotional dynamics of caregiving.

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

Caregiving 101

Who is a caregiver?

Caregivers provide care and assistance for spouses, parents, children and other family members or friends who need support. A caregiver may support someone because of age, medical conditions, injury, long term illness or disability.[1]

Caregivers come from all walks of life – old and young; female (predominantly) and male (increasingly); and can be found across all income levels. Caregiving responsibilities can occur suddenly; are typically chronic; and do not always have a happy outcome.[1]

Are you a caregiver?

You may not see yourself as a caregiver, but rather someone simply taking care of a person who needs you or fulfilling your responsibilities as a wife, husband, sibling or child. Seeing yourself in the role of caregiver acknowledges the important work you're doing for the person you're caring for.

Introduction

Depending on your situation, becoming a caregiver is not always a straightforward or natural progression. You may feel forced and pressured into taking on a caregiver role. You may have conflicting demands, such as a young family or a busy job, or not be very close to the person you care for. (TCCN, Carer Resource)

Becoming a caregiver could be a big change for you, and it may take some time to adjust to your new role and responsibilities. It is quite natural to have strong emotions; feeling confused and stressed is common. You may think the only way to cope is to put aside your own feelings and needs. This may work in the short term, but it will be hard to maintain, and your health may be affected. As a caregiver you have an important role, and you must be healthy and well to perform at your best. A caregiver needs to care for themselves too. (TCCN Carer Resource)

> “You are not alone. Did you know that approximately one out of every four Canadians is a caregiver like yourself? You are joined by adults of all ages caring for their spouses, parents, friends, relatives and neighbours.”

Canadian caregiver facts

- 23 percent of Canadians have reported caring for a family member or close friend with a serious health problem in 2006[1]
- Caregivers often have to juggle multiple, competing priorities such as work and caregiving. Over one in four (27.8%) working Canadians have responsibilities for the care of elderly friends/family. This number is expected to grow as the baby boomers get older[2]
- Almost one in five employed Canadians (16.8%) have responsibility for **both** childcare and eldercare. These caregivers are considered to be in the 'sandwich' generation[3].
- While more men are becoming caregivers, the majority are women – about 77 percent[4]
- Caregivers make a huge economic contribution to Canada in the unpaid work they provide – this contribution is estimated to be in the many billions[5]

Caregiver Compass Overview

Who should use this resource?

This information is relevant to you whether you are someone’s primary caregiver, meaning you coordinate the majority of a person’s care, or if you are helping to care for someone. For example, right now you may be helping a few hours a week with things like shopping or driving someone to medical appointments.

We hope that the resource may provide you with some tips and suggestions to help you care for both the person you are helping and yourself.

How to use this resource

This resource contains a lot of information about caregiving. Some of it will be relevant to your role as a caregiver now, and other information may be helpful in the future.

There is no right or wrong way to use this resource. You can come back to it as often as you need. You may wish to search through the table of contents and identify the information that is of interest to you or choose to read the complete resource from start to finish. You may decide to share it or discuss it with others.

The main sections include:

Caregiver Responsibilities – This section provides an overview of some of the responsibilities that caregivers participate in while providing support for those they are caring for. From assisting with daily living needs to home safety considerations, this section will guide you through some of the most common caregiver responsibilities.

Navigating the System - This section will review some of the most common medical illnesses in Canada and provide you with links for further information. You will review how to manage the personal information of the person you are caring for including health, financial and legal information, and how best to communicate with health care providers. In addition, it provides an overview of the specific health care and supportive services available to you as a caregiver, including where to access help and equipment.

Providing Care at End-of-life - This section is for individuals caring for someone at end-of-life. It will help to answer questions about being a caregiver at this time, including some direction on the things to say and do. The section will provide skills such as communication, compassion, patience, and practical hands-on care. It also includes an overview of how to work with the dying person to find out what they need and prefer during this time.

Caring for the Caregiver - The focus of this section is to explore how to take care of yourself while still fulfilling your commitments as a caregiver. It will review some common emotions you may experience as a caregiver and some strategies to help you cope with negative emotions. In addition, the section will provide a review on how to recognize when you need help and the types of assistance available.

Glossary – Definitions of terms that are referenced in the Caregiver Compass.

The information is here to provide you with information as you provide care.

Introduction

Terms of use:

The Caregiver Compass resource does not provide medical advice. Please be advised that all of the information in this resource is provided for informational purposes only. It is not a substitute for professional medical advice, diagnosis or treatment. Reliance on any information provided by the Caregiver Compass resource is solely at your own risk.

Special Recognition:

This resource is a collection of wisdom contributed by staff at Saint Elizabeth Health Care, partner organizations and other experts in the field of caregiving. We would like to thank the following people for their contributions and support in creating this resource:

- Vicki Lejambe
- Laura Jakob
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- Monica Goulet
- Christi Lindensmith
- Christine Stewart

References

This area is compilation of the supporting documents, references, glossary of terms and web sites that are referenced in the Caregiver Compass.

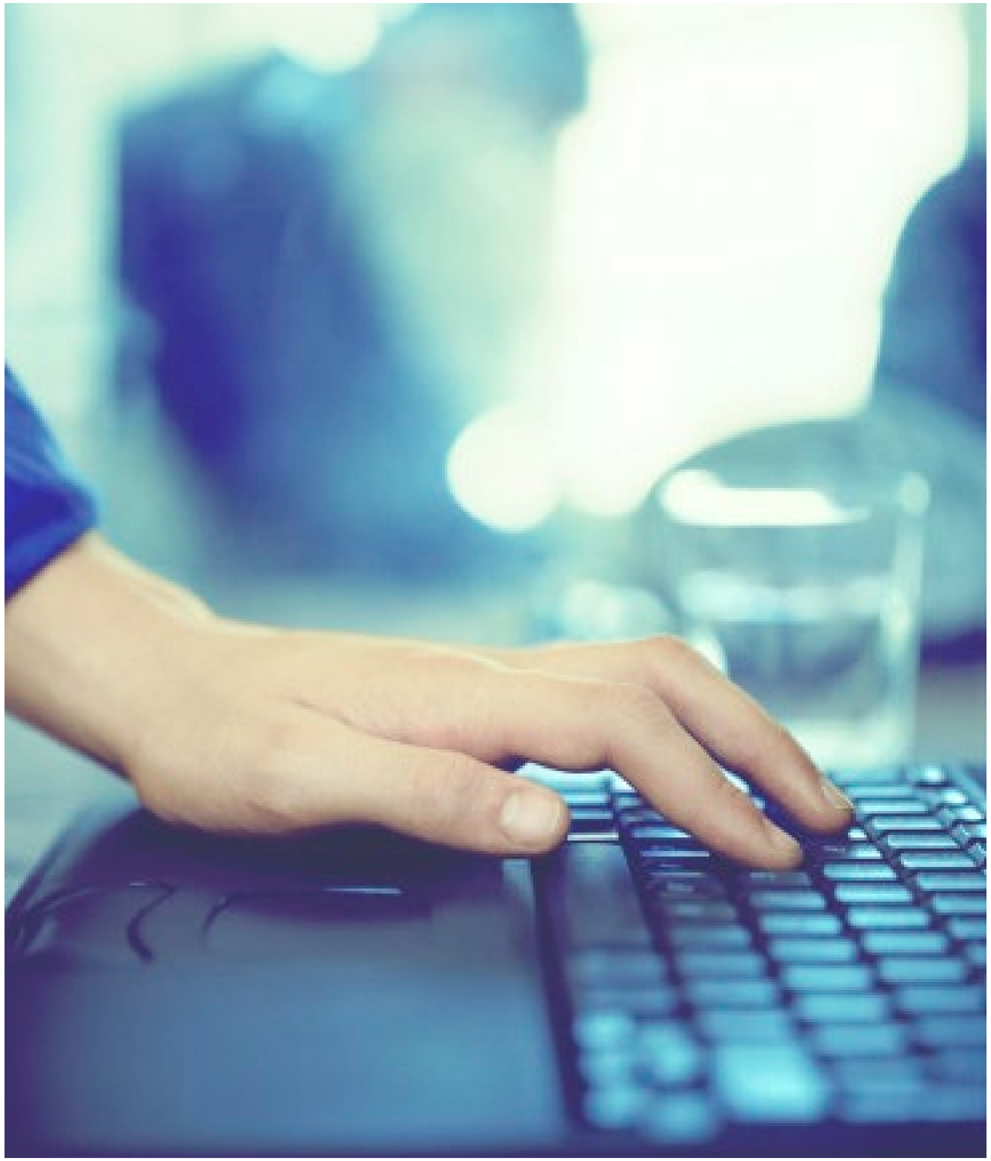
[1] National Profile of Family Caregivers in Canada – Final Report. Health Canada. 2002. Web. www.hc-sc.gc.ca. 2010.

[2] Duxbury, L., C. Higgins, and B. Schroeder. "Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada." *Canadian Policy Research Networks*. 2009. Web. www.cprn.org/doc.cfm?doc=1997&l=en. 2010.

[3] Ibid.

[4] Ibid

[5] Hollander, M.J., G. Liu, and N.L. Chappell. "Who Cares and How Much? The Imputed Economic Contribution to the Canadian Healthcare System of Middle-Aged and Older Unpaid Caregivers Providing Care to the Elderly." *Healthcare Quarterly*, 12.2 (2009).



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Overview

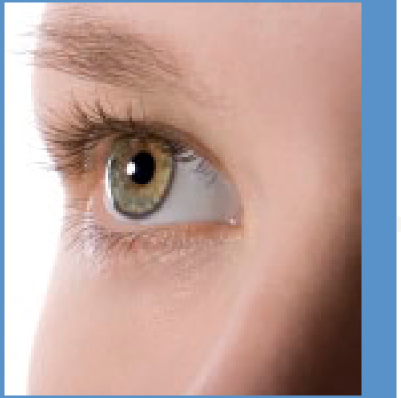
Many caregivers report that they feel better prepared and less anxious when they are equipped with information about the skills and tasks that may be required of them as a caregiver.[1] The skills needed to become a caregiver are sometimes far more complex than they initially appear. For instance, driving an elderly person to an appointment is not just about hopping into the car and going for a drive – it may involve dressing the person, transferring them into and out of a wheelchair, into the car and out again and ensuring there are no potential safety risks to the person.[2] This activity requires many different skills!

Often caregivers learn the skills needed from health care providers.[3] The information in this section of the resource aims to complement this information or fill in the knowledge gaps so you can complete the practical tasks that may be required of you.

While not all of the information in this section may apply to you at this time, it may be helpful to be familiar with the content in case you ever need to refer back to it. If you have questions, be sure to bring it up with a health care provider, as they are the best person to give you specific advice about your role.

Key Tips

- Don't be afraid to ask for help! Some of these skills may be new to you. If you have questions or need support ask a health care professional, family member or friend. Community organizations may also provide some of the help you need
- Remember part of being a caregiver is also caring for yourself! Make time for yourself.
- Respect the choices of the person you care for, even if you don't agree with them. As long as there is no risk of danger to themselves or others, it is important for that person to be able to make his or her own decisions wherever possible.



- Try not to focus just on the physical needs. Individuals still need to feel connected to the people around them and to participate in activities just like they did before they became ill. By making them feel part of a normal, functioning household, and by providing them with favourite distractions such as music, television, crafts, etc., you may also have more time for yourself!

Assisting Someone with Daily Living Needs

Providing practical care is an important element of caregiving. The following are some key activities that make up a person's daily needs. Caregivers report that assisting someone complete these tasks is easier when they understand ***how*** to help.

Helping with bathing/showering and grooming

Bathing/showering is a personal activity. Try to allow the person you are caring for as much privacy and independence as possible during this activity. Minimizing how physically exposed a person is can help. You may wish to help a person to wrap a towel around private body parts and clip it with a clothes pin (or Velcro tabs), or the person may prefer to wear a long, plastic apron in the tub or shower for additional privacy.

Keep in mind that even though a specific task may be done more quickly if you do it, you should try to let the person do things for him/her self when possible (and when they are safe). For example, someone may be able to take a bath independently, but needs your help with washing his or her back. Remember to take your lead from the person as to how much or how little to help out.

Try to make bathing a comfortable and enjoyable part of the day. Keep the bathroom as warm as possible and free of drafts. Some people may enjoy music during a bath. Remember that, if you are plugging in a music player or radio, you should keep them away from water or the sink. Perhaps a special scented pot-pourri can help create a comfortable bathing environment. Bath oils should be avoided, as they can make the tub slippery.

Some tips have been summarized from Harry von Bommel's book, "Caring for Loved Ones at Home: An illustrated, easy to follow guide to short or long term care" that will provide some ideas on how to support the person you are caring for.

Tips for bathing and showering

- Use a liquid soap dispenser and a large sponge to make cleaning easier
- Use mild, gentle soap and shampoo (e.g. mild baby wash)
- Always try to have everything ready for the bath or shower before you assist the person in getting to the bathroom
- Keep the area around the bathtub or shower stall dry by wiping any excess water off the floor

- Test the water temperature with your elbows to make sure the water is not too hot or cool
- Ask the person if the depth and temperature of bath water is okay
- Cover the eye area with a dry cloth during hair washing in the tub. To further avoid shampoo and water in the eyes, you may want to use a bath visor. These flexible and waterproof visors have a large hole at the top of the hat for putting the hair through and are available in the children's bathing section of a department store.
- A hand-held shower head attached to the faucet will make rinsing and hair washing much easier

Bed baths

A bed bath may be an appropriate option if the person you are caring for is unable to bath or shower. A bed bath is accomplished by filling a large bowl with water, prepared ahead of time. Test the water before washing to make sure it is not too hot. You may actually want to have two basins of water: one filled with some mild liquid soap for washing and another with clean water for rinsing.

It helps to have the wash cloths, soap and any cream you are using near the person's bed, along with a comb and brush. The person's change of clothing should also be close by. When you are giving a bed bath, wash one body part at a time with a sponge or washcloth, and keep the rest of the body covered with a warmed bed sheet or large, warm towel. Make sure to keep the room at a comfortable temperature.

Toileting

Toileting can be a very important part of caregiving[4]. If the person you are caring for requires assistance with toileting, it may be uncomfortable for both of you. Try to be very matter-of-fact when talking about toileting needs (e.g. "Tony, is this a good spot to keep the bedpan?"). Also, try to keep the conversation light and normal, and provide toileting assistance in the same way you would provide any other kind of help.

A person needing help with toileting may feel a big loss of privacy and independence. You can help to keep a person's dignity intact by allowing as much privacy as possible. For example, if someone is able to get to the toilet on their own, help them to do so and then leave the room, if possible, until you are called to help.

As you become more experienced with toileting assistance, you'll become more skilled at things such as quick clean-ups and it will become part of the regular routine, making it easier for you and the person you are caring for. Here is some information on toileting assistance items and tips that you may find helpful:

Using a bedpan or bedside urinal

There are different kinds of bedpans and it may take a few attempts with different styles until the most comfortable one is identified. To get a person onto a bedpan, ask them to lie on their back with their knees bent when you put the bedpan under the buttocks. The person can also roll to one side while you put the bedpan against the buttocks, and then have the person roll onto their back. Some people recommend putting baby powder at the top of the bedpan to help prevent the person's skin from sticking to the bedpan.

It is important to clean the bedpan regularly with hot water and soap, and rinse the bedpan thoroughly each time you empty the contents (you can keep the bedpan odour-free by rinsing with cold water and baking soda).

TIP

> Ensure that any damp skin is cleansed and properly dried after a person has used a bedpan. If not dried properly, damp skin can speed up the development of bedsores.

Bedsores are caused by constant pressure on the skin. The constant pressure damages the tissue underneath the skin, resulting in sores. Watch out for red areas of the skin that do not go away a few minutes after pressure has been removed and if noticed, report them to a health care provider.

Using incontinence pads

An incontinence pad (sometimes called a bed-pad) is a plastic pad you can place on the bed, directly under the person's buttocks. These pads protect the person's bed, and can be easily taken away and replaced when soiled. It is important that bed-pads are always fresh as soiled pads will be uncomfortable for the person and can cause skin irritation.

The pads can be disposable or reusable. Reusable pads must be washed regularly, and you can store the pads in a tightly sealed container or plastic garbage bin until washing time. If you are using disposable pads, make sure that when you put the pad in the garbage, it is brought outside immediately as soiled pads in or near the person's room will create unpleasant odour in the living space.

Using plastic bed covering

A plastic bed cover (sometimes called mattress cover) can be found in many department stores in the bedding section. This cover goes under the bed sheets to protect the mattress.

Using adult diapers/adult briefs

Incontinence (loss of bladder and/or bowel control) is not only a problem for many who are aging. In fact people who are ill, who have suffered an injury, who are in bed for extended periods, or who are receiving palliative care also frequently experience incontinence. Adult incontinence products such as adult diapers (also called adult briefs) and underpants with pad pockets can help a person stay dry and more comfortable throughout the day and evening.

Adult plastic briefs also allow for some increased independence. The person can walk around, without having to worry about leaking through cotton undergarments. The choice of products will depend on the amount of incontinence being experienced. As with other incontinence products, it is very important to regularly change adult briefs or liners.

Moving/Positioning the Person You Are Caring For

A common responsibility for caregivers is the need to assist with the moving, repositioning or transfer of the person you are caring for. This is a task you will want to approach with great care. Health care providers may have provided you with some guidance in this area and the tips outlined later in this section will provide additional considerations to assist you.

Watch these short caregiver video demonstrations for lifting and moving a person safely.

Visit the Caring for Family section of the Saint Elizabeth website at www.saintelizabeth.com/family for more caregiving information and support.

Tips for lifting and moving

- Before lifting or moving, let the person you care for know what you are planning to do (e.g. “I’d like to help you sit up now, Dad”). If they resist, try to postpone the task (if possible) until a better time. This is simply a way of showing respect.
- When preparing to lift or move, always spread your feet shoulder-width apart, and bend your knees, using your leg muscles to lower your body. Try to keep your shoulders and neck muscles relaxed.
- Before you lift or move someone, make sure the person is as close to your body as possible.
- Keep your stomach muscles tight, and use your stomach and leg muscles to lift and move.
- Be prepared for unexpected movements - any lifting or moving should be done slowly, step-by-step. Pause during each step.
- Try to avoid twisting your body. Always move your feet around with your whole body when turning or pivoting.
- If you cannot lift or move someone without hurting yourself, get help!

In addition, you may want to watch some short videos on specific moving techniques that are provided by the University Health Network (UHN). Click here to visit their web site and choose the video that best suits your current needs and will assist you in moving people safely.

View Video

Assisting with walking

Helping someone move and walk around as much as possible may help to increase appetite and will also help the person feel better. Little walks outside can be very important to somebody receiving care, and will be a special time for both of you. When walking with the person, place your closest arm around the person's waist. Use your other arm to reach around in front of you and hold the person's hand or elbow for extra support and leverage. As you walk, ask them if the pace of walking is okay and try to remember to take it very slowly, especially since the person might be dizzy after a prolonged period of lying down.

Assisting someone to move in bed

If the person you are caring for cannot move in a bed, you will need to make sure he or she is turned frequently throughout the day (about every couple of hours). This will prevent bedsores and will be better for the person's comfort. Bedsores are caused by constant pressure on the skin, usually where bones stick out more. The constant pressure damages the tissue underneath the skin, resulting in sores. Watch out for red areas of the skin that do not go away a few minutes after pressure has been removed.

TIP

In his book, *Caring for Loved Ones* at Home, Harry van Bommel provides the following steps for this technique:

- Have the person's far arm across the chest toward you.
- Bend the far leg at the knee while the foot still rests on the mattress. Bring the bent leg toward you. As you do this, the far shoulder will naturally start to move toward you through the leverage of the leg. Reach over with your hand to guide the shoulder toward you comfortably and safely. This will put the person on their side with the bent knee helping to keep him or her lying in that position.
- Place pillows to support the back and, if necessary, between the legs for added comfort. Adjust the head pillow as needed.

Assisting someone who has fallen

If someone has fallen down while you are helping to transfer or walk with them, consider the following:

- While holding onto the person, let him or her slowly go down; try to support/protect their head and go down with them by bending your knees and tightening your stomach muscles.
- Ensure the person is okay. If he or she is conscious and able to understand you, check for any pain or injury.
- At this point, you may need to call for help. If so, keep the person as comfortable and calm as possible (it may be helpful to bring pillows and blankets).

If you and the person you care for can manage it, try to help the person into a chair or wheelchair (with brakes on). If the person can kneel in front of the chair and has a strong arm for leverage, he or she may be able to pull up to a standing position. Use the pivot and turn directions (see Specific Moving Techniques) to help the person into the chair. Once the person is sitting, use regular stand-pivot-turn techniques to help the individual return to bed or another location.

Managing pain and other symptoms

The person you are caring for may experience physical pain or discomfort related to a specific disease or condition (e.g. cancer or arthritis pain). Also, pain may come from treatment of the condition or disease (e.g. medication side effects or pain resulting from surgery or radiation). Keep in mind that most physical pain can be well managed.

It is important that the presence of pain be reported to the medical team, who can suitably intervene. Often, people under-report the incidence of pain, which may occur for a multitude of reasons.[5] If the extent of pain is not properly and fully reported to a doctor, the prescription may be too weak. Sometimes it may take a few different attempts to achieve the right combination of medication and treatment to adequately relieve pain.

The experience of pain varies from person to person. One person's stomach cramps or back pain may be experienced as mildly uncomfortable, while another may experience those same aches as overwhelming or unbearable. The sensation of pain may actually be increased by negative feelings such as anger and depression. On the other hand, someone who is feeling positive and well-rested is more likely to have a higher tolerance level when it comes to feeling pain.

A person's doctor and health care team are equipped to help a person cope with a range of symptoms from mild nausea to severe abdominal pain, to post-operative pain. There is no need for someone to suffer in silence. Proper pain and symptom management will make the whole care giving experience a better one for both you and the person you are caring for.

For more information about how to manage pain, click here for free resources on the Saint Elizabeth website that will provide further guidance.

Helping with dressing

It will be easier for both you and the person you are caring for if clothing is kept as practical as possible. Pants with zippers and buttons are not helpful - choose loose fitting pants that can easily be pulled down and up. You will find that clothes with Velcro fasteners can help increase independence with dressing. It is also better for the person to wear long t-shirts or simple night shirts for bed. Make sure you involve the person in choosing what clothes they want to wear and buy.

General dressing tips:

- If the person you care for has a non-functioning limb, insert it into the garment first
- To put on a sleeve, insert your hand into the armhole and then pull the sleeve over the person's arm
- Underwear should not be tight
- Tight fitting stockings and nylon pantyhose are not recommended, however, for special occasions, you can first roll the leg of the pantyhose all the way down to the ankle - insert the person's foot, and slowly roll up over the person's leg

Helping with mouth care

Proper mouth care is an important part of pain management, as regular cleaning of the teeth and gums will help prevent mouth sores. Encourage regular brushing and gentle flossing. Also, dentures should be kept clean (brushed and rinsed thoroughly). If you are cleaning dentures, make sure you put a face cloth in the bottom of the sink or basin/bowl to prevent breakage if dentures are dropped. The person should always rinse out his or her mouth before putting in dentures. If you are storing dentures, be sure to put them in water to prevent drying or cracking. If the dentures do not fit properly, or cause discomfort the person you care for may choose not to wear them – you can bring this to the attention of a health care provider or oral hygienist.

Helping with foot care

Foot care is an important aspect of overall health and is particularly important for people with diabetes and circulatory problems.

Check the feet every day and look for:

- ✓ Cuts
- ✓ Blisters
- ✓ Sores
- ✓ Red spots
- ✓ Calluses
- ✓ Ingrown nails
- ✓ Cracked skin

If you see an open sore that is red or swollen, or has pus or is painful, make sure the doctor is made aware. For additional information, visit the Saint Elizabeth website.

Communicating with the Person You Are Caring For

Caring for people doesn't always involve physical tasks, but may also include emotional support. Communicating with someone you are caring for is not always easy. In fact, it can sometimes be quite complicated. Often people who are ill feel afraid, sad, angry or lonely - many of the same feelings you may have yourself (refer to Caring for the Caregiver section). They are also often dealing with changes in their body, their appearance, their mental abilities, the roles they play in life and thinking about what the future holds for themselves and the people they care about.

> When you are helping someone deal with these feelings, it helps to display respect and gentleness. Be a patient listener and allow them to express their feelings.

Often, although you may be unable to fix the problems, it can help if you just listen. These emotions are likely to change over time. Enquiring how the person you are caring for is feeling at different times may result in different reactions.

Caregiver Responsibilities

Review and consider some of these tips on how to communicate more effectively with the person you are caring for:

- Try to encourage the person to tell you more about his or her feelings (avoid questions that result in a yes/no answer)
- Pay attention to nonverbal communication such as body language and lack of eye contact for clues as to how the person may be feeling
- Perhaps share your own fears and emotions if the person seems reluctant to tell you what he or she is feeling – you may help break the ice
- Avoid phrases that tend to shut the conversation down like "Don't worry about that", "You'll be just fine" or "What do the doctors know anyway?"
- Listen more and talk less
- Repeat back what the person has said to make sure that you understand
- Offer reassurance that you will try to help to have the person's needs taken care of (physical, emotional and spiritual)
- Help the person focus on what he or she is still able to do
- Make eye contact when you are talking
- Avoid deep conversations when you are rushed – try to allow the person time to talk
- Express yourself physically, as well as verbally – a touch on the hand, stroking of the hair or a kiss on the cheek can make a difference

Caregiver Responsibilities

While being a compassionate listener is most important, information can go a long way to helping people with their fears. Providing information to the person you are caring for about their condition can help. Some people will want to know everything all at once; others will want information to come in stages. This is normal - we all have preferences about how and what information we receive. Ask the person what information they would like to know and try to provide it accordingly.

When people who are ill have trouble speaking, they may understand far more than they can say. Encourage them to express themselves through writing or through hand movements and other body language.

If you find you need assistance with your feelings or those of the person you care for, try reaching out for help. Help can come from another family member, a social worker, nurse, doctor, chaplain, or spiritual advisor.

Visit the Caring for the Caregiver section to access additional information on when and how to get help.

Mealtimes and Eating

Now that you are a caregiver, you may find yourself putting a lot of energy into meal planning and preparation. Helping with meals can be a wonderful way to show caring and respect for someone who needs help.

Some people will require special dietary plans, and there may be some foods a person may need to avoid altogether because of potential side effects. Speak with the health care providers about any special dietary needs/concerns. The providers can help you with important tips, such as planning the time of meals around medication needs. For example, it might be important to take medication with food or on an empty stomach.

You can also consider requesting a meeting with a dietitian. Dietitians can provide valuable information on meal planning, including reviewing the appropriate quantities of food to serve, types of foods needed, and vitamin content of various foods. With a dietitian's advice, you will be able to ensure that meals are based on the very specific condition and health requirements of the person you care for.

Preparing meals when you're short of time

If you're like many caregivers, you might be finding it difficult trying to juggle your daily meal tasks along with everything else on your list of things to do. To help make mealtime more relaxed for yourself, try to find simple recipes. It is possible to serve healthy and nutritious meals that are also easy to make and quick to prepare.

Finding the time and energy

Now may be the time to take advantage of the frozen food section or pre-made dinner section of your grocery store. Try to choose healthier pre-made food (e.g. frozen vegetarian lasagna would be healthier than frozen fish and chips). Add a whole grain bun for extra nutrition at mealtime. In some areas you might be able to order groceries from the Internet or call in a grocery order for delivery. Another alternative may be a volunteer or community service in your area that delivers hot, nutritious meals or packages of pre-frozen meals that are easily heated as needed (e.g. Meals on Wheels). When friends and family members ask how they can be of help, don't hesitate to mention a casserole or meal!

The following time and energy saving list has been adapted from Dietitians of Canada.

- Use a slow cooker or microwave (a slow cooker can cook a stew for you while you get on with other activities in your busy day).
- Use a blender, chopper or food processor rather than hand chopping foods.
- Use a blender if you need to prepare pureed food (e.g.if the person you care for has chewing or swallowing problems)
- Plan for leftovers so you don't have to cook everyday. Make large portions of each meal and freeze what is not eaten. Casseroles, soups, stews, vegetable pies and meatloaves freeze well. Store in single meal containers or freezer bags. Label packages with contents and date and make sure the labels are easy for you and the person to read.

Meal planning

Planning meals in advance is another way to save time. If you help the person you care for to plan meals a week ahead, you don't have to think each day about what to serve. Weekly plans will also provide you with a pre-made list of groceries that need to be purchased. Pre-planning meals can also be very helpful if you know someone is going in for surgery. You can plan post-surgery meals with the person and then make and freeze individual size portions in advance.

Proper meal planning can help to maximize a person's recovery or their simple, daily comfort. A healthy diet includes food from each of the major food groups: Grain Products (e.g. whole wheat bread), Vegetables and Fruits, Milk and Dairy, and Protein (e.g. meat, poultry, fish and lentils). Canada's Food Guide is a useful tool to use in planning meals. Access the guide on the Health Canada website at http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php.

Do you have more questions on healthy eating – visit www.ontario.ca/EatRight to connect with a Registered Dietician and get instant advice or search the various articles with detailed information on healthy eating.

Food safety

> Don't forget the importance of safe food handling when you're preparing meals. Food poisoning can be a painful or very dangerous result of improper food handling.

Caregiver Responsibilities

Here are some tips for safe food storage, handling and meal preparation:

- Clean out the fridge regularly. Throw out anything that's been sitting too long or has reached its expiration date.
- Cook meats thoroughly. Never let raw meat, poultry or seafood sit out on a counter – they should be taken straight from the fridge to the grill.
- Always wash your hands. This rule is especially important before and after handling any meat, poultry or seafood. Keep the cooking area around these foods very clean. Do not let raw meat, poultry or seafood touch any other food or let their juices leak in the fridge or onto the counter.
- Buy all your frozen and refrigerated foods (including meat, milk and eggs) last. Get these foods from the grocery store and into the fridge as soon as possible.

- Be sure to keep ready-to-go meals warm. Place small portions of hot meals that are not going to be eaten into tightly sealed containers to store in a fridge or freezer.
- Remember the general rule of thumb is to keep cold foods cold and hot foods hot.

Coping with poor appetites

When people are ill, they often do not want to eat that much. It is not uncommon for someone recovering from illness, injury or surgery to have a decreased appetite. If someone is in advanced stages of an illness such as cancer, he or she may be experiencing "cachexia-anorexia". This condition involves serious and progressive weight loss that may be due to treatments, medications or other illness-related factors.

If you find the person you care for is not hungry, there are various ways to enhance the appetite.

- Serve smaller meals more frequently throughout the day based on what the person can tolerate – often people will eat more if they are not presented with a large serving.
- Aim to make all meals and snacks nutritious and nourishing – they all contribute to the overall goal
- Talk to the doctor or pharmacist about the value of nutritional supplements – it help to make nourishing drinks as replacement meals
- Give favourite foods often

Older adults with dementia experience many challenges eating meals. Factsheets on nutrition and dementia provide more information on topics such as food jags and improving eating environments.

Home Safety

Home safety is a very important aspect of providing care to someone else and you may need to make some changes to the home to ensure the environment is safe.

Home safety tips

Make sure you involve the person in any changes if you are in their home and consider the following home safety tips which may help:

- ✓ Make use of assistive devices such as grab bars in the bathtub, shower seats, raised toilet seats, etc.
- ✓ Consider raising seat heights on furniture to make it easier to sit down and stand up
- ✓ Rearrange cabinets so the items that are needed frequently are within easy reach
- ✓ Make sure smoke detectors are installed and working
- ✓ Purchase a fire extinguisher and place it in the kitchen
- ✓ Set the water heater temperature at less than 49 degrees Celsius or 120 degrees Fahrenheit in case the person's skin is less able to sense heat
- ✓ Consider removing electrical appliances such as hair dryers and razors from the bathroom
- ✓ Make sure the driveway and walks are salted in the winter

Falls Prevention

Falls are a very serious issue for elderly people being cared for in the home. The risk of falls increases:

- In individuals over the age of 65
- When taking more than 4 medications daily
- When taking drugs to assist with sleep or to settle nerves
- When individuals have problems with balance, strength or sensation in their legs/feet, have difficulty walking, or getting in or out of the bathtub
- In individuals who have a history of a slip, trip or fall in the last twelve months

General safety and precautions:

- Install sturdy banisters on both sides of the stairs
- Use sturdy, non-slip rugs without rips or tears
- Salt driveways and walkways in the winter
- Install bright lights in hallways and bathrooms
- Clear pathways of any extension cords or other tripping hazards
- Remove mats or tape them to the floor

Bathroom safety:

- Use grip bars and a rubber mat in the bath/shower
- Use hand-held shower heads to help with rinsing and hair washing
- Consider raised toilet seats
- Use bath/shower seats if the person needs seated support
- Do not use bath oils
- Bath oils are avoided

Equipment and supplies are also available to help with safety. More information can be found in the Navigating the System section.

When can you leave the person you are caring for home alone?

You will want to think about whether or not a person should be left alone and you may need to re-evaluate this as time goes on. To minimize the safety risk, the person you care for should, at a minimum, be able to:

- Use the phone to call for help if necessary
- Feel comfortable with being left alone
- Recognize the sounds and signs of danger and leave the home when necessary to find safety
- Make a meal when hungry
- Use the bathroom without help
- Recognize when someone is a stranger

Other factors to consider include whether or not individuals are likely to wander or cause harm to themselves or the home, and the likelihood of suffering from a health emergency such as a fall or seizure.

Medication Safety

Avoiding Drug Reactions

> Many deaths and complications from drug reactions can be avoided. As a caregiver, you can help by making sure you have a complete list of current medications.

You can review the list with a pharmacist to identify if there are any drugs that should not be taken together. The pharmacist or doctor can also help educate both of you about potential side effects. In Ontario, MedsCheck is a program that allows you to book a free annual 20-30 minute meeting with your community pharmacist..

To avoid overdoses and make sure drugs work like they are supposed to, it is important that the person you care for takes medications at the right times and in the right dosages. You can purchase special dosettes at a drug store. Dosettes have compartments to organize all the medications that need to be taken each day. Pharmacy's can also prepare "blister packs" to reduce the confusion of which pills to take when and to act as a prompt that the medications have been taken. Old and expired medication can also pose problems. It is a good idea to go through all medications on a regular basis and discard those that have an expiry date that has already passed.

When you are at home

- Check medications, including over the counter medications, for expiry dates and dispose of them appropriately; **do not allow anyone to take an** expired medication
- Do not put out-of-date or unused medication in the garbage or down the toilet or sink; check to see if your pharmacy has a drug recycling program that disposes of unused or expired drugs in an environmentally safe manner
- Ensure the person you care for takes the medications as prescribed; don't let them stop taking a drug part way through the course of treatment, unless they are having a serious adverse reaction, without first discussing it with their doctor
- Check medications picked up from the pharmacy to ensure they are correct, have the right name on the prescription, and are what the person is used to taking (i.e. the pill is still small and pink not large and green); follow up with the pharmacy regarding any discrepancies
- Medicine should be taken only by the individual for whom it is prescribed – never take prescription medicine that wasn't prescribed for you, even if you have the same medical condition
- Encourage the person you care for to take their medication where there is enough light to read medication instructions and to see the medication
- Keep medication out of the sight and reach of children
- Consider using a dosette or, if the person you care for has difficulty remembering their medications
- Report any adverse reactions to any medication, even over-the-counter medications or supplements, to the doctor right away.

When you are with the doctor:

- Be sure the doctor knows all of the medications the person you are caring for is taking, including prescriptions, over-the-counter medicines, vitamins and herbs
- Be sure the doctor knows about any allergies or adverse reactions they have had to any medication

- If the doctor writes the prescription by hand, make sure you can read it
- Ask the doctor to write down on the prescription what the medicine is used for – not just "take once a day" but "take once a day for high blood pressure"

When you are with the pharmacist

- Take advantage of the service offered to review medications with a pharmacist when you pick them up; ask for written information.
- If you have any questions about the directions on your medicine labels, ask – medicine labels can be hard to understand (for example, ask if "four doses daily" means taking a dose every six hours around the clock or just during regular waking hours)
- Whenever possible, try to use the same pharmacy so your pharmacist can keep a record of all your medication and give you the best advice

For more suggestions about communicating to healthcare professionals please refer to the Navigating the System section of the resource.

What if I don't feel safe?

If you feel unsafe providing care and/or there aren't enough family members and friends around to help you provide safe care, and neither you nor the person you care for is able to hire the help you need, you may need to talk about making changes in living arrangements. For example, it may be time to sell the family home and move into an apartment building, seniors' residence or condominium where most of the maintenance and upkeep is not a worry. You may decide together the person you are caring for needs to move in with someone (maybe you or another family member or friend). You may also want to consider residential care options (see page 40 in Navigating the System).

> Remember that these changes may be difficult for the person you are caring for. Talk to the person about how you think these decisions will help in the long-term.

Enjoying Your Time Together

Much of your day is probably spent on routine tasks, some of which may be stressful and tiring for both you and the person you care for. It is important to find time to smile and keep your sense of humour. You're not expected to be a cheerful person all the time but laughing and enjoying yourself can make you, and the person you are caring for feel better.

Enjoying time with the person you care for can mean anything from sharing a morning joke to working outside in the garden together. Recreational activities can contribute to a person's sense of well-being and happiness, which may help them feel better.

You may choose to call on the assistance of a health care provider, or you may want to plan fun and leisure activities on your own or with the person you care for. When planning things to do, make sure the activity is meaningful for the person. Someone who has never much liked massages will probably not appreciate one now, either. Try to keep the person's interests in mind as you think about activities.

Remember that fun activities do not have to be elaborate. Even watching a sports game together (if the person likes sports) can be important for reducing loneliness and boredom. You could take a simple activity like watching a game on TV and build on it as much as possible. For example, during the ads, ask questions of the person about favourite moments in sports history, and have team shirts for both of you to wear while watching the game. Don't forget cards and board games are also great fun too!

If possible, from time to time, consider taking part in a community activity. Even sitting outside in the warm sun of a backyard is of value, if travelling is too difficult.

Ideas for activities to spend time together:

Some fun activities have been provided to give you an idea of some of the things you can do to support yourself and the person you are caring for. Most of the activites can be done at home and will be a welcome change to the day.

Picnic day

A picnic may be the ideal romantic activity for a couple and can also provide for some quality time between you and the person you are caring for. You can arrange to have a picnic in your living room (or any other room)! This may mean a nice change of scenery at mealtime. To prepare for the picnic, you'll want to make sure you tidy up and clear the room. Spread a picnic blanket out and decorate the area (perhaps with some flowers, photos etc.). You may wish to play some relaxing music in the background.

Be creative

Painting, drawing and creating art or crafts can provide a great way to relieve stress and express creativity. If the person you are caring for seems reluctant at the suggestion of artwork, remind the person this is something for fun and relaxation - masterpieces are not the expectation! Join in too, and you may feel more relaxed, centered, and in the moment -- which can sometimes be hard as a caregiver.

Relaxation exercises

Relaxation exercises are easy to do, and are wonderful for tension relief. Relaxation exercises have also been shown to help sleep, increase alertness, and improve mood and health. You can build in some meditative types of exercises for additional benefit. It is possible to purchase guided relaxation tapes/CDs and meditation music in many book and music stores. Alternatively, you can refer to the relaxation exercises located on pages 34-36 in the Caring for caregiver section.

Family/friend trivia

For fun discussions and remembering past times, make up family/friend trivia questions, and put the questions on various pieces of paper. For example, some homemade question cards might say things like:

> "How did Uncle Mike get the scar on his right leg?"
>
> "What did Jane buy for you for your 80th birthday?"
>
> "Where did Dad propose to Mom?"
>
> "What was the name of the street that our family restaurant was on?"

You may wish to involve other friends/family members but remember to not include any questions that will be too difficult or embarrassing. A variation of this game is to make up simple discussion items that will get the person talking about him/herself (e.g. What is your favorite movie of all time? What was your best holiday?)

Scrapbook exercises

Making scrapbooks can be very meaningful for people, as well as fun. When it comes to scrapbooks, you can get as fancy or as simple as you like. Let the person you care for do as much as possible, and assist as needed. Making scrapbooks is a popular activity, so you'll find everything you need at an art store or department store. There are all kinds of helpful sites on the Internet to assist. Just search for scrapbooks.

Caregiving should not be all work and no play. **Having fun is important** - not just to ease your stress but also to create a sense of self worth and belonging for the person you care for. Leisure activities can open the door to meaningful moments.

Resources

Dietitians of Canada
www.dietitians.ca

Canada Food Guide
www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php

Saint Elizabeth Health Resources - Topics include diabetes, senior care, wound care and more.
www.saintelizabeth.com/Health-Info/Health-Resources.aspx

Moving People Safely Videos – University Health Network (UHN)
www.uhn.ca/patients_&_visitors/health_info/videos/videos.asp

Canadian Virtual Hospice: Caregiver Video Demonstrations
www.virtualhospice.ca/gallery

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Navigating the System

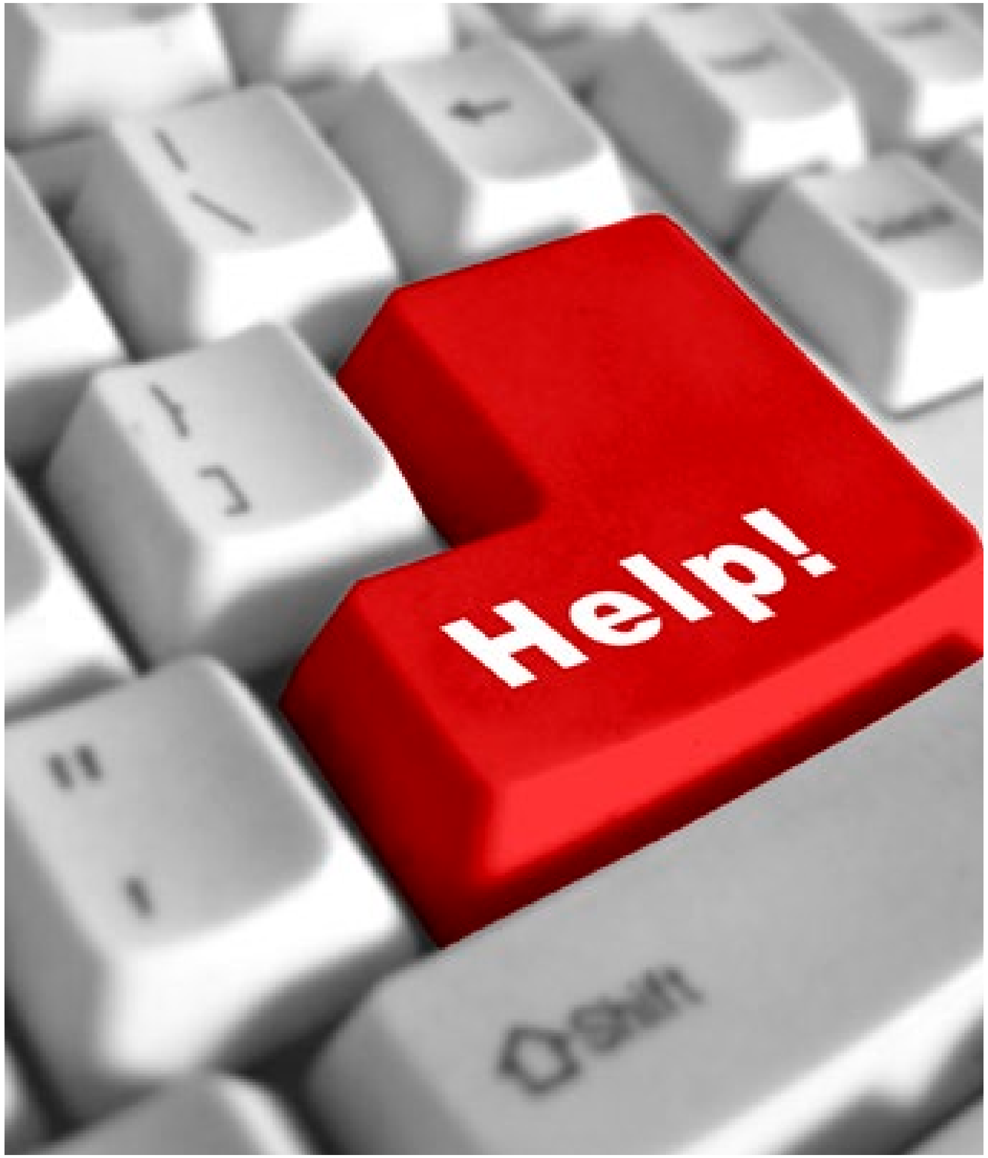
Table of Contents

Overview

Caregiving can be like a maze, where you must try to figure out not only how to be a caregiver to the person you are caring for, but also where you fit within the health care system. Sometimes this can be overwhelming, especially if you are not very familiar with the system. This section will provide some tips and strategies to help you navigate the health care system.

This section will review some of the most common medical illnesses in Canada and provide you with links for further information. In addition, you'll review how to manage the personal information of the person you are caring for including health, financial and legal information, and how best to communicate with health care providers.

The final part of this section provides an overview the specific health care and supportive services available to you as a caregiver, including where to access help and equipment.



General Tips

Understanding the illness or health conditions affecting the person you are caring for may be helpful. Some caregivers report they feel better equipped as caregivers when they know more about the illness, as it allows them to be prepared for the changes that may happen over time and better able to plan ahead for their loved one's future needs.

Keeping health, legal and financial information of the person you are caring for organized can help you by reducing stress and frustration when these are needed. In addition, keeping health care information freely available can help you to communicate more effectively with health care providers.

There are many different types of health care and supportive services available – half of the challenge is finding out where they exist and how to access them. Always start with your primary care provider for information, but using services such as Telehealth, the Internet and Yellow Page searches may also help. As a first step refer to the RESOURCE section for some suggestions.

Look into the many types of medical supplies and equipment available. These products may help the person you are caring for to be more independent and make your caregiving easier.

Understanding Common Health Conditions

> Caregivers provide care to people with a broad number of conditions. Some caregivers find it helpful to have an understanding of the illness that is impacting the health of the person they are providing care for.

Information can help you provide care for a person now and plan for person's future care, as his or her condition changes for the better or worse. For example, the level of independence of the person you are caring for may decrease over time, and he or she may need much more of your assistance. What follows is a very brief overview of some common medical conditions with links to organizations that can provide further specific information.

Multiple Sclerosis

Multiple sclerosis (MS) is a progressive degenerative neurological disease. To date, scientists have been unable to identify the cause of the disease however we do know that it causes of a variety of symptoms including (but not limited to): loss of balance, impaired speech, extreme fatigue and paralysis as well as impacting upon the sensory functions (Corey & White, 2009) (MS Society of Canada, 2009) (link to ms society). The result of these symptoms and of the illness can have an impact a persons physical, emotions and financial health however, it is important to note that the symptoms and progression of the illness vary significantly between individuals and from time to time in the same person.

MS is most commonly diagnosed neurological disease affecting young adults in Canada and is often diagnosed in young adults aged 15 to 40 years of age. It is three times more common in women than in men.

There is no known cause for MS, however it impacts the person by attacking the protective covering ((myelin) — of the brain and spinal cord, causing inflammation and often damaging it. When this happens, nerve impulses are interrupted or distorted. The result may be the wide variety of MS symptoms.

Chronic Obstructive Pulmonary Disease (COPD)

COPD includes several lung diseases, the most common of which are chronic bronchitis and emphysema.

Emphysema results in damage to the air sacs at the tips of the airways. This makes it hard for the body to take in the oxygen it needs.

Chronic bronchitis results in irritated and red airways that make too much sticky mucus. The walls of the airways are consequently swollen and partly block the air from passing through.

These illnesses combine to make it hard to breathe because:

- the airways and air sacs in the lungs lose their shape and stretchiness
- the walls between many of the air sacs are destroyed
- the walls of the airways become thick and swollen
- cells in the airways make more mucus than usual, which blocks the airways.

When breathing is impaired, this results in challenges to a person's ability to care for themselves and may result in anxiety/panic, depression and, for many people, recurrent hospital admissions.

The causes of COPD are cigarette smoking (which accounts for approximately 90 percent of COPD cases), heredity (for example, a rare genetic disorder called Alpha-1 antitrypsin deficiency), second-hand smoke, air pollution at work and in the environment (dust or chemicals) and a history of childhood lung infections.

Parkinson's disease

Parkinson's disease is a neurological disorder which occurs when certain nerve cells (neurons) in a part of the brain called the substantia nigra die or become impaired. This impairment eventually results in the reduction of the bodies normal production of dopamine. Dopamine is a chemical which allows smooth, coordinated function of the body's muscles and movement. When a significant amount of damage has occurred (e.g. when 80% of the cells have been damaged), the symptoms of

Parkinson’s disease appear.

Parkinson’s disease is most common in people over the age of 60 years, where 1 in 100 people are affected. However, it can also be diagnosed in younger people. Young-onset Parkinson’s disease (onset at age 40 or younger) is estimated to occur in 5-10% of people with the disease.

Parkinson’s disease has no cure, but the symptoms of the illness can be treated with a range of interventions including medications and surgical therapies, general lifestyle modifications (rest and exercise), physical therapy and sometimes speech therapy.

Diabetes

Diabetes is a significant health problem for people across Canada. There are three types of diabetes: type 1 diabetes, type 2 diabetes and gestational diabetes.

Type 1 diabetes occurs when the pancreas is unable to produce insulin - a hormone which ensures body energy needs are met. It is most commonly diagnosed in children or adolescents and accounts for approximately 10 % of all people with diabetes.

Type 2 diabetes occurs when the pancreas does not produce enough insulin or when the body does not effectively use the insulin that is produced. Type 2 diabetes accounts for approximately 90 % of all cases of diabetes. It is most commonly diagnosed in adults although it is being diagnosed more frequently in children.

Gestational diabetes occurs during pregnancy and is a temporary illness which affects a approximately 4% of pregnancies. The illness leads to an increased risk of diabetes for both mother and child later in life.

Treating diabetes is dependent upon the type of diabetes but may include education, physical activity, nutrition, weight management, medication and managing blood pressure.

Heart disease

Heart disease is actually a group of diseases that affect the heart and includes illnesses such as angina, artherosclerosis, cardiomyopathy, coronary artery disease, heart attacks and valve disorders (among others). The cause of these conditions varies, as do the treatments. Coronary artery disease (CAD) is the most common of these conditions and occurs when blood vessels in your heart become blocked or narrowed, preventing oxygen-rich blood from reaching your heart. This can cause chest pain (called angina) or even a heart attack.

Heart disease is very common within the Canadian population and in 2005 it accounted for 31% of all deaths in Canada (71,338 deaths – or more than 71,000). This translates to 30% of male and 31% of female deaths. Nine in 10 Canadians (90%) have at least one risk factor for heart disease or stroke which include smoking, alcohol, physical inactivity, obesity, high blood pressure, high blood cholesterol and diabetes.

Stroke

A stroke can be defined as a sudden loss of brain function. There are different types of stroke including ischemic and hemorrhagic. The former is caused by the interruption of flow of blood to the brain, the latter by the rupture of blood vessels in the brain. When these disruptions occur, the cells of the brain (known as neurons) die in the affected area. The effects of a stroke depend on where the brain was injured, as well as how much damage occurred. For instance a stroke in one area may impact upon the ability to move, and in another area it may impact the ability to see, or remember, speak, reason and read and write.

Stroke is the third leading cause of death in Canada and accounts for 6% of all deaths. Although stroke can happen at any age, it happens more frequently in people over the age of 50 years and the risk doubles every ten years from the age of 55. The incidence of stroke is high with one stroke occurring every 10 minutes. This has resulted in over 300,000 Canadians living with the effects of stroke.

There are five warning signs of a stroke which include:

- Weakness - sudden loss of strength or sudden numbness in the face, arm or leg, even if temporary
- Trouble speaking - sudden difficulty speaking or understanding or sudden confusion, even if temporary
- Vision problems - sudden trouble with vision, even if temporary
- Headache - sudden severe and unusual headache
- Dizziness - sudden loss of balance, especially with any of the above signs

Watching for warning signs is important as a stroke survivor has a 20% chance of having another stroke within two years.

Cancer

Cancer is a disease that starts in our cells. These are the building blocks of our bodies, which are made up of millions of cells, grouped together to form tissues and organs such as muscles and bones. Genes inside each cell allow it to grow, work, reproduce and die. Normally our cells obey these orders and we remain healthy. But sometimes the instructions get mixed up, causing the cells to form lumps or tumours, or spread through the bloodstream and lymphatic system to other parts of the body.

Tumours can be either benign (non-cancerous) or malignant (cancerous). Benign tumour cells stay in one place in the body and are not usually life-threatening. Malignant tumour cells are able to invade nearby tissues and spread to other parts of the body. Cancer cells that spread to other parts of the body are called metastases.

Cancers are named after the part of the body where they start. For example, cancer that starts in the bladder but spreads to the lung is called bladder cancer with lung metastases.

There are many different types of treatments available for people with cancer. These may include: chemotherapy, radiotherapy, hormonal therapy, biological therapy or a combination of all of the above.

Dementia

Dementia is a symptom of a disease and not a disease in itself. Dementia is an organic brain disorder and is characterized by an impairment in language (naming objects and people), judgment (safe and unsafe, appropriate and not appropriate), abstract thinking (planning events), orientation to person, place and time, recognition of objects, family members and others, as well as changes in personality. There are different kinds of dementia. Alzheimer disease is the most known type of dementia.

Alzheimer's disease

Alzheimer's disease is a type of dementia, which affects one in 10 people over age 65 and one third of those over age 85. Alzheimer's disease causes a gradual decline of brain functions. Symptoms include memory loss, impaired judgment and reasoning, extreme changes in mood and behaviour, and loss of ability to care for

Although there is no cure at this time, the earlier that Alzheimer's disease is diagnosed, the more effective medications and treatment will be. The following warning signs can help you identify behaviours related to Alzheimer's disease.

Warning signs include:

- Memory loss that affects daily functioning
- Difficulty performing familiar tasks
- Problems with language
- Disorientation of time and place
- Poor or decreased judgment
- Problems with abstract thinking
- Misplacing things
- Changes in mood or behaviour
- Changes in personality
- Loss of drive

Symptoms of delirium

Delirium is a type of acute confusion in the older adult. It is not caused by dementia. Delirium has a sudden onset and is often related to a medical cause such as an infection or new medication. People experiencing delirium may have confusion with an inability to have a coherent conversation. The person may experience hallucinations (visual, tactile and/or auditory) that are vivid and frightening, resulting in severe agitation. People experiencing delirium are often very inattentive, cannot follow instructions or directions, and have general disorganization of their thinking. They may be awake one moment and asleep the next. Delirium is considered a medical emergency and requires medical intervention and diagnosis to reverse the cause.

Other Illnesses and Diseases There are many other illnesses which may affect your health or the person you are caring for. For further health information refer to the LIST OF RESOURCES located at the end of this section..

Once you are aware of the illness(es) which are affecting the person you are providing care for, and as the health of the person you are caring for changes, you may need to navigate some of the Canadian health care system. The next few sections help you to negotiate this system, including how to communicate with health care professionals, and an overview of the types of services available to you. The first step in mapping this navigation is organizing the health care information for the person you are caring for.

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Getting Organized: Taking Care of Health Care and Personal Information

Throughout our lives we can collect a great deal of information related not only to our physical health but also to our financial and legal health. Although it will take some extra effort, ensuring the personal information of the person you are caring for is in good order will likely be helpful. There may be many times you will need to have information at your fingertips, especially in the event of an emergency.

Organizing health and medical information

Being able to provide details of a person's health history and medications is important for health care providers to safely provide the best care possible. Good records can also be helpful for insurance purposes, for solving communication disputes, and for keeping key people informed.

Keep a list of current medications and dosages, including any side effects and other reactions to help keep track of medication information or ask your local pharmacy who is filling your prescription to print out a list. This record should include prescription drugs, non-prescription drugs, and other products, such as vitamins and minerals the person you are caring for is taking. Keep this list with you and present it whenever you meet with a health care professional.

Write down any specific questions, or medication side effects or reactions. Make sure you receive, understand, and can read the written information about medications. Review each new medication with your pharmacist. Make sure you understand what they have been prescribed for and discuss any possible side effects.

TIP

Try to keep all health and medication information as up-to-date as possible so you can quickly grab it in an emergency, such as a trip to the hospital. This includes any medical directives or powers of attorney, which are covered later in this section. Keep an extra copy in case the records are not returned to you after such a trip.

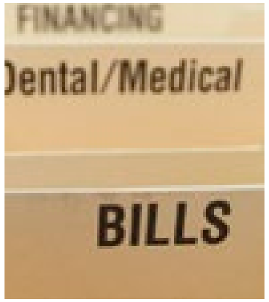
Emergency contact information

It is a good idea to post emergency information near a phone where it's easy to find. In addition to the emergency phone number for your area (e.g. 911), record the names and numbers of health care providers involved in a person's care, including who can be contacted outside of regular hours and phone numbers of others who want to be notified in the event of a sudden change in health status.

You may also want to make two copies of this information for your wallet, and one for the person you are caring for.

Managing Financial Affairs

As a caregiver, you may find the person you are caring for needs help taking care of some personal affairs. If no one you know has experience with financial and legal planning, you may want to consider hiring a financial planner and/or lawyer to assist you.



An important first step to manage this information is to create a list of important documents and their locations. This list should include the following:

- Identification (e.g. birth certificate, marriage certificate, passport, proof of citizenship, social insurance number)
- Bank account information (bank accounts, mortgages, credit cards, lines of credit, loans)
- Investments (RRSPs, pension plans, mutual funds, stocks, bonds, RESPs, etc.)

- Wills, Power of Attorney documents and any documents pertaining to pre-planned funeral arrangements
- Key assets or income (e.g. details of vehicle ownership, property ownership, income sources, most recent tax returns, insurance policies, utility payments, post office box key, safe deposit boxes
- Contact information for any lawyers, financial planners or accountants.

Keep in mind that this information may change over time and should be updated on a regular basis.

TIP

Don't rely on memory about the location of important documents.

It is a good idea to confirm their whereabouts before you need them.

The person you are caring for may be reluctant to share such personal financial and legal information with you. If this is the case, inform them that your concern is about finding out what you need to know in case of an emergency to help ensure their wishes are met.

You also don't need to see the actual documents – you only need to know where to find them in a crisis.

In some cases it may be appropriate to change the way finances are handled in order to make things easier. These changes may include the following:

- Joint access to safe deposit boxes
- Automatic payment of regular bills
- Put in place a power of attorney depending on the province you live in.
- Direct deposit of pay cheques and benefits
- Joint bank accounts so that bills can be paid and other funds withdrawn in an emergency situation – *due to risks to both you and the person you are caring for, you should seek financial advice first

> In all of this, remember that the person you are caring for is still in charge of making decisions unless he or she becomes mentally unable to do so.

TIP

It’s a good idea to talk to the person you are caring for about the possibility of **frauds and scams**. Any of us can be caught by a con artist looking for a quick way to make money, but people who are feeling lonely may be particularly vulnerable. Encourage the person you are caring for to report any suspected fraud to the police to help stop it from happening again.

If you need help you can look around for free or low-cost sources of financial advice. Some associations, membership groups and not-for-profit organizations offer such services. Don’t forget to ask your own family and friends – you may have a financial expert in your midst!

Government Programs and Benefits

There are several federal government policies and services that may be helpful for yourself as a caregiver or the person you are caring for. The following summary provides a list of some of the programs that may be available for you. For more information, please refer to the accompanying websites.

Old Age Security Program
www.servicecanada.gc.ca/eng/sc/oas/index.shtml

Canada Pension Plan
www.servicecanada.gc.ca/eng/sc/cpp/retirement/canadapension.shtml

Employment Insurance (EI) Compassionate Care Benefits
www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml

Services for Veterans
Veterans Affairs Canada
www.vac.gc.ca/clients/

Veterans Independence Program
www.vac.gc.ca/clients/sub.cfm?source=services/vip

Income Tax Deductions and Credits
Caregivers are entitled to a variety of income tax deductions and credits. Information about these entitlements is available from the Canadian Revenue Agency. You can access this information by clicking this link www.cra.gc.ca

You may want to consider looking up the following items on the Canadian Revenue Agencies web site to see if they apply to you and your situation as a caregiver

- Caregiver credit Infirm dependant deduction
- Personal disability credit
- Medical expenses credit
- Basic personal credit
- Age credit
- Spousal credit
- Eligible dependent credit
- Spousal transfer credit
- Registered Disability Savings Plan
- Child Disability Benefit (CDB)

Managing Legal Affairs

Every one of us should plan for the unexpected and make sure we have the right legal documents in place to protect those we care about and our property. It is also in our best interests to make sure our wishes both before and after death are captured.

As a caregiver, you will need to know what legal arrangements the person you are caring for has already made. If no provisions have been made then it is a good idea to talk to the person about it.

Advance directives

Advance directives are instructions, both written and verbal, for medical care in the future. These instructions are provided in advance, so that if a person is unable to speak for themselves later on the wishes are documented. When you are providing care for someone who is ill it is very important for you to get to know their wishes. Encourage the person who are caring for to share their thoughts so they can continue to make decisions regarding their care, no matter what happens. If advance directives are put in writing, the document is called a living will.

Powers of Attorney

There are basically two types of Powers of Attorney. In both cases a trusted person makes decisions for someone when they are no longer make able to make them for themselves. These wishes are also put in writing.

A Power of Attorney for Property allows a person to nominate a person to make financial decisions on their behalf. The person you are caring for will benefit from a Power of Attorney for Property by knowing someone he or she trusts will be in charge. If they are no longer capable of making decisions, a government appointed guardian will be put in charge instead.

The second type of Power of Attorney is for Personal Care. The person you are caring for can provide, in writing, the kind of care he or she would like to receive or not receive. The person who is appointed Power of Attorney will make sure their wishes are followed.

A lawyer can create a Power of Attorney for the person you are caring for, but many do-it-yourself kits also exist. For information about Power of Attorney and Advance Directives in Ontario please click here: http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.asp

For information outside of Ontario you can log in to your province or territory's website and link to the Ministry of the Attorney General for information about regional regulations for Powers of Attorney. Start by logging in to the Government of Canada's website to find provincial and territorial links. You can also check your local bookstore.

DNR (Do Not Resuscitate) Order

This order directs emergency and medical staff to not resuscitate when the person stops breathing and/or their heart stops. This order can be changed and or rescinded at any time by an individual or their alternate decision maker. This type of order would be written in the medical record by the doctor, based on an informed decision. For information about DNR orders, speak with the health care team.

Wills

A will is a legal document that lets everyone know how a person wants their estate to be divided up after death. An estate is basically everything owned or partly owned by an individual.

Most people will have specific thoughts about who they want to receive certain personal items and assets after they are gone. If they do not write this down in a will, their wishes might not be followed.

If the person you are caring for does not have a will, talk about making one. It can prevent problems in the future. You can get a lawyer to help, or use a do-it-yourself kit. You can log in to your province or territory's website and link to the Ministry of the Attorney General for information about regional regulations for wills. Start by visiting the Government of Canada's website to find provincial and territorial information. You can also check your local bookstore.

Preplanning funeral arrangements

Preplanning of funerals is becoming more and more common, as they lessen the burden on the survivors. Ask the person you are caring for if they have already made any arrangements. If not, you may want to ask about their wishes. Do they want to be cremated? Do they want an elaborate funeral or simple service?

The importance of organized information

Knowing where to find a person's health, financial and legal information will be important in the event of a change in health status or an emergency for the person you are caring for. You will need to know where and how to access information and details to ensure that proper steps are taken. If these records can be collected and kept in a single, known location, you can help lessen stress during times of already high emotions. In addition, this information can help you as you attempt to navigate through the health care system.

Don't avoid talking about a person's financial and legal wishes – it may be uncomfortable at first, but you're helping to look after the person's best interests – this may help to make it easier.

Communicating with Health Care Providers

Now that you have reviewed how to organize information, the next step is to communicate it to health care professionals. Let's face it – most of us could do a better job of talking to each other. In health care, poor communication can lead to less than ideal care. As a caregiver, you are in a position to advocate for yourself and for person you are caring for. To help you do that, we will review some tips which may help you to communicate more effectively.

Caregivers are often integral to the sharing of information with everyone involved in a person's care. For instance, you may help the person you are caring for interpret health care information, provide health information to the medical team and friends/family, offer view points and explanations and help the person (and yourself) learn new procedures. All of these things demonstrate how central a caregiver is to the communication process!

When to support communication

As a caregiver it can sometimes be difficult to know when it's appropriate to contribute to a discussion with health care professionals and when not to. It is a balance, and it's important to be clear with the person you are caring for that you are trying to help, not take control. Some ways to find out if assistance with communication is needed include:

- Asking if the person you are caring for is able to get the information he or she wants
- Asking if they are comfortable communicating with health care providers
- Seeking their permission.

TIP

You can help ensure people stay in control by looking at them when a health care provider asks a question and by allowing them to answer first.

If you are present during talks with health care providers, offer your support, while acknowledging the person you are caring for is still in charge. Remember, everyone has the right to have a full understanding of their condition and options available to them in order to make the best choices regarding their care. Sometimes it is difficult to know what you should be asking. We will explore this in the next section.

What to ask health care providers

It can be intimidating when talking to health care providers, especially when you are unfamiliar with some of the terminology they are using. The following information reviews some of the information you may wish to ask health care providers. If they do not know the answers, you can ask for their help in directing you to other reliable sources.

> To prepare for a visit with a health care provider, writing your questions down before you meet with someone helps to remind you of the information you require.

The following suggestions can act as a guide:

Tests

If the doctor suspects a particular illness, diagnostic tests may be ordered. Additional tests may also be recommended to help monitor one's condition over time.

You could find out:

- ✓ How a test will be performed and how it will affect the person
- ✓ What the test will reveal
- ✓ The risks/benefits of not conducting a particular test

The disease or condition

Ask questions about:

- ✓ Causes
- ✓ Prognosis (the most likely outcome of having the disease/condition)
- ✓ Risk of giving disease to others and ways to prevent this

Treatment options

Depending on the diagnosis there may be more than one treatment option available to the person you are caring for, including doing nothing at all.

To help someone make the best possible choice, try to make sure they fully understand all available treatments, not just the one the health care provider recommends. People who understand what will happen to them are less likely to be anxious.

Questions to ask:

- How the treatment can effect the disease or help reduce symptoms, including its success rates
- How the treatment is performed
- How the treatment is likely to affect the person (side effect) including physically, mentally and emotionally
- The risks of not having the particular treatment
- Non-medical options and their benefits and risks

When discussing medications the following questions can be helpful:

- What is the medicine for?
- How should it be taken and for how long?
- What are the side effects? What should be done if they occur?
- Is this medicine safe to take with other medicines or dietary supplements?
- Are there any restrictions around food, drink, or activities?
- Are there any tests they need while taking this medication, such as blood tests, x-rays, or other lab tests?

** Remember: if the doctor writes the prescription by hand, make sure you know what is written.*

Sometimes you will need to turn to additional sources of health information to get the most current information.

You can ask a health care provider if they have any written information and/or if they can refer you to a person/organization which may provide you with additional information. Refer to the Resource Section or visit the Health Info and Caring for Family sections of the Saint Elizabeth website for information and support.

Health Care and Supportive Care Services Available To You

Primary care

Primary care is usually the first point of contact a person has with the health system – the point where people receive care for most of their everyday health needs. Primary care is usually provided by family physicians, and by nurses, dietitians, mental health professionals, pharmacists, therapists, and others. At present, primary care services in Canada are delivered most often by family physicians and general medical practitioners who focus on the diagnosis and treatment of illness and injury.

Primary care provides services including prevention, diagnosis, treatment and follow-up of various health conditions. This may include referrals to specialists and diagnostic services for more specific care.

The primary care team of the person you are caring for is an essential part of their care and may be the first port of call for many of your questions/concerns. Keep their number in a place that is easily identifiable.

Home care

Home care includes a variety of services that allow people with a wide range of health problems and disabilities to live in familiar surroundings.

Services can include:

- A needs assessment that considers the individual who is ill, as well as family members and caregivers
- Care coordination and management
- Nursing services, including complex care and specialized services
- Homemaking and personal support services
- Rehabilitation services: physiotherapy, occupational therapy, speech language pathology, dietitian services, and social work
- Oxygen and respiratory therapy
- Respite services (temporary relief from caregiving responsibilities)

Home care is publicly funded to varying degrees, depending on the province or territory in which you live. In addition, some products and services normally available in the hospital sector, such as medications, medical equipment and supplies, and 24-hour care/supervision may not be fully covered in the community and must be paid for through private insurance plans or by the family. Personal care and homemaking services may have user fees attached.

Visit the government provincial and territorial site http://www.hc-sc.gc.ca/hcs-sss/home-domicile/index-eng.php to find out about publicly funded home care programs in your area. Geriatric outreach programs also exist throughout the country, so you may want to ask health care providers or check local community services directories for contact information.

Respite services

Respite care is temporary care provided by trained individuals that allow you to take a much-needed break from your caregiving responsibilities. This means you can take the time to do something completely for yourself to enrich your own life and renew your energy. If you are a full-time caregiver, try to get some respite on a weekly basis.

Some tips for getting the most out of your respite:

- Leave the names of other family members as emergency contacts
- Try not to focus on caregiving or the person you are caring for - he or she is in good hands
- Try to avoid feelings of guilt – remind yourself how important respite is – it will help you to be a better caregiver
- Have realistic expectations when you return from your respite – the situation itself will not have changed, but your ability to deal with it may have changed

Depending on where you live, you may be able to access respite services at very little or no cost. Services may be provided where the person you are caring for resides, or through facilities with short-term care placements reserved for respite.

Adult day programs

Adult day centres are a specific form of respite. Similar to childcare programs, adults can be dropped off at these centres to participate in planned programs. Such programs can benefit both the ill person by offering opportunities to participate in fun activities and to socialize, and for the caregiver by providing respite. Services provided will vary but can include:

- Personal care
- Exercise programs
- Social activities and other fun activities
- Activities to stimulate the mind
- Meals
- Transportation
- Therapies and other medical services
- Counselling and emotional support
- Information services

Other services

You should be aware that other services exist to help people stay in their homes and remain independent. Government-funded home care programs may cover some services:

Meal programs – services can be provided in the home or in a centralized setting (e.g. Meals on Wheels)

Transportation services – can provide transportation to and from medical appointments, day programs, etc.

Emergency response systems – activated by a voice or the press of a button, these systems allow a person to access help and emergency services and can give you peace of mind when you can't be there.

Volunteer services

Many of the services described can be provided for little or no charge through volunteer services. Trained volunteers can provide respite, companionship, meals, transportation and counselling.

Hospice/palliative Care

Palliative care services focus on providing quality of life for people with terminal or life-threatening illnesses. Services can help:

- Manage pain and symptoms
- Provide emotional, psychosocial and spiritual support
- Provide grief and bereavement counselling

These services may be offered through home care programs or other government-funded programs and may be home or facility-based. Refer to Providing Care at End-of-Life for more information on hospice/palliative care.

Residential care

Sometimes caregivers may feel guilty about contemplating residential care. However, this type of care may be most appropriate for the person you are caring for such as in the following situations:

- You don't have the skills, abilities and good health to provide the level of care required
- The person you are caring for requires 24-hour care, and other responsibilities, including work and your own family, limit your availability
- You are unable to find or pay for supports that can help keep the person you are caring for in the home
- The health and safety of the person you are caring for is at risk if he or she continues to live in an environment without trained care providers
- Your own health is at risk if you continue your current level of caregiving responsibilities

Years ago you may have made a promise to the person you are caring for that you would never place him or her in a facility. This was likely made at a time where neither of you could realistically see the challenge of keeping such a promise - it is hard to imagine what around-the-clock care looks like. It's important to carefully consider your current situation:

- Are you able to provide ideal care that keeps the person you are caring for safe and comfortable or do you find yourself having to cut corners because you can't keep up?
- Do you risk financial problems by quitting your job or hiring the help you need, thus reducing your ability to take care of both yourself and the person you are caring for?
- Is it frightening for you or the person you are caring for to be without companionship and assistance for hours at a time when you can't be there?
- Is it dignified for the person you are caring for to lie in his or her bed for an extended period of time, perhaps needing to go to the bathroom but having to wait until you return?

A residential care facility can be the best choice. It is, however, not always the easiest choice. That's why it's a good idea to involve all interested parties in the discussion, and to take time to completely research your options. It's important to note that waiting lists can be very long for residential care beds, especially those facilities receiving government funding. In a crisis situation, you may have no choice over where someone is placed. That's why planning ahead for such a need can be very beneficial.

If you are really not sure residential care is the best choice, you might want to consider trying out a respite or short-term care placement in a facility. With stays ranging from two to six weeks, this option will allow everyone involved to try out the arrangement before committing, including the person you are caring for.

There are different types of residential care facilities available. Some are funded or partially funded by government programs.

In these facilities, public programs will cover some of the costs of services, but other costs will need to be paid for by the resident. Others are privately owned and do not receive any government funding.

> This means that residents are responsible for paying for all services provided. The types of services offered will be different in different facilities and you may wish to look around for the most appropriate one to meet the needs of the person you are caring for.

Visit the Ministry of Health and Long Term Care's web site to get more information on residential care facilities.

You can find out about residential care options by:

- Speaking to the organization in your province or territory that is responsible for funding residential care – you can link to the various Ministries of Health through Health Canada's website
- Consulting local directories of community-specific services and services for seniors
- Asking health care providers for suggestions
- Seeking recommendations from friends and colleagues
- Looking in your phone book, the Yellow Pages or online under headings such as "Homes for Elderly", "Nursing Homes", "Rest Homes", "Retirement Homes", "long term care facilities"

For information on residential care facilities in Ontario, click here.

Supplies and Equipment

If the person you are caring for does remain in the home you may be interested in finding tools and equipment to make this easier and safer for both of you. You don't necessarily have to spend a lot of money on special supplies/equipment but some of these tools may be of help. Something as simple as bright night-lights in the hallway and bathroom can ensure safety for those nighttime trips to the bathroom. Sturdy, non-slip rugs by the bed and grab bars in the bathroom will go a long way in preventing falls and injury. A well-made, practical footstool can help a person get into and out of bed.

When planning for what the person you are caring for might need in the home, think about how user friendly the home is right now for the person. If the person you are caring for is in need of special or more expensive equipment (such as an adjustable bed or electric wheelchair), you can speak with your doctor or other member of your health care team as well as community organizations about how to borrow, rent or buy specialty devices and products. These products go by many different names, including: assisted living products, assistive devices, adaptive devices and independent living aids. In today's market, you can find assisted living gadgets, devices and equipment of all kinds.

> A valuable program is the Ontario Government Assistive Devices program(ADP) that is designed to provide consumer centered support and funding to Ontario residents who have long-term physical disabilities and to provide access to personalized assistive devices appropriate for the individual's basic needs.

Your local health authority, the Ontario March of Dimes and the Red Cross may be able to offer further support and guidance.

Specialty Supplies and Equipment

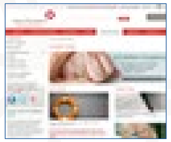
Specialty supplies and equipment are usually designed to help in one or more of the following four areas:

Safety: For example, emergency response systems are designed to help people remain safe

Dignity: For example, hand-held showers may allow someone the privacy and dignity of bathing without any assistance

Independence: For example, walkers and mobility aids help people move around independently

Comfort: For example, adult undergarments or briefs with built-in absorbency will allow a person with incontinence (a lack of bowel or bladder control) to keep dry and comfortable



Visit the Caring for Family section of the Saint Elizabeth website at www.saintelizabeth.com/family for more caregiving information and support.

The following descriptions will explore some supplies and equipment which may be helpful for the person you are caring for.

Safety equipment:

Grab bars/grip bars

These bars are usually easy to install and very helpful in preventing slips and falls. Typically, these bars are placed in the bathroom to help provide support and security for people in the bathtub or shower, or when using the toilet. Grab bars can also be placed in other areas of the home, such as hallways, for extra support and safety when walking and some may not require wall mounting.

Bedrails

Bedrails help a person get extra leverage, when getting out of or into bed. Non-metal bedrails may be more comfortable and easier to grasp. Some of these products have built-in pocket areas for personal bedside items such as magazines and books.

Emergency Response Systems (ERS)

Usually, emergency response systems involve a button or pendant that is worn on the person. When the button is pressed, monitoring personnel will immediately be alerted. Some of these systems involve two-way speakers so that you or the person you are caring for can speak from any location to staff at a 24-hour response centre. These ERS systems can contact friends, neighbours and emergency services as necessary.

Also available are special telephones that will automatically dial out pre-programmed phone numbers (emergency contacts) when the signal button on a pendent is pressed. Loud, two-way conversations can occur when the call is picked up. In addition, a pre-recorded message can alert your emergency contacts that help is required as soon as possible.

Comfort aids

A number of products are available to improve comfort, such as sheep fleece bed pads. There are also special cushions filled with foam crating material to provide softer support. The air pockets created by the foam crating can provide great comfort to people who have bedsores on their bottoms.

Shower heads/hand-held showers

Shower heads and hoses that attach to the tub faucet or existing shower head can help you and the person you are caring for with hair washing, back washing and rinsing in the tub or shower. Shower heads can be purchased at a relatively inexpensive price, depending on their features. Some of these products have built-in jet massages or extra long hose attachments.

Bath/shower seats and transfer benches

These products make it much easier for those with limited mobility to get into and out of the tub. They are ideal for people who may have problems stepping over tub walls, and/or need seated support while bathing or showering. With the assistance of shower seats and transfer benches, a person can wash his or her feet and shave her legs without having to bend. Some of these bath seats and transfer benches have built-in commodes.

Bath and shower mats

You will want to be sure you use safety mats inside the bath or shower to prevent slipping. You can purchase special safety mats that will cover most bathtubs from end to end.

Bathing undergarments

If the person you are caring for needs assistance with bathing and/or toileting, you can help the person stay covered with bathing undergarments. For example, there are special lines of undergarments that cover an adult's private areas while in the bath or shower. After the bath or shower, a dry wrap garment can be placed over the wet undergarment, so the person can quickly remove the wet underclothes in private. In addition, the dry outer garments can be easily lifted, so that someone can use the toilet without exposure. There are long plastic aprons that the person can wear while bathing, or towels that stay wrapped around the person (with a clothes-pin, clip or velcro tabs).

Raised toilet seats and bedside commodes

Many people find it difficult to stand up from regular toilets. A raised toilet seat can help. There are different kinds of raised toilet seats, including seats with arms and lids and other special features. Plastic is more comfortable than stainless steel. Bedside commodes and bedpans are also available in varied selection.

Adult diapers/undergarments

As the population ages, it is becoming more acceptable to talk about adult diapers/adult briefs. Incontinence is not unusual, especially for seniors and people with various health problems and conditions. The choice in absorbent adult briefs will depend on the person's needs. For example, plastic liners in the underwear may be sufficient for those who have still have moderate or good bladder control. Many of these adult diapers are slip-on and look and feel very much like regular underwear. This can help a person maintain dignity and be more comfortable during day-to-day activities. For more information on toileting assistance items, please see the section on Toileting in the Practicalities of Caring section.

Dressing Aids:

Stocking aids

These specially-designed gadgets help a person pull up socks, without having to bend. There are also aids designed for putting on pantyhose.

Long shoehorns

Extra-long shoehorns can help a person put on a shoe without bending.

Clothing, button and zipper aids

Specialty gadgets such as button pulls and zipper pulls can be extremely helpful for someone with arthritis or problems with moving fingers. Dressing sticks have different size hooks on both ends to help with zippers and putting on jackets, shirts, pants or socks. These can be very helpful if a person has limited mobility or the use of only one arm. If these aids allow people to dress themselves instead of relying on help, they can help preserve independence and dignity. Usually, dressing aids cost about $10 to $20.

Mobility Aids:

Specialty chairs (lift chairs) and cushions

Lift chairs are designed to tilt forward and assist someone getting into and out of a chair. There are a wide selection of lift chairs available, and they are often quite modern and comfortable looking. Chairs with power buttons can help lower and raise the person from a sitting position to a standing position or vice versa.

You can also get special cushions to assist a person in sitting and/or getting up off of a chair or sofa. For example, self-powered portable lifting cushions can help a person get into and out of any chair by automatically raising people as they begin to push off the chair. Swivel cushions can help a person get into and out of car seats and chairs by swiveling or turning in place, so the person does not have to turn or swivel.

Electric or manual wheelchairs

Since wheelchairs are very expensive (several hundreds or thousands of dollars), you may want to examine options such as buying used wheelchairs, borrowing the equipment through a community/health care programs, or getting financial assistance through a program such as the Assistive Devices Program in some areas. Talk to your family doctor, government health offices or local community organizations and centres about these possibilities. When choosing a wheelchair, you will need to think about the height and weight of the person you are caring for and their primary needs. Will the wheelchair be used only occasionally for short distances? Will you need a wheelchair for both indoors and outdoors? A qualified sales representative or rehabilitation professional can assist with proper selection.

Canes, walkers and walking aids

These devices can help people walk around with added security and stability. Some walking aids have wheels to allow for easier turning and moving around. Walkers may or may not have seats, baskets and fold-up features. Canes are available in many forms with various types of grips and durability. Canes with three-pronged feet provide increased balance. You can also obtain picks to attach at the bottom of a cane for greater stability on ice. These picks can be raised when a person goes back indoors. As with other mobility aids, you will want to make sure that the fit of the cane is correct, based on the person's height. The cane should reach from the top of the ribcage to the floor.

Specialty utensils

Utensils with specially designed, easy-grasp handles make eating easier for people with weak hands.

Specialty dinnerware

Plates, bowls and other products are available and are designed for people who have difficulty using conventional dinnerware. For example, there are plastic, circular rails available that fit around any plate. This plastic guard keeps food on the plate as it is being pushed onto utensils.

Bedside tables and serving trays

These can be found in many stores, not just places specializing in assisted living supplies. Some of these tables have wheels and are easily collapsible. Bedside tables and trays not only allow a person to eat or snack in bed, but also provide a space for personal items (e.g. tissues, books, crossword puzzles).

Finding supplies and equipment

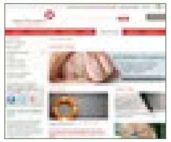
To find the right supplies and equipment, the first thing you might want to do is speak with the family doctor of the person you are caring for, government health offices, or local community organizations. These people may know of the best places to go.

You can also check your local yellow pages under the listing Medical Supplies and Equipment. You'll also find plenty of vendors and suppliers by searching on the Internet. Many not-for-profit organizations associated with specific conditions or diseases can also point you in the right direction.

TIP

For general Internet searches, try phrases such as assistive devices, assisted living, or independent living. If you're looking for a specific product, type in the name of the product when doing a search (e.g. grab bar or dressing stick)

The cost of some supplies and equipment may be covered by private insurance and government-funded programs at the federal, regional and provincial/territorial levels. Help the person you are caring for to check out the details of any private insurance policies and contact government health offices. Family doctors and local community organizations may also be able to tell you about programs that help cover costs.



Visit the Caring for Family section of the Saint Elizabeth website at www.saintelizabeth.com/family for more caregiving information and support.

Resources

General information

Health Canada www.hc-sc.gc.ca
Saint Elizabeth: Caring for Family www.saintelizabeth.com/family

Public Health Agency of Canada

www.phac-aspc.gc.ca

Diabetes

Canadian Diabetes Association www.diabetes.ca
American Diabetes Association www.diabetes.org/home.jsp

Seniors care

Canadian Coalition for Seniors Mental Health www.ccsmh.ca
Canadian Association of Gerontology www.cagacg.ca
Canadian Centre for Activity and Aging www.uwo.ca/actage
Seniors Health Research Transfer Network www.shrtn.on.ca

Palliative Care

Canadian Virtual Hospice www.virtualhospice.ca
Saint Elizabeth Health Care: Palliative Care
www.saintelizabeth.com/Caring-for-Family/Caregiving-Information/Caregivers-Palliative-Care-Guide.aspx
Changes Toolkit www.changestoolkit.ca

Cancer

Canadian Cancer Society http://www.cancer.ca/

Wound Care /Continence

Canadian Association of Wound Care http://www.cawc.net/
Ostomy Wound Management www.o-wm.com

Pediatrics / Maternal Newborn

About Kids Health www.aboutkidshealth.ca

Mental Health

Centre for Addiction and Mental Health www.camh.net

Ontario Ministry of Health and Long Term Care: Mental Health www.health.gov.on.ca/english/public/ program/mentalhealth/mentalhealth_mn.html

Canadian Mental Health Association www.cmha.ca/bins/index.asp

The Law Society of Upper Canada

www.lsuc.on.ca/public/a/faqs---lawyer-referral-service/

Ontario Government Assistive Devices Program

www.health.gov.on.ca/english/public/program/adp/adp_mn.html

Ministry of Health and Long Term Care

Seniors' Care : Home, Community and Residential Care Services for Seniors

www.health.gov.on.ca/en/public/programs/ltc/

Safe Medication Use

Ontario MedsCheck www.health.gov.on.ca/en/pro/programs/drugs/medscheck/medscheck_original.aspx

Power of Attorney

www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poakit.asp

Visit the Caring for Family section of the Saint Elizabeth website at www.saintelizabeth.com/family for more caregiving information and support.

Table of Contents

Overview

This section is for individuals caring for someone at end-of-life. While the last stages of life may be a long period for some people, it may be short for others.

You may have many questions about being a caregiver during this time. What are right things to say and do? Caring for someone at end-of-life requires skills such as communication, compassion, patience, and practical hands-on care. It also includes the ability to work with the dying person to find out what they need and prefer during this time.

This can be stressful for caregivers as the demands of the role often increase as the dying person becomes increasingly ill.[1] The purpose of this section of the resource is to provide you with some information and strategies to assist you during this time.

As with all sections of this resource, some information will be more relevant to you than others. Take what you need now but know that you can always come back to it at a later time.

Providing Care at End-of-Life

Understanding Hospice Palliative Care

There are many terms that you may hear when you are caring for someone with a terminal illness. You may hear the terms palliative care, hospice care or hospice palliative care. These terms are all used interchangeably, and refer to the actual approach to care, regardless of the location that care is being provided (Canadian Virtual Hospice, 2009). The goal of palliative care is to reduce suffering and improve quality of life.

To achieve this, palliative care:

- focuses on the concerns of patients and their families;
- provides relief to pain and other physical symptoms such as loss of appetite and confusion;
- examines the whole person - considering the emotional and spiritual concerns of patients and families while respecting their social and cultural needs;
- ensures that care is respectful and supportive of patient dignity;
- is provided by an inter-professional team that may include different people including volunteers, social workers and spiritual leaders in addition to medical and nursing professionals (Canadian Virtual Hospice, 2009).

Palliative care can be delivered in a number of different locations or settings including the hospital, home, residential or long-term care facilities, dedicated hospices or other settings.

Sometimes, family and friends provide palliative care, with no outside help. As a caregiver, you may be the main provider of hospice palliative care. However, it is wise to seek help, as this type of care is very difficult to do alone. For example, professional and volunteer agencies in the community can assist you to provide palliative care.

A first step would be for you and the dying person to decide what type of care you think you may need. To assist with this, you may wish to speak with doctors and nurses who are providing care right now.

Providing Care at End-of-Life

> If you are booking an appointment to discuss this you may wish to ask for a double appointment. Remember to tell what the purpose of the visit is so the doctor knows what you want to discuss.[2]

The emotional and spiritual needs of someone in the last phases of life

People who are dying experience many emotions some of which you may not have seen before. The dying person may be grieving the anticipated loss of their life, which is very normal.

Other common emotions may include the following: [3] [4]

Uneasy – when a person may feel unease about their future and the prospect of dying

Anger – a really common experience where the person may exhibit behaviour such as yelling, sarcasm, hostility (amongst others). The cause of anger may be related to an illness, failure of the medical treatment or the person may simply feel frustrated with the situation they are in.

Feeling guilty – sometimes people feel that they have become a burden to family/friends and may therefore blame themselves for requiring care.

Embarrassment – as care increases and the dying person is dependent on others, there may be feelings of embarrassment.

Sadness – it is normal for the dying person to feel sad as they think about life after their death or that they are unable to do activities that they enjoy as a result of their current illness (this may cause them to also feel lonely). It is important to remember that sadness does not always mean that a person is depressed.

All of these emotions are common and normal. It can be difficult for you as a caregiver to witness and experience them. You can encourage the dying person to share their feelings and what is happening to cause them. Open communication can help to get to understand and resolve problems.

However, sometimes there are no answers to a problem. Being present to listen and encouraging the dying person to share their emotions can be very helpful.

> Remember, you are not alone in doing this. People such as doctors, nurses, spiritual leaders, social workers and volunteers can help to support you and the dying person.

Spiritual needs

Spirituality has many definitions. It can be defined as 'that which gives people meaning and purpose in life'.[5] Although spirituality is not religion, religion is an expression of a person's spirituality. Some people say that religion helps them find meaning or understand suffering. It gives them purpose and helps to deal with the uncertainty of life.[6] Spirituality is an important part of the last stages of life. Some people may want to discuss their beliefs and get support. This care may come from a number of health care team members including a spiritual leader, doctors, nurses, friends and family.

Your Emotions as a Caregiver

As a caregiver, you may experience many emotions. While some caregivers find it easy to deal with these emotions, others find it difficult. Here are some common emotions you may experience:

Grief

Grieving the loss of someone can begin long before the death happens. This is called anticipatory grief. During this time you may feel intense sadness, and mixed emotions about the death. There may be good days where you feel ready for the person you are caring for to die. Other days you may feel overwhelmed and you need more time with the person you are caring for before letting go.

Guilt and regret

You may feel a sense of guilt or regret for what you may or may not have done when the person was well. You may also feel resentment or regret for what the person you are caring for did or did not do for you. Although you should not ignore or dismiss these feelings, try not to dwell on them. At some point, you may wish to seek support or counseling to assist you to work through past emotional issues.

Feeling Hopeless/Helpless and Feeling Spiritual

Many people find that their strength and limits are tested during this time. The person you are caring for may be going through things that will be difficult for you. You may feel helpless and comfort in your faith or your spirituality at the same time. You may have a particular poem or holy verse that will comfort you.

Feeling Angry and Feeling at Peace

Many caregivers experience anger during this time. Give yourself permission to be angry. Your anger may be caused by many things. For example, you may feel frustrated with the lack of understanding by family and friends. Some caregivers report feeling angry that some people were supportive at the time of diagnosis, but were not supportive at the end-of-life. You may also feel angry with health care providers. You may feel that they do not know what it is like for you. Your anger may lie with God (for taking your person away), with members of your family (why aren't they helping more?), or with the dying person. Remember, the anger will pass, and that it is only one piece of a much bigger picture.

You will still find opportunities to laugh. Many caregivers report that there is a great peace that comes over them amidst the challenge of being a caregiver at end-of-life. This peace may come in knowing that you are helping a person to be more comfortable. This can be a difficult time, but also a special time filled with precious moments and rich memories. [7]

Communication with Children About Terminal Illness

Talking to children about a dying loved one or friend can be difficult for adults. Most people want to protect children from what is happening. It is important to realize that all children experience losses and need help to learn to deal with them. Open and honest communication can provide children good information about death and dying.

Children are often able to 'pick up' on the fact that something is wrong. Do not spare children from knowing that a loved one is dying. Begin by learning what the children understand and their reaction to the situation. It is best that children are told about what is happening. Children should be given opportunities to ask questions and express their feelings.[8]

Providing children with information about the end-of-life and what is happening within the family enables them to learn to trust both others and their own perceptions about situations. It also allows them to work through their feelings with other people.[9]

Watch these videos on the Canadian Virtual Hospice website that may help you deal with this type of situation.

It can be challenging to figure out the best way of approaching this type of discussion, but there are many resources available to you to help you plan your approach, some of these are available in the RESOURCES section. You can also seek help from members of the health care team involved in the dying person's care. They should be able to give you some support and advice regarding the best way to manage this subject.

Practical Information For Caregivers

Addressing your information needs: Questions to ask health care professionals

Caring for someone at end-of-life involves more than practical care, however information about caring for the physical health of someone remains important.

Everyone is different and may want different information about their health conditions. Some people will want to know every detail while others will not.[10] Remember to ask the dying person for their input into things such as medications, pain management and treatment and what information they would like to know and who they would like to share it with.[4] When you receive information from health care providers, you can share this information honestly with the person. This is a way of helping to make them feel valued, informed, and in control.

To Do:

Sometimes is it hard to know what questions to ask or what information may be important.[11] Review this list of questions which you can discuss with members of the health care team for the person you are caring for:

- ✓ What is happening to the person I am caring for? What is his/her prognosis?
- ✓ Is the person I am caring for dying? What can I expect when they are dying? What will this look like?
- ✓ Will the person I am caring for be in pain?
- ✓ What care will I need to provide for the person I am caring for?
- ✓ What should I do if I am unable to cope with this?
- ✓ Who can I call if I have questions or need help?

Financial considerations

Caring for someone towards end-of-life can be stressful for some caregivers. This is sometimes complicated by other priorities and responsibilities such as working, caring for children or other family members etc. The Canadian Federal Government has established a program to assist caregivers who are caring for people at the end of life.

Find out about Compassionate Care Benefits:
www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml#Definition

In addition, each provincial and territorial government will have differing policies and benefits for caregivers which may be of assistance during this time. A list of possible resources have been provided:

Assistive Devices Program (ADP) - Ontario Ministry of Health and Long-Term Care
1-800-268-6021
www.health.gov.on.ca/english/public/program/adp/adp_mn.html

Canada Pension Plan Disability Benefits
1-800-277-9914
http://www.hrdc-drhc.gc.ca/isp/cpp/disabi_e.shtml

Veterans Affairs Canada - Health Benefits
1-866-522-2122
www.servicecanada.gc.ca/eng/sc/cpp/disability/disabilitypension.shtml

TIP

If you are having financial challenges, ask your health care team to refer you to a social worker. Social workers are employed in a variety of environments including hospitals, community health centers and social service agencies. They may be able to help you to address some of the challenges that you may be facing.

Managing Physical Symptoms

Managing physical needs of a person is an important aspect of hospice palliative care. The goal of care is to reduce suffering. To achieve this, care is focused on the whole person including managing their physical comfort. This is done by using medications but may also include massage, relaxation exercises and/or through making changes to someone's diet and meal preparations to ensure that they are comfortable.[13]

Pain

Pain can be described as an unpleasant sensation or a feeling that happens when tissues in the body are damaged. The person you are caring for may experience physical pain or discomfort that is related to their illness. Pain is a subjective experience whereby each person experiences it differently. For example, one person may describe their pain as excruciating while another person may describe a similar pain as moderate.[14]

Assessing pain is the first step to controlling pain. Every person expresses pain in different ways. Assessing pain is an ongoing process. Living with pain can be both physically and emotionally tiring. Your loved one may feel afraid, anxious, sad, angry or tired. All of these can make physical pain feel worse. Pain may also be worse if the person is having other physical symptoms such as nausea or shortness of breath.

> You can help to manage the pain of the person you are caring for by listening when they complain of pain. Each person experiences pain differently. When describing the pain of the person you are caring for to the healthcare team, it is important to go into as much detail as possible.

To Do:

These questions will help you provide the doctor or nurse with information that can help control the pain of the person you are caring for. These questions can also be used to collect information about other physical symptoms.

- When did the pain [symptom] begin?
- What were you doing when it began?
- Where is the pain?
- What does the pain [symptom] feel like? (describe your pain)
- Have you had a pain [symptom] like this before?
- How bad is the pain [symptom]? Using a scale of 0 to 10, how would you rate your pain [symptom]? (0 is that there is no pain and 10 is the worst pain ever).
- How long does it last?
- Does anything make the pain [symptom] better? Worse?
- Does taking your medication or other treatments stop the pain [symptom]?

Medications to manage pain

There are many pain medications available to treat different types and levels of pain. The person you are caring for may believe they should put off using them for as long as possible and only ask for help when the pain becomes unbearable. There is no reason for the person you are caring for to suffer through pain at any level. If they wait too long, the pain may be harder to control and it may take longer for the medications to relieve the pain. The goal of treating pain is to prevent it from occurring at all.

Different pain medications are often used to control the pain and can be used to make the person you are caring for more comfortable. The medications used most often to control pain are called opioid analgesics or narcotics. Opioids reduce or sometimes block the pain, so that you no longer notice it.

Some names of opioids are:

- Morphine
- Hydromorphone
- Oxycodone
- Fentanyl

With the help of your healthcare team, you and the person you are caring for should be able to find ways to manage their pain. Many people find that medication helps with pain and they are satisfied with their pain control. For some people, it may not be possible to make all the pain go away, but the pain that remains is more manageable.

What you can do to manage pain

You can play an important role in managing your pain by recognizing the person you are caring for has pain or other physical symptoms and asking the healthcare team for help.

When the person you are caring for is prescribed medication make sure it is taken as directed. This will help keep the medication in their body at the same level and make sure that the pain control is constant.

They should not stop taking the medication. A sudden change in medication levels may produce unpleasant side effects. If you or the person you are caring for is worried about taking a medication or having side effects from it, talk to the healthcare team and discuss other choices together.

It may take a few days for you/the person you are caring for and the healthcare team to decide on the right amount (dose) of medication and how often they will need to take it. The dose should be enough to control pain right through until the next dose.

TIP

Many people have questions about pain medication. It is important to clarify any of your concerns with health care providers. Here are some questions that might help get the conversation flowing:

- What pain medications will they need? Are there any risks to using them?
- Will the pain medicines stop working if used too often? Can they cause addiction?
- Can the pain medicine stop their heart or cause him/her to stop breathing?

Controlling other physical symptoms

Depending on the illness and situation of the person you are caring for, he or she may experience other physical symptoms such as nausea and vomiting and shortness of breath. The healthcare team can assist with the management of these symptoms. It is important that these symptoms are reported to the healthcare team so they can help you to manage these symptoms.

Practical tips to help manage physical symptoms

Some strategies have been listed that can help you to effectively manage the symptoms of the person you are caring for.[15]

Ask questions

Try to encourage the person to share information about their symptoms. If they do report that they are experiencing symptoms try to get them to be as specific as possible about them. Things may change over time, so it's important to ask questions about symptoms regularly and report the information to the healthcare team.

Report symptoms early

Symptoms (like pain) are easier to manage when they are reported early and a plan to manage them is put in place. Symptoms that are not reported early may become worse and as a result more difficult to manage. If a symptom does appear, report it to the healthcare team and follow the plan of care that the team has agreed on. This plan may include taking regular doses of medications. Following the plan can better manage symptoms.

Consider other management techniques

There are many techniques or options available to managing your loved one's symptoms. If the first option does not work, consider speaking with your healthcare team about other options. There is both medications and other non-medication options that may help to manage symptoms. This may include complementary therapies such as relaxation techniques, massage, and music. It is best to explore these complementary therapies with the healthcare team, to ensure safety.

Keep a diary

A pain or symptom diary can help to record what has happened and to share with the healthcare team. A diary can be used to record pain or symptoms levels and what medications are taken and when. A diary can record information over time that can be used by the healthcare team to adjust medications and other treatments as needed.

Understand medications and their side effects

You may need to share information about medications with the person you are caring for. Become familiar with the medications being prescribed and how to manage any expected side effects. For example, constipation is an expected side effect with many pain medications. Bowel medications can be prescribed to prevent and manage constipation. Report any medication side effects to the healthcare team as soon as possible so actions can be taken to manage these side effects.

Encourage relaxation and fun

Laughter releases endorphins (natural pain killers) in the body. People who have social contact and have positive moods often handle pain better. Plan things that the person you are caring for enjoys. This may include a good movie, listening to relaxing music, a good book or funny jokes.

Tips for Caregivers Providing End-Of-Life Care

Be present

Your presence can make end-of-life more meaningful. Others may also wish to be involved and you can bring these people. Make a schedule with family members and friends, so they have an opportunity to be with the dying person. It's important to seek the dying person's permission and to identify somebody to be the coordinator of this schedule.

Allow time alone

If you find that the person you are caring for needs time alone, allow this to happen. They may need some time to reflect on the past and prepare for their death. Take your lead from the dying person. If you're sensing that the person wants people close by, try to provide that opportunity.

Support feelings

Provide opportunities for the person to share feelings. While some may not want or be able to talk about their feelings (such as sadness, fear and remorse), many people find it a great relief to be able to openly express emotions. During this time, try to be patient and calm. If you are unable to cope with this sort of discussion, try to think of other people who may be able to discuss these feelings with the person. This may be another family member, a friend, or spiritual advisor.

Touch and talk

Two of the most important human senses are hearing and touch. They both play an important role in communication. Eye contact is very important and smiles and hugs can be as important as talking. If a person can no longer speak, or if they are withdrawing then sometimes gentle communication and touch can be helpful.

Laura, a caregiver to her grandmother recalls:

> My grandmother was not an overly 'touchy' person, however, when she became progressively ill I noticed the importance of touch. She started to enjoy it when I rubbed her back and held her hand to let her know I was there. This became a very important part of our time together.

Be respectful

People who are dying should always be treated with respect. Do not talk about them as though they are not there or about them in the past tense. Try also to be respectful of the person's values and beliefs, even if you don't agree with them.

In a Canadian radio interview, Kate (a woman dying of leukemia) mentioned that she did not appreciate how people around her suddenly became interested in preaching to her about religion. Kate talked about how she really just wanted people to respect her own religious beliefs during her time of dying.

Encourage independence and control

People who are dying should have the right to actively participate in their care and where able, make decisions. This helps them feel in control of their lives. Try to promote this where possible. For example a person's preferences regarding how care is provided should be considered and they should be involved in the care planning process. You can support them by offering encouragement and advice.

For people who have lost much or all of their ability to communicate, and for people who are mentally confused, you can still provide opportunities for personal control and independence. For example, you can ask very simple questions like: "Would you like to be turned, now?" You can also offer choices: "Would you like to wear this red sweater or this orange shirt?" If people cannot speak, they may be able to point to clothes they want to wear.

Keep routines and special times together

One way to be supportive at end-of-life is to protect time for special routines/events each day or week. This may involve reading a book, looking at photo albums, praying together, or listening to music. Try to find activities that help the dying person feel that he/she has contributed and valued by others. You can do something simple like ask for advice about a topic of importance, or ask for help with something such as making a quilt or scrapbook of memories.

Don't be afraid to talk about death and to say goodbye

Sometimes it can be a relief for a dying person to talk to others about what is happening It can provide people with emotional comfort knowing they are able to talk about their fears and wishes. If the person you are caring for is interested and able, involve them in the pre-death planning (e.g. funeral planning). Take your cues from them as to how much or how little to talk about death.

Be yourself

Probably the best gift you can give someone at end-of-life is the gift of yourself. Remember that if you stop acting as you normally would, the person you are caring for may feel uncomfortable. If you've always been a joker, continue to tell jokes. If it's in your nature to talk a lot, you can continue to be your chatty self (within reasonable limits). Try to live life as normal as possible.

Take care of yourself and recognize your limits

This may be a meaningful yet difficult time in your life. Be good to yourself. Recognize you need to take breaks. Taking care of yourself helps you take care of the dying person. Rely on family, friends, volunteers and the health care providers. If you can no longer provide care in the home, you may need to consider an alternative location such as a residential hospice or palliative care unit. Do not be ashamed to ask for help.

Jane, a caregiver found it hard to deal with her role as caregiver for her mother in law at the end of life but found it easier when she used humour to help cope. Sometimes a wry joke helped to inject humour into a situation which was proving to be stressful. This helped to remind both women about the laughter they had shared throughout their lives together,

> It cannot be stressed enough that simply being there is extremely important. You don't have to worry about the right thing to say or do at this time. There are no rules. [16 17]

Caring for the Physical Changes

There are certain physical changes that are likely to occur in a person who is dying. The more you know about these changes, the more prepared you will be to care for them. In addition, you can help the dying person and others to prepare for and understand these natural changes. The following provides information on what you may expect.

Loss of appetite

The person you are caring will begin to eat and drink less because the body is slowing down. In fact, they may not want food at all. At this point, swallowing may be very difficult, and the person may simply not be interested in eating or drinking. This is normal part of the dying process and can be very difficult for caregivers. Try to remember that you do not have to worry about a person eating if he or she is not hungry. Forcing eating and drinking can be more harmful than good as it can cause choking. If the person you are caring for wishes to eat or drink then small amounts of food or fluids may provide comfort. It is often not appropriate to give fluids intravenously and any questions about this should be discussed with your doctor or nurse.

Bladder and bowel problems

As the person’s muscles relax, and there may be a loss of bladder and bowel control; often referred to as incontinence. A catheter or condom catheter may help to control incontinence and prevent skin problems. You may also notice that the amount of urine decreases and becomes dark in colour. Your health care provider will be able to give you with information on how you can comfort and care for the person you are caring for. You can also refer to the **Practicalities of caring section.**

Changes in sleeping

When someone is dying they sleep for much longer periods and may be difficult to wake. You may find that the person is frequently slipping into a dreamlike state where he or she seems only semi-alert, even when awake. This is natural. Keep a comfortable sleep and resting environment for the person through plenty of silence, dimmed lights, and peaceful surroundings. If they show signs of alertness at certain times in the day, plan short visits for these times.

The person you are caring for may fall into a deep sleep or coma state. At this point, you can continue to speak gently and calmly to the person. Remember that hearing and touch are the last senses to leave a person.

Breathing changes

If the person is experiencing breathlessness, this is called dyspnea or shortness of breath. If you notice this, it is important for you to stay calm and remember that breathlessness will not lead to choking or suffocation. You can help by reassuring the person and having them reposition themselves. They may appear restless and calming music, relaxation and breathing exercises may also help. Keep as much fresh air and moisture in the room as possible. You can speak with the family doctor about any medication relief or possible oxygen treatment, if this becomes a big problem.

You may notice the person isn't breathing at all for many seconds. Irregular or shallow breathing is also not uncommon. Although this may be alarming for you, it is not uncomfortable for the person. You may hear odd vocal and breathing sounds, as the person unconsciously uses vocal cords. These sounds are most likely not an indication of pain. If you care concerned however, check with the health care team.

The person's breathing may begin to sound louder and wet. This type of breathing is not painful for a person. Saliva at the back of the throat causes this sound, as the person cannot swallow properly. By turning a person on one side, you can allow saliva to rest at the side of the mouth. Speak to a doctor or nurse if wet breathing continues, as medications may be available.

Mouth problems

Mouth problems commonly occur in people with a terminal illness. These include thrush (a fungal infection, also called candidiasis), mouth sores or dry mouth.

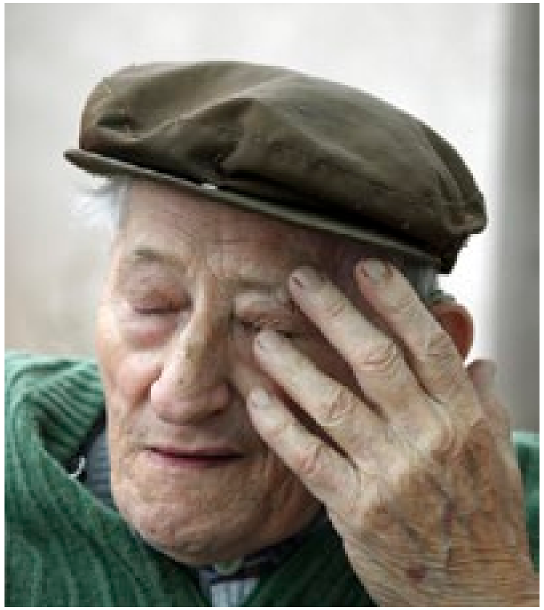
White patches (thrush) may appear inside a person's mouth and they may complain of a mouth sore or problems swallowing. Inspect the mouth to see if there are any white curd-like patches on the tongue, roof of the mouth, inside the cheeks and lips and back of the throat. You will need to tell your doctor or nurse immediately. The doctor may prescribe medications to treat the thrush.

Mouth sores can also occur and can be very painful and interfere with eating and drinking. Make sure that the person's teeth are gently cleaned after meals and snacks. In addition, you want to keep the mouth as moist as possible. Offer sips of water as tolerated and use lip balm as required. Do not use mouthwashes that contain alcohol (these dry the mouth).

Confusion

It is not uncommon for people to become mixed up and confused due to chemical changes in the body. Sometimes medication might cause the confusion. These periods of confusion might be short-term (lasting hours or days) or permanent. The person may not be able to recognize you, may be suspicious of everyone, or may begin making comments that make no sense at all. You may notice forgetfulness or a mix-up of days and nights. You may also notice bizarre behaviours, and even hallucinations.

Hallucinations might occur due to medication side effects, dehydration or other changes. When a person is hallucinating, he or she may actually see or hear something that is not there. It is recommended that you stay with a person during a hallucination, and try to help him or her stay calm and relaxed. It is very important that you report any hallucinations to the doctor.



During periods of confusion, if a person cannot remember you, kindly identify yourself. Use visual cues like photos or favourite pictures to help a person to remember. Continue to treat them with compassion and kindness. Even though they are not showing it, confused people need human connection and understanding. Although they may not consciously remember you, they still do remember what it feels like to be treated with kindness and love.

Last days of life

In the final days before death, a person goes through changes as the body shuts down (CHPCA, 2004). Here is some information on what you may expect.

Social withdrawal

Often, people who are dying will show signs of withdrawing from those around them. For example, they may let go of your hand. They may turn to face the wall. This is not meant to be an insult to those around them. They just need to let go and prepare to leave this world.   You should note that people might exhibit many signs of the above and then improve for some time. For some caregivers, this may be difficult. You may be expecting someone to die one day, and then find that they are suddenly doing much better. Try to take things on a day-by-day basis and cope as best you can with the ups and downs. (von Bommell, 2006; Edmonton Regional Palliative Care Program)

Changes in level of awareness

In the final days, ability to think clear and respond to surroundings may be affected. These changes often happen together with the physical changes at end-of-life.

- The person may not be able to follow simple directions
- There may be restlessness or irritation for no known reason
- The ability to communicate what the person is thinking is reduced
- Familiar objects and people may not be recognized or forgotten
- Hallucinations may be a problem
- Drowsiness may come and go or be all the time

(CHPCA, 2004)

As death approaches

As death approaches the body undergoes many changes. Understanding what to except can help you to deal with what is happening:

- Changes in breathing – respirations become shallow, quicker or slower. There may be difficulty breathing and periods of no breathing. Rattling or bubbling noises in the throat or chest may also be heard.
- Swallowing may become difficult
- Heartbeat may become irregular
- Restlessness may increase
- There may be a decreased level of consciousness

- There may be little interest in food or drinks
- Urine may be reduced and dark in color or no urine at all
- Skin may be cold and purple in color, mostly the arms and legs

(CHPCA, 2004)

At time of death

Sometimes people are not sure what signs to look for to know that their loved one has died. Here is what you will need to know.

At the time of death, the body stops working:

- There will be no breathing and no pulse
- The person will not respond to sound, touch or movement
- The eyes will be in a fixed position; may be opened or closed
- There may be loss of control of the bladder and/or bowels
- The facial muscles and jaw will relax and the mouth may open slightly

(CHPCA, 2004)

Planning For an Expected Death

Some people choose to make arrangement prior to the death. This allows you more time to make decisions about arrangements. This will also allow you to visit with family and mourn your loss at time of death without worrying about details. Encourage the person to be as actively involved and in control as possible in pre-death planning. You may wish to contact or visit a funeral home to make arrangements.

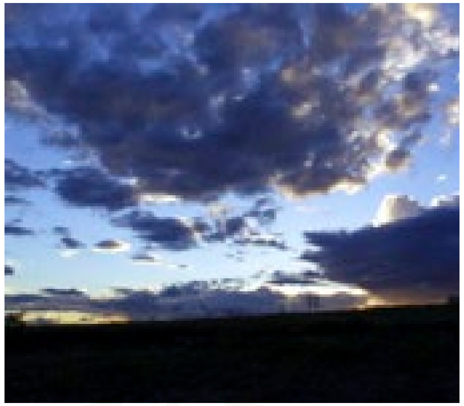
Checklist: Preparing for the end

- ✓ Create a list of phone numbers of people who should be notified after death.
- ✓ Include the names and numbers for the funeral director and doctor.
- ✓ List specific names and numbers of those you can call on a 24-hour basis (e.g. the name and number of a health care provider you can call in the middle of the night, instead of calling emergency services and any other family or friends).
- ✓ Avoid calling 911/emergency services at the time of death.

After the death, take all the time you need to spend with the person you are caring for. This may be the time you have to say final goodbyes, cry, and talk to the person and to other family members and friends. You do not have to call the doctor or funeral director immediately after the death. Follow whatever cultural or religious practices you are comfortable with. When you are ready (and this could be several hours later) call your physician to tell them that the person you are caring for has died. If the death happened during the night, it is okay to wait until the morning to call the physician.

Eventually, you will need to contact the doctor to officially declare that the person you are caring for has died also known as certification of death

Understanding Grief



When people are trying to adjust to the death of a loved one, they usually grieve. Grief is a normal part of the healing process. Grief helps people let go of the past and adjust to a life without the loved one who has died (CHPCA, 2004).

Before or after the death of a loved one, you may feel a number of responses to grief.

Normal **physical** responses include:

- Feelings of hollowness in the stomach
- Tightness in the chest
- Heart palpitations
- Weakness and lack of energy
- Stomach upset
- Weight gain or loss

Normal **emotional** responses include feelings of:

- Sadness
- Fear
- Anger
- Guilt
- Loneliness, isolation
- Need to review what happening at the time of the death

Normal **cognitive** responses include:

- Disbelief
- Denial
- Confusion
- Unable to concentrate
- Preoccupied with or have dreams of the person

Normal **social** responses include:

- Being on auto pilot
- Withdrawal from others
- Dependence on others
- Fear of being alone

The experience of grief

There are many explanations of the grief process which help us to try and give structure to what we are experiencing but it is important to remember that there is no set order to what you will feel. Just as each of us follows a different path in life, each individual experiences grief differently and walks the path to recovery at different speeds and in different directions. Try to avoid comparing how you are reacting to grief with how others are dealing with it. We are individuals and experience grief with our entire beings, with our mind, body and spirit all reacting to loss. There is no right or wrong approach.

People who have suffered the loss of a loved one often go through stages. These include:

1. To accept the reality of the loss: Common emotions and experiences you may feel include shock, numbness and disbelief. You may feel overwhelmed and overcome with physical responses including palpitations, crying, and physical symptoms of shock. You may even feel a sense of relief for the deceased, as they are no longer suffering or yourself as you no longer have the stress of being the caregiver.
2. To experience the pain of grief: Once the numbness and shock begins to fade, you may start to feel the emotional pain of the grieving. Common emotions and experiences include sadness, anger, guilt, feelings of anxiety, regret, not sleeping well, social withdrawal, and restlessness.
3. To adjust to an environment in which the deceased is missing: This is where you begin to adjust to living without the person you are caring for. You may develop new interests. The losses are not forgotten but become an important part of their life. You may begin to become more interested in social activities, physical symptoms subside and emotions begin to settle down. You are also likely to remember your love one and it is less painful.
4. To rebuild a new life: Finally, as grief proceeds, you begin to use your energy to become involved in new activities and relationships.

(CHPCA, 2004; Victoria Hospice Society 1998; 2006)

How long does grief last

It is difficult to say how long you will experience grief. Many people find that grief comes and goes over time. There may be good days and bad days. After a few months the intense feelings often begin to become lessened. It may take months or longer for you to return to normal. Over time, coping gets easier but it may take longer for you to do some of the things you enjoyed doing with the person you are caring for. Although you are able to rebuild your new life, it may take years for you to feel you can live without the person you are caring for. There may be days, memories or events that trigger feelings of grief. These feelings do get better and become part of your life. (CHPCA, 2004)

Caring for yourself and grieving

Grieving can be a painful experience and learning to cope with grief can be difficult. It is easy to distract ourselves from the emotional turmoil by keeping ourselves busy with work and family, telling ourselves that we need to be strong for everybody else. However, avoiding our experience of grief is pointless since it only causes us to suffer further emotional turmoil later in life.

Sadly, there is no magical formula for coping with grief – different things work for different people. The following are suggestions for coping with grief. Try to identify what things might work best for you and/or the people that you care about but know that coping with grief takes time and you will not feel better over night.

- Talking and listening are important throughout the grief process. Ensure that you share what you are feeling and listen to others.
- Surround yourself with caring people who love you.
- Reach out for help and accept help when it is offered to you. You may not always be able to rely on others to make the first move as they may not know what you need. Tell others that you need help and what they can do to support you.
- Share with yourself. Keep a written journal, draw, paint, sing, dance - express yourself and your emotions.
- Acknowledge your emotions and allow yourself to feel the pain. Allow yourself to cry, it helps you to express your painful feelings.
- Be patient with yourself and take it one day at a time. Grieving takes time and you need to give yourself permission to go through the process at your own pace.
- Accept the loss. It is natural to not want to accept the reality of the loss you have suffered. However, with the passage of time it is important to accept the loss you have experienced and move forward with your life. Although it may take time, letting go of their possessions is a positive sign of acceptance.
- When you're ready, let go of the grief. This does not mean that you have forgotten them, but simply that you have let go of the grief and are able to remember happier times.
- Take care of yourself! Take time to look after your emotional, physical and spiritual health.
- Don't commit yourself to things that you do not need and want to do. Set limits and stick to them.
- Postpone major life changes as your judgment may be impaired during the grieving process.

- Try to limit your consumption of cigarettes, alcohol, and any other form of medication or chemical substance used to reduce anxiety.
- When you're ready, try to resume some of your normal activities.
- Continue to remember the good times you shared with the person you are caring for.

(CHPCA, 2004; Edmonton Regional Palliative Care Program)

Children and grief

Children do grieve differently than adults. Their understanding and ability to deal with a loss depends on their developmental level. Children may not have the language to describe their feelings and experiences. Instead their changes in behaviours will provide clues to how they are struggling with the loss.

- All ages sense sadness, feel the loss and pain, fear dying and being alone.
- All ages may feel guilt for what is happening to the dying person.
- Children under 3 do not understand that death is forever.
- Children under 10 may fear getting sick and dying. If a parent has died, they may worry that the other parent will die too.
- Children over 10 better understand what is happening but may not be able to talk about the death.

Include children in discussions, planning and events can provide them with positive experiences and gives them permission to grieve. Respecting their choices, where appropriate, allows children to be involved and in control.

If they want to attend or take part in the funeral or service, this should not be discouraged. It is important however that adults explain what will take place so children know what to expect. It is also important that an adult is available to answer any questions they may have during these events.

(CHPCA, 2004; Victoria Hospice Society, 1998; 2006)

Supporting children

There are many books available at local bookstores or Hospice organizations that may help children during their grief. Here is some information about how you can offer comfort to children:

- Do not try to "spare" children from knowing that a loved one is dying. Tell children the truth and listen carefully to what they are saying. Provide them with opportunities to ask questions and to express their feelings.
- Avoid using words such as "passed away", "gone to heaven" or "sleeping" as this may cause more confusion. Instead use the real word 'death' or 'dying'.
- Reassure children that illness does not always lead to death. Remind them that they are loved as much as ever.
- Tell children that what they are feeling is normal and it is okay to cry. Encourage them to express their feelings by talking, painting, coloring, puppets and music.
- Try to keep children's routines as normal as possible.

(CHPCA, 2004; Victoria Hospice Society, 1998; 2006)

Where to get help

End-of-life can be a challenging time for caregivers especially when there are children involved. There are resources available for you to assist children with what is happening to a loved one. You can start by speaking to a member of the health care team involved in the care. They should be able to give you some support and guidance and offer suggestions about resources that can help.

Resources

Caring to the end of life – Princess Margaret Hospital

Web site for anyone who needs information about palliative care for cancer patients

www.caringtotheend.ca/index.php

Canadian Virtual Hospice

Information and support for living with life-limiting illness, end of life, loss and grief.

www.virtualhospice.ca

Saint Elizabeth Health Care

Caring for Family - Palliative Care and End of Life

www.saintelizabeth.com/Caring-for-Family/Caregiving-Information/Caregivers-Palliative-Care-Guide.aspx

Changes Toolkit

Canadian resources and tools for palliative care patients and their family caregivers.

www.changestoolkit.ca

Doris Inc: A Business Approach to Caring for Your Elderly Parents

By Shirley Roberts

Available at bookstores or

ca.wiley.com/WileyCDA/WileyTitle/productCd-1118100220.html

BestEndings

Making it easier to talk about and plan for life’s end.

www.bestendings.com

Communicating with children – additional resources:

Brown LK, Brown M. *When dinosaurs die. A guide to understanding death.* New York, NY: Little Brown Books for Young Readers; 1996.

Eaton RC. *Living dying. A guide for adults supporting grieving children and teenagers.* Toronto, ON: Max and Beatrice Wolfe Centre for Children's Grief and Palliative Care; 2008.

Hamilton J. *When a parent is sick. Helping parents explain serious illness to children.* Halifax, NS: Pottersfield Press; 2001.

Silverman PR. *Never too young to know. Death in children's lives.* New York, NY: Oxford University Press; 2000.

Buscaglia L. *The fall of Freddie the leaf. A story of life for all ages.* New York, NY: Henry Holt & Company; 1982.

Mellonie B. Lifetimes. *A beautiful way to explain death to children.* Toronto, ON: Bantam Books; 1983.

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[7] Edmonton Regional Palliative Care Program. What to Expect as the Final Stage of Death Approaches. www.palliative.org/NewPC/_pdfs/grief/WhatToExpect-FinalStageOfDeath.pdf

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[14] “Nursing Best Practice Guideline: Assessment and management of pain.” Registered Nurses Association of Ontario. 2007. Web. http://rnao.ca/bpg/guidelines/assessment-and-management-pain. 2013.

[15] “Pain control for people with cancer.” National Cancer Institute. Web. www.cancer.gov/cancertopics/paincontrol/page1. 2009.

[16] Edmonton Regional Palliative Care Program. What to Expect as the Final Stage of Death Approaches. www.palliative.org/NewPC/_pdfs/grief/WhatToExpect-FinalStageOfDeath.pdf

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Table of Contents

Overview

Combine one part guilt with two parts responsibility, add a pinch of competing priorities, mix in a slice of time, sprinkle with frustration and you have the perfect recipe for caregiver stress!

Just as the person you are providing care to is unique, so is the impact of the caregiver role upon your health. You may find that providing care provides you with an opportunity to learn new skills and strengthens your relationships with family/friends, but you may also feel stressed, anxious or depressed. It may actually feel like a roller coaster ride, one day you feel incredible joy, and the next, incredible frustration.

Chances are you'll probably feel all of these, and it's important to know it's not abnormal for caregivers to feel these emotions – it's actually quite normal.[1] In fact, research has shown that caregivers have higher levels of depression and anxiety than the general population.[2]

The focus of this section is to explore how to take care of yourself while still fulfilling your commitments as a caregiver. Often caregivers neglect themselves while taking care of the people they are caring for, and underestimate the impact this has on their health.

The first section will review some common emotions you may experience as a caregiver and some strategies to help you cope with negative emotions. We'll then look at stress and give you some specific exercises that have been shown to help you manage it.

The second section will look at how to recognize when you need help and the types of assistance available.

While not all of the information included within this section may be relevant to you, it may be helpful to review it so you are aware of the issues you may encounter during your caregiver journey. Research tells us that caregivers risk 'burnout' from too many competing demands and too little time to take care of themselves. This resource just might provide some information that could be of assistance to you.

The cardinal rule of caregiving: Take care of the caregiver

Research tells us that the demands placed on caregivers often means that they face significant health problems themselves. Caregivers, on average, take more medications and have higher levels of depression and stress than people who are not caregivers. They are also more likely to not properly take care of themselves (e.g. going to the doctor, maintaining regular exercise).[3]

Some key tips to help you in your role as caregiver include:

- Be prepared for the fact that caregiving may take up a lot of your time and energy. This may be an opportunity to build a new and deeper relationship with your loved one.
- It is OK to say no! You shouldn't feel like someone is taking advantage of you.
- Don't be afraid to ask for help! This point can't be stressed enough. Family members and friends are often very happy to assist but don't know where to start. By asking for their help, you may actually relieve any guilt that they may be feeling.

Community organizations can also provide some of the help you need.

- Take time to take care of yourself every day, no matter what. It will allow you to be a better caregiver. It is important that you have time to sleep, see to your own medical needs and maintain your own health by going to the doctor and keeping fit.[4]
- Try to be aware of your own limitations and learn about how to recognize the signs of stress and how you can help to reduce it.
- Some people find it helpful to seek out and talk to others who have been through what you are going through. They can be a valuable resource and source of support to you.
(See our resources section)
- Be aware that the stress and emotions experienced during a time of illness can easily affect relationships between family members. Try to take steps early on to keep communication open and constructive.
- Keep in mind that an illness will not change the character of the person receiving care. He or she won't suddenly become more or less easygoing.

Caregiver's Bill of Rights

These points highlight some simple truths that you may wish to reflect on during your time as a caregiver.

Often, the emotions and demands of the caregiver role mean you may not have the opportunity to take time for yourself. These rights may help you give yourself permission to take care of yourself. It's suggested that you review these rights every day as a reminder.

I have the right:

- to take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my relative;
- to seek help from others even though my relative may object. I recognize the limits of my own endurance and strength;

- to maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself;
- to get angry, be depressed, and express other difficult feelings occasionally;

- to reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger, or depression;
- to receive consideration, affection, forgiveness, and acceptance for what I do for my loved one for as long as I offer these qualities in return;

- to take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative;
- to protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help;
- to expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers;
- to add my own statements of rights to this list. I will read this list to myself every day.

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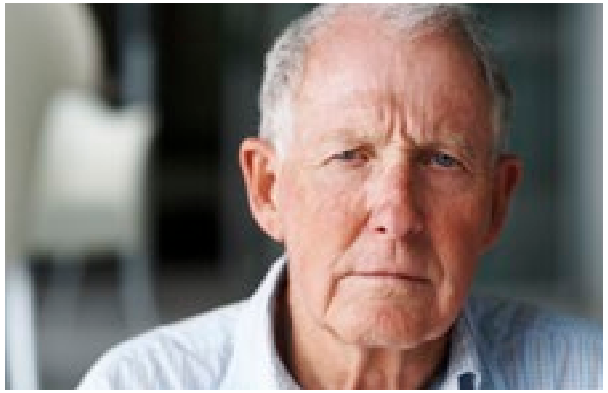
Retrieved from Family Services Toronto
www.familyservicetoronto.org/programs/seniors/billRights.html

The Emotions of Caregiving

Having emotions is part of being human. Emotions allow us to bond and communicate with others. As a caregiver, you are often faced with sensitive situations which may generate both positive and challenging emotions – this is normal.



Sometimes being aware of and acknowledging emotions can help you to cope with them. Don't worry about what you think you should be feeling or what others believe you should be feeling. Give yourself permission to experience your emotions. Once you acknowledge and accept them, you can start to do something about the more negative feelings.

Long-term caregiver Maureen shares these thoughts:

> I think what I would have benefited from early on is knowing that it's okay to get angry about additional responsibilities being given to you. It's not necessarily okay to display your anger in certain ways. And it's okay to say no.

Take a couple of minutes to read through and explore some of the common emotions that caregivers experience and see if you can relate to them

Positive feelings about caregiving

Caring for a person can be a wonderful, positive experience, full of laughter and intimate moments. You may find a tremendous sense of satisfaction from being able to help someone you care about when they need you most.

Of course, like challenging emotions, the positive feelings you have about caregiving are likely to depend on your unique situation.

Personal growth

Some caregivers report that they feel like they have grown personally. This may be as a result of the situations they find themselves in, such as having to learn to be more patient, or understanding in order to provide the best care.

Greater appreciation for health and well-being

Some caregivers feel the role they have played in caring for another has changed their outlooks on life and death. Havingprovided care for people who are very ill, some people view life more as an opportunity than they may have previously.

This may result in a new understanding or meaning of life and perhaps a change in priorities or shift in personal goals.

Strengthened relationships

Often the caregiving role allows you to become much closer, physically and emotionally to the person you are caring for. This may result in feelings of closeness and being appreciated. Some caregivers report that this results in the development of a stronger relationship.[5, 6]

Challenging emotions

Caregivers are faced with complex situations and challenging emotions. Sometimes you may try to push through negative feelings, not acknowledging, or coping with them. In an effort to deny these feelings, you may find yourself trying to keep busy and telling yourself why you shouldn't feel a certain way. You may simply ignore your emotions completely. It is important to remember that these methods of coping are short-term solutions to a long-term problem. There may come a time when your hidden feelings catch up with you.

It is sometimes difficult to pinpoint the exact cause of the emotion you are experiencing. One feeling can lead to another feeling, making it harder for us to recognize the real problem.

To illustrate, the sadness we feel is often really caused by guilt or anger. Guilt and anger, in turn, can result from a whole range of unmet needs. For example, in order for you to feel worthy and useful, it may be important for you to take care of your parents when they need help. If you are unable to do this for some reason, you may feel unworthy and this can lead to guilt or anger. It can help to try and identify the real cause of your emotion so you can learn how to deal with it. Of course, this isn't always as easy as it sounds.

Below we have listed some of the emotions caregivers have acknowledged they sometimes feel.

Anxiety

A situation that makes you feel uncertain about the future can cause you to feel anxious. Often times we are anxious because we feel something bad is going to happen. For instance, you may feel anxious that you don't have enough resources to cope with your current situation (financial and otherwise) or you may feel the situation won't get better and may actually get worse.

Fear

You experience fear when you feel threatened. Fear is often accompanied by confusion and feelings of being overwhelmed. You may be fearful of some of the responsibilities of caregiving, or of doing something wrong. Sometimes information about what to expect can help. This may mean learning more about the illness or disability of the person you are caring for, or finding tips about how to care for someone (such as communication skills or how to give someone a bath). The information in this resource is designed to assist you, and further information is also available from health care professionals.

Guilt

Guilt is a powerful emotion and can prevent us from taking any action at all. Guilt lets us know how we think and feel about how we have acted towards someone or some situation. As a caregiver, you may be faced with situations that will cause you to feel guilty, no matter what choices you make. You may feel guilty because:

- You don't think you're doing enough - your loved one isn't getting better, emotionally or physically, despite your efforts

- You don't think you have the energy to deal with one more day
- You aren't able to keep promises you made many years ago to the person you are caring for
- You are maintaining a life for yourself outside the home while the person you are caring for may not be able to do so

Frustration, resentment and anger

These emotions often go hand in hand. You may be frustrated because you can't find enough time for yourself. This could be because your loved one expects too much or other family members don't help enough. If you feel frustrated for a long period of time, it may lead to resentment and eventually to anger.

Hurt feelings and isolation

There may be days when you feel that no one appreciates what you are doing. The person you are caring for may actually be angry with you. It may be hard not to feel very hurt by these moments, or to feel like you are all alone.

The responsibilities of caregiving may mean you are not able to attend the social activities you enjoy or meet up with friends/family as you once did. These changes may lead to feelings of isolation. There are services available to help you take some time for yourself and enable you to do some of the activities you enjoy. You are entitled to a break.

Grief

Grieving is the process of adjusting to the loss of something important in our lives, such as coping with death or the loss of health through disability or illness. Grief causes us to experience a wide range of emotions we don't often understand. For example, we can feel sad, angry, lonely, anxious, and frustrated all at the same time. As a caregiver, you may experience grief at several different points throughout the caregiving process. If you are caring for someone who is suffering from a devastating illness you will undoubtedly experience feelings of shock, numbness, sadness, and perhaps depression.

Depression

We know that depression is common among caregivers. In fact, it is reported to be three times higher than the general population. Caregivers are thought to be more susceptible to depression due to the stresses of caregiving, including isolation, fatigue, and frustration.[7] Depression causes you to stop getting pleasure from your life or the activities you previously enjoyed. When you are depressed, you may feel sad, anxious, empty, guilty, hopeless, and worthless.

Some of the signs and symptoms of depression are listed below. Consider this list. Are you experiencing these symptoms? If so, you can get help.

Do you experience headaches frequently?

Are you having increased health problems (e.g. high blood pressure, ulcers, or difficulties with digestion)?

Do you suffer from stomach and other digestive problems?

Do you find it hard to concentrate and/or to remember things?

Do you have feelings of despair, or are you overwhelmed, depressed, and/or overanxious?

Are you crying for no identifiable reason?[8]

Speak to your doctor about what is happening or see What Type of Help Do You Need on page 50 of this section.

Stress

Stress is a really significant issue for caregivers. Caregiver stress often results from the emotional and physical strain of caregiving.

Our bodies produce a response that helps us cope with stress. Referred to as the fight or flight response, a stress response is triggered when we see a situation as stressful. It causes our bodies to undergo significant physical changes. These changes come in three stages, which are outlined below:

Stage 1 - Mobilizing energy

During this stage your body releases adrenaline, your heart beat increases and your rate of breathing increases.

Stage 2 - Consuming energy stores

If you remain in the first stage of stress for a period of time, your body begins to release stored sugars and fats. You will then feel driven, pressured and tired. Some people may drink more coffee, smoke more and drink more alcohol. You may also experience anxiety, have decreased immune system (and therefore be more likely to get sick), think more negatively or experience some degree of memory loss.

Stage 3 - Draining energy stores

When the body is a state of stress for a prolonged period without resolution, your body will need more energy than you can provide.

This stage may result in things like insomnia, errors in judgment and personality changes. You may also develop a serious illness. In fact, most people suffering from constant stress will experience poor health such as anxiety and depression or cardiovascular illness.[9, 10]

Just as we each have unique fingerprints, each of us is unique in our stress response – no two people react the same way to the same situation. The key to understanding stress and controlling your reaction to it is to understand yourself and the situations or events you consider stressful.

What Is caregiver burnout?

Although being a caregiver will bring a certain amount of stress, we know there are some things that can put a caregiver at increased risk for burnout.

> Burnout refers to feeling unable to continue to provide the best care to the person they are caring for, not because they aren't trying or don't want to, but because they are emotionally or physically spent.

This list outlines some key questions to help you identify if you are at risk for caregiver burnout.

- Did you answer yes to many of the questions regarding depression?
- Do you feel you are being pulled in many directions?
- Do you feel like you are trapped in your role as a caregiver?
- Is there conflict amongst the people closest to you and the person you are caring for?
- Do you feel you are not getting support from other people?
- Is the person you are caring for placing unrealistic demands and expectations on you?
- Do you feel like you are unable to meet the expectations and needs (physical and emotional) of the person you are caring for?
- Are you unable to communicate effectively with others around you?
- Is your health or the health of the person you are caring for getting worse?
- Do you feel overwhelmed? [12, 13]

> If you have identified with many of the items on the previous page it is a sign you may be at risk of caregiver burnout.

It is important to start taking care of yourself as a caregiver. This may mean changing some things about how you care for yourself and/or getting some support for you or additional help for the person you are caring for. Some suggestions to get you started are listed below but you may also wish to read What type of help do you need on page 50 of this section.

Managing your stress

Managing your stress is easier said than done, but there are specific tips and techniques that can help. Let's start with a few basic steps you can implement now.

Identifying stressors in your life

One key step to help you manage stress is to try to identify what issues are the key stressors are in your life. Once you identify them, you can start addressing them. Learning how to identify these stressors, however, can be a challenging task. It will take time for you to recognize and pinpoint the exact sources of stress in your life.

> Once you understand how to recognize your stressors, remember that you may not be able to remove them completely. However, the most important lesson you can learn is that *only you are in control of how you react to the stressors in your life.*

There is no sense in using extra amounts of energy trying to control a stressor over which you have no control (e.g. your loved one's condition, the doctor's bedside manner). Trying to control something over which you have no control is like banging your head against a wall. The wall won't move an inch and you'll only end up feeling more frustrated and suffering from a splitting headache!

Resist the need to be perfect

Remember that no one in this world is perfect, including you.

It is important to learn not to expect perfection from yourself 24 hours a day, seven days a week. You are not a superhero and neither are the people around you. Be kind to yourself and others around you and remind yourself that no one is perfect. Doing your best is all you can ask of yourself and others.

Ask for and accept help

There comes a point in all of our lives when we need help.

It is important to recognize when you need help and give yourself permission to accept it. Caregiving is not about being a martyr. Feeling exhausted and stressed is harmful to your physical and mental health and does not help you or the person you are caring for. It is often difficult for to admit that you need assistance and to seek out support. However, it is crucial to recognize when your limits are reached and to know where to go for help. Often, people will not offer help because they don't know that you need support or what type of assistance you require.

> When asking for help, be specific and positive. Tell them what your needs are so they can help you.

Taking some time for yourself!

A guaranteed way to keep yourself in a constant state of high stress and anxiety is to ignore your physical health. Things like exercising regularly, eating a balanced diet and getting enough sleep are stress busters that can help you get rid of all that stress!

These suggestions are explored in greater detail in the next section.

Video

Watch this video from the Christopher Reeve Foundation to get an inside look at how other caregivers feel. It offers varying perspectives of life as a caregiver and some new ways of thinking about your role.

The views expressed in the video are those of the participants, and not necessarily those of Saint Elizabeth Health Care.

View video on YouTube

Taking care of yourself

In this next section we explore some general things you can start doing now to help you take care of yourself. Sometimes simple steps can be helpful and contribute to your overall well-being.

Nutrition

Food is our body's only source of fuel and is required for us to get the energy we need to cope with stress. Compare the food you put in your body to the gas you put in your car. We can fill our cars with different types of fuel that cause our cars to perform in different ways. Lower octane gas generally causes poorer performance compared to higher octane premium gas. You certainly can't drive your car if there is no gas in the tank. Likewise, little or poor nutrition does not supply the body with enough fuel, causing it to perform poorly, especially under conditions of extreme stress.

Eating the recommended servings of fruits and vegetables, meat and dairy, as well as avoiding things like sweets, caffeine and alcohol, will all contribute to a body that is healthy and well equipped to effectively cope with stress.

Sleep

Stress and anxiety have the nasty habit of haunting us when our bodies try to shut down and go to sleep. It is easy for your sleep to be interrupted if stress is causing you to worry at night. Too little sleep leaves us feeling tired and unable to handle the stressors we encounter on a daily basis.

Try adopting some of the following tips if you are having trouble sleeping:

- Avoid caffeine, cigarettes and alcohol near bedtime and try to cut down your use during the day.
- Try to wake up at the same time everyday, even on weekends.
- Try to avoid eating large or heavy meals before bedtime.
- Exercise is best during the late afternoon, as vigorous exercise three to four hours before bedtime may interfere with sleeping.
- Minimize any distractions that may be present in your bedroom. This may include light (from a window or alarm clock), noise, excessive heat or cold, and the telephone.
- No matter how tired you are, resist the temptation to nap during the day.
- If you find you can't sleep, get up out of bed and onto the couch or a comfortable chair. All that anxiety, tossing and turning, and watching the clock doesn't help with relaxation. Even if you don't actually sleep at least you'll be relaxed.

Exercise

Exercise is great for everyone. Our hearts, lungs and bones are all healthier and happier if we follow a regular exercise program. However, did you know that exercise also makes your mind happy? Exercise causes the body to release hormones known as endorphins that improve our mood and cause us to feel good. So get active and make your mind smile!

Start off slowly…Taking 30 minutes a day can begin to make a difference in how your body and mind feel. Doing yard work or going for a walk can help you change how you feel and assist you to be healthier and happier.

Deep breathing

One easy but important technique that can help you relax is simple deep breathing. It is an easy tool to have and you can use it anywhere at anytime to help address over-breathing during times of stress – a very common problem. Slowly breathe in through your nose, expanding your diaphragm with the incoming air.

Breathe out slowly (try to make it twice as long as the inhale) through your mouth. This is a learned technique but if you practice everyday you can use this technique whenever you feel stressed.

Meditation

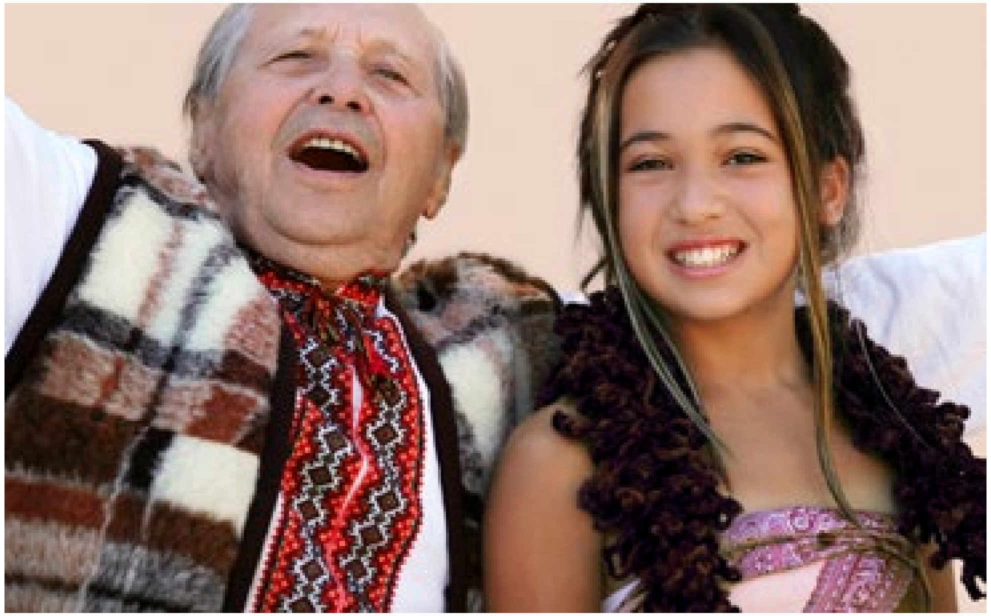
Meditation has been used for centuries as a way to relax your mind and body. It allows you to be in control of your thoughts as it forces you to be present in the moment and become aware of your thought patterns. Meditation is believed to calm your mind and help you think more clearly throughout the day. It is important to note that the benefits of meditation are only felt through daily practice.

Visualization

Visualization allows you to mentally transfer yourself from a stressful environment to one that allows you to feel peace and tranquility. Visualization can be done anywhere and at any time. For effective visualization you can sit in a quiet place and close your eyes and picture yourself in a place that makes you feel peaceful and calm. This space will be entirely individual – you may picture yourself in a field full of spring flowers, lying on a sunny beach or watching the wave of the ocean crash against a rocky hillside. Try to pay careful attention to the sights, sounds and smells of your vision. How do they make you feel? Hold the vision for as long as you need to - a few moments or a few minutes.

Yoga

This ancient system of body and mind disciplines is used to help reduce stress and find tranquility in life. Although there are many different forms of yoga, most western practitioners focus on physical postures, breathing exercises and meditation. You can check for yoga classes in your community through your local



recreation centres and telephone directories.

Massage

How do you feel after you get a great big hug? Relaxed? Relieved? Comforted?

Science has proven that the experience of touch reduces stress and anxiety we experience. Through the use of touch and other techniques, massage helps to relieve the body of stress, tension and pain. It is important to remember massage is a therapy and there are many different types of massage. All massage therapists are required to receive extensive academic training and should be registered by the appropriate governing bodies.

Humour and laughter

Humour and laughter are the body's natural way to prevent stress. They are good to help improve the function of your mind, body and spirit. Research suggests that the ability to laugh at a situation gives us a feeling of power and perspective over our problems.

Laughter and humour foster positive and hopeful attitudes and can lessen our likelihood of suffering feelings of depression and helplessness. After all, it's difficult to feel anxious and tense when you have an enormous smile on your face.

Here are some ideas to help bring humour and laughter into your life during stress emergencies:

- Watch your favourite funny movie or TV show
- Read the comics in the daily newspaper; clip them and keep them handy when you need a smile
- Try to tell at least one bad joke every day
- Read a funny book
- Wear clothes that make you feel happy
- Listen to music that makes you feel happy
- Call up a friend who always makes you laugh and smile
- Surround yourself with things that make you laugh such as a funny photograph, favourite toy or picture

Remember – *take care of yourself!* The more time and energy you put into taking care of yourself, the more you will be able to care for those around you who need your time and assistance.

Regular medicals

It is important that you keep regular contact with your family health care provider. Regular checkups and physicals are key to keeping your mind and body in tip top shape.

Take time for yourself

There are things in life that make us all come alive inside – activities and/or hobbies that make us feel good about ourselves. During times of extreme stress and anxiety, it is important to take time for yourself.

Betty, a caregiver to her adult son with Down's Syndrome says,

> I take advantage of the regularly scheduled times where I can have some respite care. During this time I do things that I enjoy, things that make me feel good.

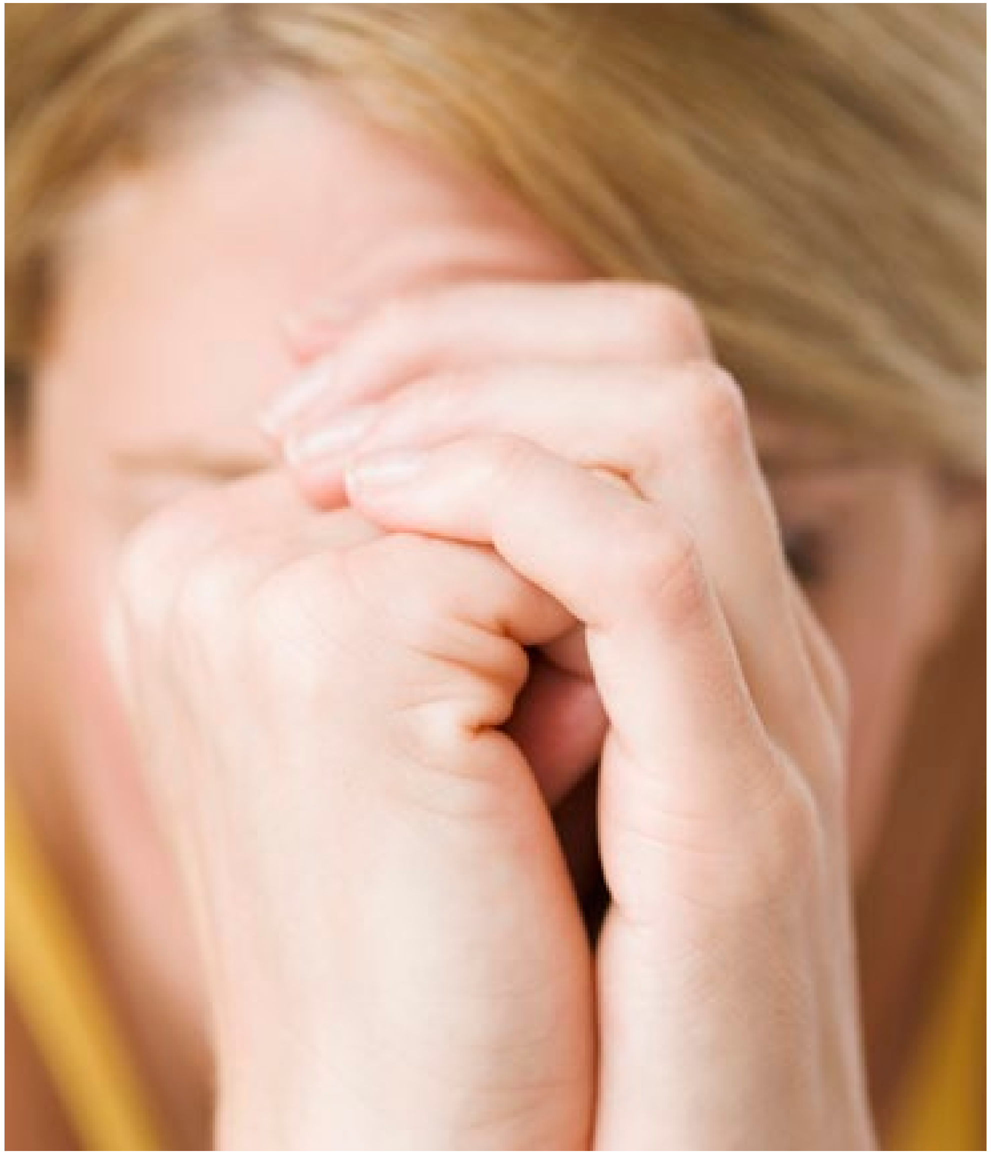
Perhaps the most powerful and effective stress busters are those that allow us to connect with our inner selves. It may be something as simple as curling up in your favourite chair and reading a great novel, visiting an art gallery, taking pictures at the local zoo, playing your favourite sport or taking up that new hobby you've always wanted to try. Whatever the activity, the point is to remember to stay involved in your life. Express yourself and do something you enjoy!

Recognizing When You Need Help

As a caregiver, the stress of your additional responsibilities and the emotions that go along with providing care for someone who is ill can take an incredible toll on you, often without you realizing. When your body and emotional well-being are affected, you are more likely to get sick yourself.

When you are both mentally and physically exhausted, you are less able to provide good care. This doesn't mean that you're a bad caregiver, it just means that you have reached your limits and have no more internal resources. You should feel proud of what you are able to do and realize that you have a right to continue to make a meaningful life for yourself.

You need to know that it is okay to ask for help. In fact, it is key to providing the best care possible and being able to advocate on behalf of yourself and the person you are caring for. Many caregivers we've talked to offer the following advice that they wish they had been given: Don't be afraid to ask for the help you need!



There are many reasons why caregivers don't seek the help they need:

- Feelings of guilt and shame
- Lack of understanding that others are in the same situation
- Lack of knowledge about available options
- Inability to pay for formal caregiving services
- Insufficient time to seek out supports
- Cultural issues that discourage help from outside the family
- Lack of services to meet specific needs
- Feelings of depression, which can reduce the motivation needed to seek out supports
- Lack of comfort in communicating feelings

Consider the reasons and how one or more of them might be stopping you from getting help.

Ideally, you should try to plan ahead for any help you think you might need in the future. Of course this is not always possible. Even if you plan well, an individual's condition may change unexpectedly, suddenly creating the need for more intense caregiving. The other responsibilities you have in your life may also change and you might not have as much time for caregiving.

Below we have listed some of the signs and symptoms we have explored in previous areas of this section. You should be aware of the following signs to know when your mental and physical limits have been reached. Take steps to seek out help as soon as possible.

Signs you may need help

- Pains that seem to have no cause, including chest pains
- Headaches
- Stomach problems
- Sleeplessness
- Teeth grinding

- Tense muscles
- A reliance on alcohol and drugs
- A lack of interest or awareness in the world and people around you
- Strong emotions and mood swings
- Forgetfulness
- An increased number of accidents
- Restlessness
- Changes in eating habits
- A lack of energy
- Difficulty concentrating
- A worsening of existing health problems
- Loss of sex drive
- Feelings of depression

Physical limitations

You may have some health problems that limit your ability to act as a caregiver. For example, if you have heart disease, you may not be able to lift or move the person you are caring for without risk to yourself. The stress of caregiving can also negatively affect your condition. The physical part of caregiving can make a breathing problem worse, and may be almost impossible if you have any trouble with your bones and joints.

If you cannot hear or see very well, you may also need help with caregiving. You could put the person you are caring for in danger if you miss hearing a health care provider's instructions, or if you can't hear the person call out for your help. When your vision is poor, there could be an increased chance of mistakes with medications.

It is a good idea to talk to a health care provider about your health and how it may affect your ability to take good care of the person you are caring for.

A final check

As a final check on whether or not you should seek help, you may want to ask yourself how you would use the time away from your caregiving responsibilities.

- ✓ Would you spend more time with your children and spouse?
- ✓ Would you take part in an activity you enjoy?
- ✓ How important are these activities to you?
- ✓ If you are not able to spend your time as you would like, how do you think your life will be affected in the future?
- ✓ Can you accept those changes?

What Type Of Help Do You Need?

Once you have decided you need outside help, you must determine the type of help that will best meet the needs of your unique situation. This may be an opportunity to gather your family and friends together to get support for your decision.

> It is not unusual for other people who are not directly involved in a person's care to deny that additional help is needed.

They can be unaware of the true health status of the person you are caring for because they don't have the chance to be there day to day. To help bridge this gap it can be helpful if you and the person you are caring for agree to try and maintain regular communication with other people regarding the health status of the person that you are caring for and try to include them in decisions about his or her care.

Try to think about the types of tasks for which you need help. For example:

- Are you physically unable to lift and move a person?

- Is the person you are caring for no longer able to manage his or her own finances, but you lack knowledge in this area?
- Do you have all the skills you require to meet the person's needs, but you just need a break?
- Are you comfortable with providing personal care for a person that is close to you (e.g. helping them go the toilet or helping them to bathe)?

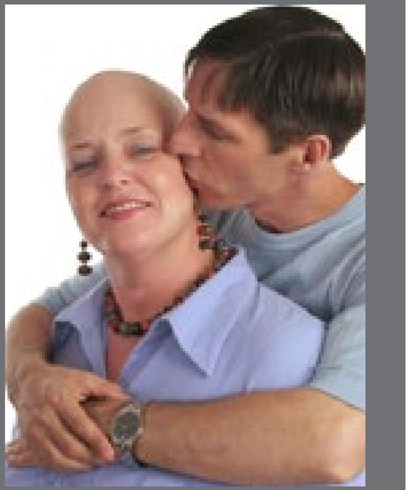
Think about the skills you have and don't have and what you can and cannot do. Then think about how often you need help. Is it everyday? Once a week? In the evenings? During the day when you are at work?

Once you have identified what you need and how often you need it, you will also have to consider any limitations on the ability to pay for services. A variety of funding options exist for support services. Government funded programs may cover some types of assistance, others may be covered by private insurance, and some will require you to pay out-of-pocket.

Family, friends and neighbours

The people closest to you and your situation are a possible source of assistance that won't strain finances. Very often these people want to help – they just don't know where to start. You can let them know by simply asking and by being specific about what you need. When tasks are spread among a large number of individuals, any one person might only need to offer a few hours every two weeks, for example. This can be quite manageable even for the busiest of people.

Mary Lou, along with a network of other friends and neighbours, offered support to a woman with breast cancer and her husband. Everyone took turns taking care of the couple's children so that they could have some time alone together.



Family/friend meetings and discussions are helpful, as is having respect for each other's opinions and limitations. For example, different individuals have different abilities to cope. Recognize that one person may feel stress at being asked to provide four hours of care a week, while another may be able to manage twice that amount without feeling stressed. At the same time, everyone has something to offer, even if they live far away or aren't providing direct care to the person. For example, people can help by:

- walking the dog
- preparing meals in advance
- running errands
- helping you take care of your own household and family

A neighbour may be willing to assist with shovelling snow or may remain on standby for the person you are caring for in case of an emergency during the day while you are at work. Think about the various skills everyone has and take advantage of their strengths. Is one person a whiz with finances? Then get that person to help with managing the household bills and investments.

Support groups

Support groups form to help people who are dealing with similar issues. Members of a support group share their emotions and experiences in a safe and accepting environment, both in person and online. You can find out about community resources, get tips on caregiving and just feel better about your situation by being with people who understand what you are going through. As a caregiver, you can seek out support groups geared to caregivers, or ones focused on a particular illness or condition.

If you are planning to join a support group, you will be investing precious time, so you may wish to consider the following in an effort to see if it is going to meet your needs:

- Does it make you feel welcome and secure?
- Will it protect your confidentiality?
- Is the environment respectful?
- Are meeting times and places convenient? (a Web-based support group may be more convenient)
- Are experienced health care providers involved?
- Does the organization invite experts to speak?

Visit the Caring for Family section of the Saint Elizabeth website at www.saintelizabeth.com/family for more caregiving information and support.

If you are a member of faith community, it may also be able to provide you with a support network. In addition, don't overlook the possibility of professional counsellors - they can help you better manage conflict, stress, grief, anger and other emotions.

To find out about the various support options in your area, talk to health care professionals, including social workers and hospital discharge planners. You can also contact organizations and associations devoted to particular illnesses and conditions. Some of these organizations have been listed in the resources at the end of this section.

Other sources of information for supports in your area include local community directories and general phone directories like the Yellow Pages (try looking under headings such as Home Health Care Services and Supplies and Charitable and Not-for-Profit Organizations).

Your province or territory may have an association dedicated to caregivers and caregiver supports. Try searching for links from your Ministry of Health's website which you can find by clicking on this link to Health Canada. You can also talk to the department responsible for community and social services in your municipality.

Medical help

Occasionally, the feelings you have and stress you feel may not be completely alleviated by any of the previous suggestions. If you continue to feel low or stressed, it is important that you speak to a health care provider. You may be clinically depressed or anxious – in fact caregivers are more likely than the general population to be diagnosed with depression.[13] There are treatments available however you need to reach out for help as the first step.

You can start with your primary care team (for instance, your General Practitioner) or contact a service such as the Canadian Mental Health Association who can help you find some support. Find your local CMHA.

- Learn to recognize when you need to seek help.
- Don't feel guilty or useless if you need to ask for help.
- Work with other family members to decide on the best solution and don't forget to include your loved one.
- Congratulate yourself regularly for all you have been able to do

Resources and Support Services

Family caregiver resource centres/programs

Family Service Association of Toronto, Seniors and Caregivers Support Service

Provides social work services to older people and caregivers. Their work includes counselling, group work, advocacy, training and educational sessions on a variety of topics such as aging and memory loss, anger and guilt, how to access community resources, abuse of older adults, etc.
416-595-9618
http://www.fsatoronto.com/programs/seniors.html

Caregiver Alliance of Simcoe County

Exists to support informal caregivers and to promote the significance of their role and contribution to health care, social policy and society as a whole and provides a range of services
80 Bradford St. Unit 541, Barrie ON L4N 6S7
705-734-9690

Family Caregivers' Support Network

A service which aims to provide a coordinating body of caregiver services for the public and to use community input, to identify and fill areas of support identified by caregivers

1-888-283-8806 – Maintains a peer support telephone line for caregivers of seniors which operates Tues/Wed/Thurs 1-4 pm.

Alzheimer Society of Canada: Support

With services right across Canada, the Alzheimer Society supports people with dementia, family members, caregivers, and health-care professionals.

www.alzheimer.ca/en/We-can-help/Support?gclid=COuY2aKSjrYCFeyPPAodDiAAXA

The Family Caregiver Connection, Hamilton

A group of caregivers who work to increase public awareness of caregiving issues; provide forums for educating and informing the community and caregivers about caregiving needs and issues; offer peer support in groups and via telephone, the computer or mail and pursue fund-raising opportunities to ensure the sustainability of ongoing activities.

familycaregiverconnection@yahoo.com
http://greaterhamiltonarea.com/familycaregiverconnection/

Caregivers Nova Scotia: Caregiver Support Groups

http://caregiversnovascotiablog.wordpress.com

The Friends: Muskoka Parry Sound Caregivers' Support Network

705-746-5102
info@thefriends.on.ca
www.thefriends.on.ca

CANES Home Support Services, Caregiver Support

416-743-3892 ext. 243
canes@canes.on.ca
http://www.canes.on.ca/services/caregiver-support-counselling

Vancouver Coastal Health: Caregiver Support

604-709-6437
caregiversupport@vch.ca
http://caregivers.vch.ca

Etobicoke Services for Seniors

agency@ess.web.ca
http://www.esssupportservices.ca

Ontario Community Support Association

ocsainfo@ocsa.on.ca
http://www.ocsa.on.ca

Alberta Caregivers Association: Community Caregiver Groups

807-623-2353
www.albertacaregivers.org/caregivers/ccg

Community Home Assistance to Seniors (CHATS)

A nationally-recognized organization that delivers a continuum of services to meet the changing needs of more than 5,500 York Region seniors and family caregivers each year.

905-713-6596 or **1-877-452-4287**
http://www.chats.on.ca/

Ottawa Public Health: Seniors’ Health and Caregiver Support

613-580-6744 or 1-888-426-8885
healthsante@ottawa.ca
http://ottawa.ca/en/residents/public-health/healthy-living/caring-senior

Care-Ring Voice Network

A free, bilingual and confidential program that connects caregivers and families to information and support through the use of teleconferencing.

514-488-3673 ext.1556
http://careringvoice.com/contact.php

Online Materials

Canadian Caregiver Coalition

The Canadian Caregiver Coalition is the national body representing and promoting the voice, needs and interests of family caregivers with all levels of government, and the community through: Advocacy and leadership, Research and education and Information, communication and resource development.

http://www.ccc-ccan.ca/index.php

Saint Elizabeth: Caring for Family

Information, support and community on being a family caregiver - and caring for yourself.
www.saintelizabeth.com/family

Canada Cares

www.canadacares.org

Caring for Caregivers Resource Centre

Search for caregiver support and support programs by province or territory.

www.caringforcaregivers.ca

By Us For Us Guides

Guides created by a group of talented and passionate persons with dementia and/or partners in care.

www.marep.uwaterloo.ca/products/bufu.html

Canadian Mental Health Association - Coping with Stress

http://www.cmha.ca/data/1/rec_docs/403_CMHA_coping_with_stress_EN.pdf

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A

abnormal
Something is not considered ‘normal’. For example, a temperature is abnormal if it below or above the typical level.

abscess
A sac of pus formed by the breakdown of infected or inflamed tissue.

a.c.
abbrev. = before meals.

acupressure
A method of pain relief using finger pressure on the same points used in acupuncture.

acupuncture
Chinese medical practice of inserting needles through the skin in specific points to restore the balance of a body’s energy flow.

acute
Condition with symptoms that develop quickly, are severe, but do not last long. Opposite to chronic condition.

acute care facility
Hospitals and medical centers where patients come for relatively quick care for sudden illness, surgery, testing or treatment. Opposite is chronic or long-term care or hospice facilities.

addiction
Uncontrollable craving for a substance with an increasing tolerance and physical dependence on it.

adjuvant treatment
An added treatment to what is already being done.

advance directives
One of two types of legal documents that either give specific instructions or name a substitute decision- maker. They may describe what medical treatments a person does, or does not, want under certain circumstances.

adverse effect
Negative side effects of a treatment or medication.

allergist
A doctor who also specializes in the treatment of allergies.

Glossary

allergy
A reaction substances that may cause a rash, swelling or more serious physical response.

alopecia
Temporary or permanent loss of hair (may occur as a side effect of chemotherapy).

ambulatory
The ability of someone to walk. Ambulatory centers refer to health care facilities where people go for part of a day for treatment.

amyotrophic lateral sclerosis (ALS)
A deterioration of the spinal cord that results in the wasting away of muscles. Also called Lou Gerhig's Disease.

analgesic
A pain-relieving drug.

anaphylaxis
An exaggerated, often serious, allergic reaction to proteins and other substances.

anemia
A decrease in red blood cells or in the hemoglobin content of the red corpuscles. The normal count is 4.0 to 6.0 x1012.

anesthesia
Total or partial loss of sensation from an injection, ingestion or inhalation of a drug. General anesthetics put a patient to sleep for a short time. Local anesthetics numb an area of your body without putting you to sleep (e.g., dentist's anesthetic for a tooth filling).

anesthesiologist
A doctor specializing in providing an anesthetic during surgery and monitoring the patient's vital signs.

aneurysm
A swollen or distended area in a blood vessel wall.

angina
The pain that results from not enough blood going to the heart.

angiogram
X-ray studies in which a dye is injected into the bloodstream to detect abnormalities in blood vessels, tissues and organs.

Glossary

anorexia
The loss of appetite experienced by most people near the end of their lives.

antacid
A substance that neutralizes acid.

antibiotic
Drugs that check the growth of bacteria but do not work against viruses.

antibody
A substance produced in our bodies to fight against bacteria.

anticonvulsant
A medication used to prevent seizures.

antitussive
A drug used to relieve coughing.

apnea
Extended periods when breathing stops during sleep.

apoplexy
(See stroke)

arrhythmia
An abnormal heartbeat.

aspiration
Fluid that gets into the lungs.

asthma
A tightening of the air passages that leads to wheezing and difficult breathing.

assets
All of a person's properties, including real estate, cash, stocks and bonds, art, furniture etc., and claims against other people (e.g., loans).

asymptomatic
Someone without any symptoms.

atrophy
A wasting or withering away of part of the body.

autopsy
An examination of a dead body to determine the cause of death; the post-mortem ordered by the coroner or medical examiner.

Glossary

B

barbiturate
A type of sleeping pill.

barium enema
Radiopaque barium (visible by x-ray) is put into the lower bowel (colon) and rectum by an enema for an x-ray. Also called a Lower GI Series.

bedsore
A sore that develops when pressure causes inadequate blood circulation to the skin. For persons confined to bed, good skin care, repositioning, cushioning and some limited activity are the best treatment. Also called decubitus ulcers.

beneficiary
Person who receives a benefit from a will, insurance policy or trust fund.

benign
Non-malignant self-limiting condition that is not life threatening.

b.i.d.
abbrev. = twice a day.

biopsy
An examination of body tissue with a microscope to help in diagnosis. Tissue is removed from the body by surgery, insertion of a needle into tissue and other methods.

blood gas test
A blood test to determine the level of oxygen and carbon dioxide in the blood.

bolus
An amount given all at once.

bone marrow test
A needle is inserted into a bone (hipbone or breastbone) to remove a sample of bone marrow for diagnostic purposes e.g., to diagnose leukemia, aplastic anemia.

brain scan
Also called carotid angiogram. A radioactive substance is injected into a neck artery for a brain x-ray using a scanning camera.

C

Glossary

CAT (or CT) Scan
A computerized axial tomography scan. X-rays of the body or head are taken using a computer to give a slice-by-slice view of the area.

CCU (Coronary Care Unit)
Unit in a hospital which provides intensive care to heart patients.

cancer
A malignant tumor that tends to invade healthy tissue and spread to new sites.

candidiasis
A fungal infection known as 'thrush' in one's mouth, throat, esophagus or other dark, moist areas (e.g., vagina).

carbohydrates
Best source of energy for your body. Found in most foods but especially sugars and starches. If you eat too much, however, your body changes and stores them as fats.

carcinogenic
Something that can cause cancer.

cardiac
Refers to the heart.

cardiac surgeon
Doctor specializing in heart surgery.

cardiologist
Doctor specializing in the diagnosis and treatment of heart conditions.

cardiovascular surgeon
Doctor specializing in surgery of blood vessels of the heart.

caregivers
include professional health care providers and volunteers. Primary caregiver is usually a family member or close friend who provides most of the physical care for a person at home (e.g., wife, husband, lover, best friend).

catheter
A plastic or rubber tube that puts in or takes out fluids from your body. A common example is a bladder catheter (Foley) to allow urine to leave the bladder freely.

Glossary

c.c.
abbrev. = cubic centimeter; also can mean with meals or food.

cerebral palsy
Impaired muscular power and coordination from failure of nerve cells in the brain.

chemotherapy
Drug therapy against infection or cancer that can destroy bacteria or dangerous cells.

cheyne-stoking
A pattern of breathing where the respiration rates increase and then decrease followed by increasing periods of not breathing.

chiropractor
Doctor without a medical degree specializing in manipulation of the spine; cannot prescribe medication or perform surgery.

chronic
A prolonged or lingering condition.

clinical nurse specialist (CNS)
A registered nurse with a Master's Degree in Nursing who specializes in one aspect of health care and is involved in research and teaching.

codicil
An appendix or supplement to a will (e.g., to change the name of your beneficiary).

colostomy
A surgical opening from the body surface (usually through the abdomen) into the colon which acts as an artificial anus. Colostomy bags collect the body's waste. Depending on a patient's condition a colostomy may be temporary or permanent.

coma
A deep, prolonged unconsciousness.

competence
Legal competence to make decisions for one's self is difficult to determine because incompetence may not be permanent and definitions of legal competence depends on where one lives.

Glossary

complementary therapies
Includes therapies like: acupuncture, aroma therapy, art, autosuggestion, biofeedback, chiropractic, herbal, homeopathy, music, naturopathy, osteopathy and therapeutic touch.

congenital
Something present since birth.

COLD (Chronic Obstructive Lung Disease)
(see COPD)

conjunctivitis
A redness and irritation of the thin membrane that covers the eye.

COPD (Chronic Obstructive Pulmonary Disease)
Includes illnesses like emphysema. Also called COLD for chronic obstructive lung disease.

coronary
Refers to the blood vessels that supply the heart.

CPR (Cardiopulmonary resuscitation)
It is used on patients who are not breathing and have no pulse. Trained professionals or volunteers use artificial respiration (mouth-to-mouth breathing) and manually pump the patient's heart by compressing the chest with their hands to simulate a regular pulse.

culture
A test for infection or organisms that could cause infection.

CVA (Cerebrovascular accident)
Also called a stroke.

cystoscopy
A long flexible tube, attached to a miniature camera, is passed through the urinary tract into the bladder.

D

draw sheet
A folded bed sheet placed sideways on the bed under a patient. Two people on either side of the bed can then lift the draw sheet and the patient to move them up or down in bed or to help them turn the person onto their side or back.

dur dolor
abbrev. = while pain lasts.

dx
abbrev. = diagnosis.

dysphagia
Difficulty in swallowing

dysplasia
Abnormal cells.

dyspnea
Shortness of breath

E

ECG
See EKG.

echocardiogram
Sound wave test of the heart.

EKG (electrocardiogram)
A record of the electrical current produced by the heart. Diagnoses abnormal cardiac rhythm and damage to the muscle of the heart. Also ECG.

EEG (Electroencephalogram)
A record of the electrical current produced by the brain.

edema
Excess collection of fluid in the tissues.

electrolyte imbalance
When salts or chemicals in the blood are not balanced correctly.

embolism
Blockage of a blood artery by a clot. In the brain it can cause a stroke.

Glossary

EMG (electromyography)
Test to evaluate the electrical activity of nerves and muscles.

emesis
vomiting.

emp
abbrev. = as directed.

empiric
Based on experience.

emphysema
A condition of the lungs with labored breathing and increased risk of infection. The lungs lose their elasticity and function.

endocrinologist
A specialist in diagnosing and treating disorders of the endocrine glands (glands affecting hormones) and their secretions.

endoscopic exam
Using a thin, lighted tube to examine an internal part of the body.

enema
A fluid injected into the rectum to clean out the bowel or to give drugs.

enteral
Something given by way of the intestines.

epidural anesthesia
Medication given through a thin tube into your spine. Common in woman having babies as it allows the mother to be alert with pain relief.

estate
All of one's assets and liabilities, especially those left by a deceased.

executor
The person named in a will to dispose of the assets and pay, from estate funds, the liabilities of a deceased.

executrix
The female noun for executor.

Glossary

F

family

Includes people who are part of one's immediate family and those we define as members of our family through friendship and love. In legal terms, each province and state has different definitions that may restrict family members to biologically related members.

family practitioner

Doctor who diagnoses and treats the general illnesses and problems of patients and refers them to a specialist when necessary.

febris

Latin for fever.

fibrillation

Irregular heart beat or an involuntary muscle contraction.

G

gastroenterologist

Doctor specializing in the digestive system: esophagus, stomach and bowels.

geneticist

Specialist in genetic diseases -- hereditary disorders and abnormalities.

geriatrician (gerontologist)

Specialist in the diagnoses and treatment of illnesses in older people.

GI (gastrointestinal) series

An x-ray examination of the esophagus, stomach, colon and rectum.

GI series-lower

(See Barium Enema)

gm

abbrev. = grams.

gr.

abbrev. = grains.

gtt.

abbrev. = drops.

H

h
abbrev. = hour.

hallucination
The feeling of seeing or hearing something that is not there.

hematologist
Doctor specializing in conditions of the blood.

hematoma
Swelling caused by bleeding into tissues as in a bruise.

hemiplegia
One-sided paralysis of the body, usually from a stroke. A right-sided paralysis indicates left-sided brain damage.

hemoglobin
The protein in red blood cells that carry oxygen to the body tissues. The normal count is 12-18 g/dL.

hemorrhage
Extensive abnormal bleeding.

heparin lock
A needle is placed in the arm with blood thinner to keep the blood from clotting inside the needle or tubing.

hepatoma
Cancer or tumor of the liver.

hereditary
Something inherited from parents.

high blood pressure
(See Hypertension)

hodgkin's disease
A form of lymphoid cancer that has high fever, enlarged lymph nodes and spleen, liver and kidneys and a dangerously lowered resistance to infection.

hormone
A glandular excretion into the blood that stimulates another organ.

Glossary

hospice

(see palliative care) Also name for a free-standing institution where palliative care is given to people with a terminal illness. Programs often have major home care component and may also be part of an established institution such as a hospital.

h.s.

abbrev. = at bedtime, before retiring. From the Latin hora somni.

huntington's chorea

A hereditary condition with symptoms of uncontrolled movements and progressive mental disorder.

hypercalcemia/hypocalcemia

Too high (more than 10.5 mg/dL), or too low (less than 8.8 mg/dL), calcium level in the blood.

hyperkalemia/hypokalemia

Too high (more than 5.0 mEq/L), or too low(less than 3.8 mEq/L), potassium level in the blood.

hypernatremia/hyponatremia

Too high(more than 145 mEq/L), or too low(less than 136 mEq/L), sodium (salt) level in the blood.

hypertension

High blood pressure The systolic number is usually above 140mmHg and the diastolic number is usually above 90 mmHg. Can lead to a stroke, heart failure or other serious condition if not treated. The pressure measures the force of the blood expelled from the heart against the walls of the blood vessels.

hypnotic

A drug used to induce sleep.

hypnotism

A treatment that puts a patient into a sleep-like trance to enhance memory or make the person susceptible to suggestion. Can be used in pain relief and to eliminate some negative habits.

hypotension

Low arterial blood pressure.

hypoxia

Low oxygen level in the blood.

I

I&O
abbrev. = intake and output refers to fluids into and out of body.

iatrogenic disease
A condition caused by a doctor or a hospital stay.

ICU (intensive care unit)
Unit within a hospital where seriously ill or post-operative patients receive intensive care.

incontinence
Lack of bladder or rectal control.

in d
abbrev. = daily. From the Latin in dies.

idiopathic
Unknown cause.

infarct
Death of tissue because of lack of blood supply.

infarction
Blockage of a blood vessel especially the artery leading to the heart.

infection
Inflammation or disease caused when bacteria, viruses and other micro-organisms invade the body.

infectious disease
Disease which is passed from one person to another person.

inflammation
Swelling or irritation of tissue.

insomnia
An inability to sleep.

intern
A recent medical school graduate undergoing supervised practical training.

internist
Doctor who specializes in the nonsurgical treatment of the internal organs of the body.

intramuscular

Something (e.g., medication) given into a muscle.

IV

abbrev. = intravenous in which a needle is kept within a vein for the injection of medication or blood.

intraperitoneal

Into the abdominal cavity.

intubate

Putting a tube into a person’s airway to help them breathe.

invasive procedure

Anything that punctures, opens or cuts the skin.

L

laxative

A drug that causes bowel movements.

lethargy

Sleepiness.

leukemia

Cancer of white blood cells in which these cells reproduce abnormally.

liabilities

Debts owed to others such as a loan, mortgage, utility bills, credit card payments, etc.

life-sustaining procedures

These may include artificial means of keeping someone hydrated and fed, CPR, blood transfusions and mechanical ventilation.

life-threatening illness

Any condition or disease that can lead to sudden or quicker-than-expected death.

lipid

Fat.

living will

A form of advance directives that lists what life-sustaining treatments the person does, or does not, want in situations listed in the document.

lumbar puncture
A diagnostic procedure in which a hollow needle is inserted between two lumbar vertebrae in the spinal cord to remove some spinal fluid.

lymph glands
Nodes of tissue that provide a system of protection against bacteria and other attacks against the body's immune system.

M

m et n
abbrev. = morning and night.

malaise
A vague feeling of discomfort; feeling bad.

malignant
Progressive or terminal condition.

malnutrition
Insufficient consumption of essential food elements whether by improper diet or illness.

mammography
An x-ray of the breasts to detect tumors.

meningitis
Inflammation of the membranes covering and protecting the brain and spinal cord.

metastasis
The spreading of an infection or cancer from the original area to others in the body.

mg.
abbrev. = milligrams.

MI
abbrev. = myocardial infarction; a heart attack.

mor dict
abbrev. = in the manner directed.

morbidity
Serious disease; an undesired result or complication.

mortality
Death or death rate.

mobility
The ability to move.

MRI
abbrev. = magnetic resonance imaging; a picture of the body that uses magnetic energy rather than x-ray energy.

multiple sclerosis
A degenerative disease of the central nervous system where parts of the brain and spinal cord harden.

muscular dystrophy
A degenerative muscle disease in which muscles waste away.

myalgia
Muscle aches.

N

nasogastric tube
A tube from the nose to the stomach to give nutrition and medication.

neoplasm
A tumor or a new growth of abnormal tissue where cells multiply. (See cancer).

nephrologist
Doctor specializing in kidney conditions.

neurologist
Doctor specializing in the nervous system.

neurosurgeon
Doctor specializing in surgery of the nervous system.

non rep
abbrev. = do not repeat.

nosocomial pneumonia
Pneumonia acquired in the hospital.

Glossary

notarize
A notary public authenticates or attests to the truth of a document (e.g., attests that a document was signed by a particular person).

notary public
A public officer (can be a lawyer) who certifies documents, takes affidavits and administers oaths.

nurse practitioner
Registered Nurse who has received additional training in order to perform more specialized care than other nurses.

O

o
abbrev. = none.

obstetrician/gynecologist
Doctor specializing in conditions of the female reproductive system. Obstetricians specialize in pregnancies and births.

occlusion
A closing or an obstruction.

oncology
The study of tumors or cancer.

oncologist
Doctor specializing in tumors and cancer.

ophthalmologist
Doctor who specializes in diseases of the eye.

opioids
These drugs come from opium. They are generally used to relive severe pain. Heroin, methadone and morphine all come from the opium plant.

optician
Non-doctor trained in filling prescriptions for eyeglasses and contact lenses.

optometrist
Non-doctor trained to measure vision and make eyeglasses and contact lenses.

orthopedist
Doctor specializing in bones.

osteopathy
Diagnosis and treatment of disorders by manipulative therapy, drugs, surgery, proper diet and psychotherapy.

osteoporosis
The bones become weaker because of a loss of calcium.

otolaryngologist
A specialist in conditions of the ear, throat and nose.

P

palliative care
Treatment to relieve symptoms, rather than cure, a disease or condition. Includes meeting the physical, emotional, spiritual and information needs of patients. Also called hospice care.

paracentesis
Fluid drainage by inserting a tube into the body.

parenteral
Administration of medication or nutrition into the body by injections.

parkinson's disease
A progressive nervous disease. Symptoms are muscular tremor, slowing of movement, partial facial paralysis and impaired motor control.

pathogenesis
The initial cause of a disease.

pathologist
Doctor who examines tissue and bone to diagnose if there is a malignancy. They also perform autopsies.

pathology
The scientific study of disease.

patient
Someone who receives treatment. Sometimes called client, consumer or customer.

pc
abbrev. = after meals.

pediatrician
Doctor specializing in the care of children.

Glossary

per os (po)
abbrev. = by mouth.

percutaneous
Through the skin.

pH test
Determines the degree of acidity or alkalinity in the urine.

pharmacokinetics
Study of how the body absorbs, distributes and gets rids of a drug.

phlebitis

Irritation or inflammation of a vein.
physiatrist

Doctor specializing in rehabilitative therapy after illness or injury.

physician
A medical doctor as opposed to doctors with a Ph.D.

placebo
A substance containing no medication. It can help a patient who believes that it will work. A practical and effective treatment for some people.

plasma
The liquid part of blood (55% of total volume).

plastic surgeon
Doctor specializing in reconstructive and cosmetic surgery.

platelets
Small particles in the blood that help with blood clotting.

pneumonia
An acute or chronic disease which inflames the lungs and fills them with fluid.

p.o.
abbrev. = by mouth. From the Latin per os.

podiatrist
Non-doctor who specializes in the care, treatment and surgery of feet.

powers of attorney

There are two main types of legal powers of attorney documents that a person signs to delegate legal decision making to one or two people of their choice. The first gives someone financial and legal decision-making power from the time the document is signed until the document is revoked by the patient, and the second gives all health care related decisions away only if the patient cannot speak for themselves at the time. It is advisable to separate the two types of documents so that one person is not responsible for all decisions and not in a conflict of interest.

primary caregiver

(See caregiver).

prn

abbrev. = give as needed, as often as necessary.

proctologist

Doctor specializing in diagnoses and treatment of disorders and diseases of the anus, colon and rectum.

prognosis (Px)

A prediction of the future course of a condition or illness based on scientific study. It is only a prediction and should not be accepted as fact.

prophylaxis

A drug given to prevent disease or infection.

prosthesis

An artificial substitute for a part of the body such as an arm or leg.

protocol

A plan of study.

psychiatrist

Doctor who specializes in the diagnosis and treatment of emotional and medical disorders.

psychologist

A professional with a Ph.D. in psychology who diagnoses and treats psychological disorders. They may not prescribe medication.

pt

abbrev. = patient.

pulmonary

Refers to the lungs.

Glossary

Q

px
abbrev. = prognosis.

q
abbrev. = every.

q.d.
abbrev. = every day; daily.

q.h.
abbrev. = every hour. From the Latin quaque hora.

q.i.d.
abbrev. = four times a day. From the Latin quater in die.

qn
abbrev. = every night. From the Latin quaque nox.

qod
abbrev. = every other day.

qs
abbrev. = proper amount, quantity sufficient.

quack
Opportunist who uses questionable or worthless methods or devices in diagnosing and treating various diseases.

ql
abbrev. = as much as desired. From the Latin quantum libet.

R

radiation therapy
X-ray or cobalt treatment.

radiologist
Doctor who interprets X-rays. Sub-specialties include nuclear medicine and angiography.

radiology
A branch of science using radiant energy, as in x-rays, especially in the diagnosis and treatment of disease.

recombinant
New combinations of genes.

refractory
Not responding to treatment.

regimen
A program or set of rules to follow for treatment of a condition.

relapse
The return or reappearance of a disease.

remission
Disappearance of evidence of cancer or other diseases.

renal
Refers to the kidneys.

rep
abbrev. = repeat.

resect
Remove or cut out surgically.

resident
Doctor receiving specialized clinical training.

respirologist
Specialist who diagnoses and treats diseases of the lungs and respiratory (breathing) system.

respite care
Time away for rest. This might mean that a family caregiver goes away for a few days or that the person who is ill goes to a hospice program.

rheumatologist
Specialist who diagnoses and treats rheumatic diseases that cause by inflammation or pain in the joints and muscles.

rx
abbrev. = prescription or therapy.

S

satiety
(early) Feeling full or bloated quickly after eating very little food.

sedative
A medication to calm a person or make them less anxious.

senility
Loss of mental ability and memory (especially of recent events).

shiatsu
(See acupressure).

shock
Sudden, acute failure of the body’s circulatory function.

sig
abbrev. = write, let it be imprinted.

somnolence
Sleepiness.

spinal tap
(See lumbar puncture).

standard of care
A treatment plan which the majority of health care providers accept as appropriate.

stat
abbrev. = right away. From the Latin statim.

stomatitis
Mouth sores or inflammation of the mouth.

stroke
Sudden loss of muscular control, sensation and consciousness caused by the rupture or blocking of a blood vessel in the brain.

subclavian
Under the collarbone.

subcutaneous
Often refers to medication placed under the skin by a needle.

sublingual
Often refers to medication placed under the tongue.

substitute decision-maker
This person is chosen by a patient in an advance directive document to make decisions about health care and treatment when a patient cannot speak for themselves.

supine
Lying on the back.

supportive care
General medical care that treats symptoms; not intended to improve or cure the underlying disease or condition. Sometimes called palliative care although not limited to people with a terminal or life-threatening illness.

suppository
A medication given in solid form and inserted into the rectum or vagina. Dissolves into a liquid by body heat.

surgeon
Doctor who treats a disease by surgery. Surgeons generally specialize in one or more types of surgery.

symptom
An indication of a certain condition or disease.

symptomatic
Having symptoms.

syndrome
A group of symptoms that indicate a specific disease or condition.

systolic
Top number in blood pressure; refers to the contraction phase of a heart beat.

T

TENS Trans-cutaneous electrical nerve stimulation
A device that provides mild amounts of electrical stimulus to different parts of the body as a way to reduce pain.

temperature
Normal oral temperature is 97-99Â° Fahrenheit or 36-37.2Â° Celsius. Changes +/- one degree during the day.

terminal illness
Often classified as any illness that will lead to death soon. The length of time used is often between 3-12 months.

thoracic surgeon
Doctor who specializes in chest surgery.

thrombosis
Blood clotting within blood vessels.

t.i.d.
abbrev. = three times a day. From the Latin tres in die.

titration
Gradual change in drug dose to determine the best effect or dose of a drug.

tolerance
Drug tolerance is when there is increased resistance to the usual effect of a drug as a result of long-term use.

topical
On the skin or surface.

toxicity
Side effects or undesirable effects of a drug.

toxin
A poison or harmful agent.

transdermal
Through the skin.

trauma
An injury or wound.

tumor
(See Neoplasm).

tx
abbrev. = treatment.

U

ultrasound scan
A picture of internal organs using high frequency sound waves.

urologist
Doctors specializing in urinary tract and male prostate gland diseases plus male sexual dysfunction

ut
dict abbrev. = as directed.

V

vascular surgeon
Doctor specializing in blood vessel surgery.

venipuncture
Going into a vein with a needle.

vital signs
Measurement of temperature, pulse, respiration rate and blood pressure.

Glossary

vomiting
A reflex action that contracts the stomach and ejects the contents through the mouth.

WBC
White blood cells that fight infection. The normal count is 5,000 to 10,000.

X

x-ray
Electromagnetic radiation used to create pictures of the body's internal structures.

x-ray dye
A substance injected into a vein before an X-ray to highlight an area for examination. May cause an allergic reaction.

For more caregiving information and support, including important tips, tools, blogs, and our Ask an Expert feature, visit: www.saintelizabeth.com/family

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

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