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Community
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Muskoka*

Caregiver's Support Guide

ACKNOWLEDGEMENTS

The Caregiver's Support Guide has been an extraordinary effort.

The Family Alliance Service Team (FAST) Family-Centred Care for Adults with Physical Disabilities and their Caregivers first developed The Caregiver's Support Guide in response to a growing need for advice. Many questions and concerns surfaced during interviews between the FAST Team, clients and their caregivers.

The plan was to pull together some of the best material and resources under one cover and provide it to families and caregivers.

The overwhelming response to The Caregiver's Support Guide from Simcoe County and beyond, led us to re-write the guide in a more generic way. We are grateful to the many people who reviewed and provided crucial input into the many drafts, giving us a personal view of the contents.

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NOW YOU ARE A CAREGIVER: YOU ARE NOT ALONE

This booklet has been written to acknowledge you and to provide some ideas about caregiving. We hope that you will refer to it often.

Your role as a caregiver is important to the well being of your loved one. As a caregiver, you may find the experience very rewarding and satisfying. It can also be challenging and frustrating.

The adjustment into the role of caregiver is often rocky and abrupt. Many people do not learn about being a caregiver until they are left with no choice.

Caregivers are strong, courageous people and are expected to take on new and challenging responsibilities when the person they care about becomes ill and relies on them for support. It is important to recognize the value of the role that has been undertaken and the impact this will have on a loved one's care and comfort. Sometimes, acknowledging this can be difficult as much attention is directed towards the person who is ill or in need.

The needs of the person you are caring for take up most of your thoughts. But, as a new caregiver, you must be made aware of the number one rule of caregiving - you need to look after yourself. Otherwise, the quality of care that you are capable of giving, your relationship with the person you are caring for, and the quality of your own life may suffer greatly.

Those who make a point of attending to their own needs in addition to the needs of others will be happier and healthier. You will also be a more effective caregiver.

ACCESS COMMUNITY SERVICES WITH SUCCESS

The Community Care Access Centre (CCAC) was formerly known as Home Care. It is the agency that you can contact to get information about health and community support services. Your Client Care Coordinator works for the Community Care Access Centre and organizes services available. The goal of the service providers (professionals who provide care) is to support you and the person you are caring for at home.

In addition to case management, you may be eligible for any of the following services from the Community Care Access Centre:

- Nursing
- Occupational Therapy
- Personal Support
- Physiotherapy
- Respiratory Therapy
- Placement services (long-term care, short stay respite and convalescent care)
- Social work
- Speech & language pathology
- Nutritional Services
- Access to adult day services

If a Client Care Coordinator is involved, he/she will meet with you and your loved one in the hospital or may come to your home to identify any needs and then set up the appropriate services. Sometimes services can be set up after a telephone interview. The Client Care Coordinator will let you know if there may be a waiting period for any of these services.

You can talk to your Client Care Coordinator about what each service provider does and how they may best help you fulfill your responsibilities .

HOW TO EDUCATE YOURSELF ABOUT CAREGIVING

One of the most effective ways to prepare yourself for the various responsibilities you will be faced with is to learn about:

- How the person you will be a caregiver for is progressing;
- What their needs will be when they return home;
- What services are available to help you both;
- Who you can turn to with questions and concerns in the future;
- What other sources of information you can use to learn about wise caregiving;
- What the disease/condition is and how it will affect a person.

Ask questions of the professional care providers:

- Do you have enough information about the person's medical condition?
- Do you know what the lasting effects of the illness will be?
- Do you know what changes may occur due to the illness/condition?

Ask to sit in on meetings with care providers about the care plan. This can be an excellent way to gain information on their progress and the treatment plans of the professionals involved. Caregivers need to understand the disease issues fully.

Read books or watch videos about caregiving which may be recommended to you.

Use support groups to get first-hand information and support from other caregivers.

Contact the organization dealing with your loved one's condition.

Call _____ at _____.

- Become an expert on your situation.
- Educate yourself: find out what's available in your community.
- Become active: advocate for you and your loved one's rights.
- Speak with other caregivers. Do not wait to seek support as a last resort.
- Help is available to prevent Caregiver Burnout (see page 14).

THE PERSPECTIVE OF THE PERSON RECEIVING CARE

Like you, the person you are caring for is experiencing a wide range of emotions due to the changes and losses he/she is experiencing. In order to understand these emotions fully, you need to know what they may be.

As a normal adjustment to new health concerns, the person you are caring for may experience:

- a sense of losing control over their life because of their condition; in an attempt to try to maintain control, they may resist your attempts to care for them. This is a common reaction to the loss of independence;
- sadness from a changed self image;
- fear of becoming dependent and a burden to the family;
- fear that old friends will distance themselves;
- anger and frustration towards their condition (which can at times be misdirected);
- denial of the condition or its lasting effects;
- fear of becoming isolated from the world, since they may no longer be able to get around as easily as they once did.

With time and support, your loved one will adjust to their new situation. Encourage them to get involved in something outside the home such as a Day Program, support group, or leisure activity. This can provide an outlet for their emotions and can help them feel less alone and helpless.

DEALING WITH YOUR EMOTIONS

As a new caregiver, you may be experiencing a wide range of emotions. In order to get through this time of transition, it is important that you understand and deal with them effectively.

You may experience:

- depression and resentment over loss of income, social activities, freedom, privacy, companionship, sexuality, and loss of your loved one's contributions.
- anger and frustration with the illness for forcing you into this new caregiver role and for putting your future plans on hold.
- anger and frustration with your family and friends who may have conflicting ideas about what you should be doing.
- feelings of being alone and uncertainty about becoming a caregiver.
- guilt for feeling angry and resentful when you are healthy and your loved one is ill or for not living up to unrealistic expectations.

You may feel:

- good about the contribution that you are making. Know that you are doing the best that you can, and do not hold onto feelings of guilt, as they only wear you down.
- pride in all that you have accomplished.
- an improved ability to reach out and be sensitive to someone else's needs.
- a new sense of strength in watching your family pull together.
- pleasure in maintaining your loved one's dignity and comfort.
- gratitude for the blessing of having developed a closer, more intimate relationship with the person you are caring for.

As you can see, your feelings can be very complicated and overwhelming. The first step in dealing with them is to allow yourself to feel and express the full range of your emotions; they are all valid. Denying your feelings most often leads to negative outcomes.

Caregivers need to express their feelings in a safe environment where they will not be judged. Only by acknowledging and expressing feelings openly can we begin to deal with them.

What can you do to help yourself deal with these emotions?

1. Accept your emotions for what they are.
2. Find support that works for you such as:
 - talking to your Client Care Coordinator, therapist, social worker, physician;
 - talking to another caregiver;
 - getting help from community resources;
 - talking to friends, family members or a spiritual advisor you are close to.
3. Be open to expressing your feelings in other ways - paint, pray, sing, cry, laugh, write or exercise. Release your feelings in a way that best suits you.

THE GROWTH CYCLE - HEALING

You and the person you are caring for may be experiencing many changes as a result of the health concerns he/she is facing. Some of these losses you share, while others are specific to each of you. The way in which you work through your emotions is a very individual process that takes time. In order to understand each other's moods and behaviour, it is important to realize where each of you are on the cycle of emotions shown below. This cycle represents the normal and healthy range of emotions that people go through when they experience any form of loss.



You and the person you are caring for may not be at the same stage on this cycle. The speed at which you move from one stage to the next is different for everyone. These stages do not always follow each other in order. More than one stage may be experienced at a time. It is common to move back and forth between stages.

CARING FOR A PARTNER

Caring for a partner can be hard on any relationship. You may have to cope with the loss of their companionship, wage-earning capacity, sexual contact and your future plans. At the same time, you may feel less important, since all the attention is focused on your partner and the full responsibility for managing the household, child care and finances, now lie squarely on your shoulders.

What can you do to cope?

Accept help from family, friends and professionals so that you can take a break from one another. This will give you more time to talk and do things together that are not related to caregiving. Allow yourself to feel all of your emotions, the good ones and the difficult ones, and share these with each other. Understanding what it is like for the other person will open lines of communication.

Caregiving does not mean parenting. Encourage your partner to continue to do as much for themselves as possible. This will result in increased confidence, feelings of self-worth, and an improved sense of control over their environment. It will also decrease the number of tasks you must do.

Seek counselling if you are having difficulty resolving your concerns. It may assist both of you to effectively deal with your emotions and concerns. Ask your family doctor for a referral to a counselling agency or counsellor.

Role Imbalance

In many relationships, the various responsibilities are shared by two people. If one half of the team is down, the other half must shoulder more of the burden - in addition to caring for an ill person. For some, the new or added responsibilities are related mostly to household chores. For others, becoming the head of the household and shouldering all the financial responsibilities is the greater challenge. This can be very overwhelming, especially if you also have to deal with job demands or your own health problems.

The key is not to try and do it all by yourself. Accept help - seek support! Both of you will experience a period of adjustment. Adding caregiving duties to your role will have an obvious impact on your relationship. Allow your partner to offer you support from time to time. It will give them pleasure to know that they have been able to help or comfort you. This will allow them more balance in your relationship.

CARING FOR A PARENT

I feel blessed to have the opportunity to give back some of the love I received from my father.

These days, the emphasis is to help people maintain their independence in their own home for as long as they can. When the ability of a parent to take care of themselves diminishes, family members are suddenly faced with the task of coordinating and providing hands-on care and support.

The adult child who recognized the denial, stubbornness, complaining and other such behaviours are just defensive reactions to the changes and losses their parent is experiencing, and not the care that they are receiving, will be better able to understand and cope with the situation. Learn not to react to the behaviour but the reason behind them. Only then can their needs be met.

Regardless of who provides care, resentment can arise between siblings when the primary caregiver does not feel they receive adequate support from other family members. Many of these caregivers can feel angry, abandoned, and unappreciated by their family.

Why is the responsibility sometimes left to one person?

- A parent wants only one particular child to care for them.
- Family members who contribute financially may feel they have given enough.
- You may not be assertive enough in demanding help from other members of the family.
- You may be unwilling to give up control and share the task even when exhausted by it.
- Family members who live far away are unable to help with daily caregiving tasks.
- Some family members refuse to cooperate or ignore the situation altogether.

- Siblings who work outside the home may feel that the family member who does not is the only one with enough free time to assume the burden.
- Some people may hold the old-fashioned belief that caregiving is a female's responsibility. (Carter, 1994)
- Family members who have young children may feel that those without children have more time to provide care.
- Most medical teams request one person be appointed as the family spokesperson.

What can you do to cope?

- Communicate your parent's progress to your family frequently. Explain to them and your parent the things that you may be experiencing difficulty with, and why. Try to work on a plan that allows managing of your parent's care to be more than one person's responsibility.
- If you feel you are unable to arrange these discussions because you are too upset or exhausted, speak with your Client Care Coordinator; he or she can help you accomplish this.

DEALING WITH ISOLATION

Do you feel:

- that you have no one to talk to, to support you or give you advice?
- like you're so busy taking care of your loved one's needs that you have no time to even share a cup of coffee with a friend?
- that old friends have pulled away from you?
- everyone always asks how your loved one is doing, but never asks how you are doing?
- like you are imprisoned in your own home?
- that only those who have been a caregiver before can truly understand what you are experiencing?

If you have answered yes to any of the questions above, then you may be physically or emotionally isolated. This is a very common and serious concern as it can lead to feelings of anger and/or depression.

Caregivers need support!

You can gain support by linking with other caregivers. This may be done in the form of support groups or by having a telephone buddy. Sharing your experiences with others is the best way to fight the feelings that you are the only person in the world with these problems. Having someone with whom you share information and support can significantly improve your ability to cope with your responsibilities.

Peer support can be an excellent way to:

- learn about your loved one's condition;
- alleviate your aloneness;
- give you an opportunity to focus on yourself;
- brainstorm solutions to your problems;
- relieve stress;
- give you hope as you listen to how others have coped in similar situations;
- give you the opportunity to laugh about your circumstances with others who understand and are not judgmental;
- gain first hand information about community resources, the most responsive professional help, and the latest equipment;
- give you the opportunity to cry or talk with someone who understands that you have your own needs, and therefore will not make you feel guilty about your feelings;
- give you the opportunity to help another with your suggestions and ideas.

TAKING CARE OF YOURSELF

At first, most caregivers go through a “honeymoon” phase where they accept this new role with a sense of idealism, hope and eagerness to do well. But as time goes on, fatigue may set in, disappointments and frustrations can and do occur. It is after this honeymoon phase that you may start to feel the effects of burnout.

Burnout is a sense of being completely overwhelmed and unrewarded (Carter, 1994). It is a common feeling among caregivers that can have various negative consequences if it is not addressed quickly.

This can be dangerous to both you and the person for whom you are caring. Feeling stressed over long periods of time will affect your health, motivation, attitude, and mood as well as your ability to cope with your daily responsibilities but it can be avoided and it is not permanent.

What creates burnout?

- High expectations of yourself and others.
- A strong and unrealistic dedication to making things ideal for the person you are caring for.
- Difficulty saying “no”.
- Having difficulty asking for or accepting help.
- Consistently sacrificing yourself and your needs for the benefit of others.
- Feeling as though you are the only person capable of providing care.

How do you avoid burnout?

1. Acknowledge your new roles and responsibilities.
2. Be able to recognize the symptoms of burnout.
3. Pay more attention to yourself.

Common physical symptoms of burnout include...

- Being unable to sleep well
- Headaches and backaches
- Feeling tired most of the time - physically drained
- Changes in your weight
- Lingering colds

Common emotional symptoms of burnout include...

- Being easily irritated and frustrated
- Feeling anger and resentment
- Sadness and feelings of loneliness
- Feeling overwhelmed or overloaded
- Decreased self-esteem
- Depression

What are other things that you can do?

1. Focus on your loved one's strengths. Encourage them to do more for themselves, and acknowledge their efforts. This will increase their self-confidence, lessen resentment of being dependent on you and decrease the number of tasks you have to do.
2. Let go; one person can't do it alone. You are human and have limitations. It is okay to say "no" to increasing demands. It is rarely true that you are the only one that can provide care. Accept help. Ask for help from friends, family and community services. Don't wait for your own health, emotions or relationships to suffer.

Consider the following questions to help you identify your needs:

- What exactly is it that I need help with? (i.e. groceries)
- Who will I ask to help me with this? (list who you will ask first, and then second if your first choice is not available)
- When and how often will I need this help? (i.e. once a week)
- When will I make the call to ask for this help? (i.e. this morning)

As you come to understand and accept the ways you cannot and should not help, you allow yourself to do what is uniquely yours to do.

3. Prioritize tasks and learn to manage your time. Schedule tasks throughout the day/week, including breaks and private time for yourself.

Define your limits about what you are prepared and able to do. This will help you see more clearly what is needed and what is realistic for you to provide.

4. Take advantage of respite care. Respite care is when a friend, volunteer, family member, or a professional takes care of your loved one while you take a break for a few hours or a few days. You can take advantage of professional respite services. Ask your Client Care Coordinator about respite care options.

5. Use your caregiving team to help solve problems. Learn to trust them; they are there to support you.

Appreciate your own efforts.

Draw strength and comfort from the dignity, care and love you have provided, and remember that it is not your responsibility to "fix it all".

6. Maintain a life outside your home. Insist on private time for yourself - you deserve it!
7. Keep a good sense of humour.
8. Find strength in your religion/faith. This can be an excellent source of inspiration.

Respite is important for you as a caregiver to regain strength and allow you to be healthier and better able to cope with your responsibilities. Examples of respite services for the person you are caring for include Adult Day Programs, homemaking services, Friendly Visitors, temporary stay in a Long-Term Care Home and Hospice services.

PREVENTING CAREGIVER BURNOUT

In some circumstances, the caregiver may be under such extreme stress that he/she may put themselves at risk for mistreating or neglecting their loved one. In most instances, this behaviour is not intentional, however it can have various undesirable consequences.

Stress is experienced in many different ways and it can result from many different circumstances. Stress may be experienced by some in the form of exhaustion, frustration, guilt, resentment, sadness, etc. Having an outlet to release or vent these feelings is healthy. Hopefully, it can be done in a way that is productive, such as exercise, art, or by talking with friends or professionals. Venting becomes inappropriate, however, when the care receiver becomes the target of the venting and they are not in a position to help alleviate the situation. Abusive situations may arise if the caregiver feels justified in continuing this behaviour, or does not seek outside support.

An individual may experience extreme stress when:

- there is a depletion of resources (money and supports for enhancing physical, mental and emotional health);
- when there are unrealistic expectations and the person feels overwhelmed in trying to achieve these expectations;
- when a person feels frustration, resentment, and sometimes anger.

What is the definition of abuse/neglect?

Abuse is the misuse of power or the betrayal of trust or respect of an individual which can sometimes result in physical or emotional harm. Abuse or neglect of a person can be unintentional such as in the actions of a stressed but caring spouse, or in an act of omission such as inadvertently failing to provide the necessities of life. Denial of a vulnerable person's fundamental rights is also considered abuse; for example, withholding information, denial of privacy, denial of visitors, restrictions of liberty, denial of independent legal advice, or mail censorship. (Protocols for Abuse of the Vulnerable Adult, Simcoe York District Health Council, February, 1999)

Who are the potential abusers?

Friends, spouses, children, hired homemakers, landlords, or caregivers... anyone who has some control or power over the individual's care and well being.

What are the types of abuse care receivers may fall victim to?

- **Physical abuse** - pushing, shaking, hitting, withholding or over-medicating, using restraints, or any other treatment causing injury or physical discomfort. Indicators include unexplained injuries, depression, obvious changes in behaviour (sleeping a lot).
- **Financial exploitation** - dishonest use of a vulnerable person's money or assets, misuse of Power of Attorney, theft, selling of property/valuables, fraud, withholding money, etc. Indicators include unexplained difference between income and standard of living, and possessions disappearing.
- **Psychological or emotional abuse** - any verbal or non verbal behaviour which demonstrates disrespect and diminishes dignity and self worth, such as humiliation, withholding affection, treating adults like children, threats or intimidation, manipulation, etc. Indicators include socially withdrawn, decreased self esteem, appears nervous when abuser is around, care receiver may feel unable to exert control over situations.
- **Neglect** - denied basic necessities of life (food, shelter, and clean/ appropriate clothes for the season), denied medical attention, denied social contact, abandonment, leaving an individual in unsafe or isolated places. Indicators include weight loss, confusion, pressure sores, dirty clothes/ environment, unkept appearance, poor health, and loneliness.

(Taken in part from Protocols for Abuse of the Vulnerable Adult, Simcoe York District Health Council, February, 1999)

When is the caregiver most at risk for abusing or neglecting a loved one?

The following factors in combination may lead to abuse:

- when the care receiver's capabilities have diminished, resulting in increased burden on the caregiver;
- when there is a lack of support for the caregiver or knowledge of community resources;
- when the caregiver has many other demands/commitments placed upon him/her;
- when the caregiver has never had a very good relationship with the care receiver.

(Taken in part from "Elder Abuse" brochure, Ontario Network for the Prevention of Elder Abuse.)

What can you do to prevent yourself from venting your feelings of stress on your loved one?

The best way to avoid unintentionally venting your stress on your loved one is to prevent day-to-day responsibilities or stresses from building up to the point that they are overwhelming you. This requires that you be honest with yourself about what you are realistically able to manage, that you inform yourself about community resources and services that can support you and that you take care of yourself.

For more information, refer to the section in this booklet entitled "Avoiding Burnout - Taking Care of Yourself Too". It reviews what caregiver burnout is, what creates it, how to recognize it in yourself, and how to avoid it.

If you don't live with your loved one, what can you do to help protect him/her from becoming a victim of abuse?

As a caregiver, you may not be living in the same place of residence as your loved one. In this case, you are required to manage his/her care from afar, which can offer some unique challenges. Some of these challenges and suggestions for coping with them are outlined in the section of this booklet entitled "Being a Long Distance Caregiver". In these circumstances, your loved one will be receiving most of their direct care from one or several other persons.

If you suspect that someone is mistreating your loved one, don't hesitate to take some action. It is not necessary to have proof of mistreatment before seeking help. Report your concerns to the police so that a counsellor may try to resolve the abusive situation. If you suspect that a resident of a nursing home is being mistreated by a staff member, visitor or other resident, you are required by law to report it to the Ontario Ministry of Health. Your report will remain confidential.

The following are some steps you can take to protect your loved one from falling victim to mistreatment:

- stay informed about the care your loved one is receiving, who they are receiving it from and when they are receiving it;
- stay involved - communicate often with your loved one, visit regularly;
- know what the indicators of abuse are;
- suggest that your loved one not keep valuable jewellery or large amounts of money in the house;

- warn your loved one not to sign any documents they do not fully understand;
- arrange for automatic deposit of pension cheques and withdrawal for payment of monthly bills;
- instruct your loved one to never give personal information to someone they do not know.

(Taken in part from “Let’s Break the Silence” brochure, Information Orillia.)

BEING A LONG DISTANCE CAREGIVER

Family members may live some distance apart, so long distance care is sometimes done.

Long distance caregivers must deal with:

- travel costs and long distance phone bills;
- difficulty exchanging information;
- feelings of guilt or anxiety about not being able to be with your loved one more often;
- difficulty travelling frequently due to one’s own family responsibilities or job demands.

What you can do to cope:

1. Get information and support from your Client Care Coordinator to help you coordinate care. Attention to detail is critical to successful long distance caregiving.
2. Plan for emergencies to reduce anxiety. Leave a key to your loved one’s home with a friend or neighbour for quick and easy access in the case of an emergency.
3. Consider an “emergency response system” so your family member can contact emergency attention at the touch of a button. For further information, contact your Client Care Coordinator.
4. Consult with your Client Care Coordinator regularly to discuss concerns and assist with relaying information to the other professionals involved. He or she can also help you learn about community and private services.

5. Attend care provider meetings whenever possible to meet the care providers, to discuss their roles and to be brought up to date on your loved one's progress. Usually the Client Care Coordinator arranges these meetings.
6. Use a "Communication Book" where all care providers can note concerns or questions for you. You can use this as a way to update yourself on the week's events and communicate back to the care providers.
7. Prioritize tasks that you want to accomplish with each visit. Keep a list of people to talk to and things to do. This will help you stay focused and avoid confusion.
8. Make sure all care providers know how and where to reach you. Leave your name and phone number with people who may not be directly involved, i.e. the bank manager.
9. In some cases, the condition of your loved one may lead you to move in with them or to move closer to them to provide care. This may be a temporary or permanent arrangement. In other cases, some people decide that their loved one needs to move in with the caregiver. Whatever the arrangement, there will be significant transitional issues for all concerned. For example, loss of privacy, loss of control, and change in routines.

BEING A CAREGIVER IN A RURAL SETTING

Caregiving in the country may be a challenge. Due to smaller populations, the use of services in rural communities is often less than in city centres; this makes funding to keep the services in existence harder to get.

What can you do to cope?

1. Talk to your Client Care Coordinator about what services are available in your community. Therapy, personal support, and nursing services can be set up in your home. Meal delivery, in-home foot care, and hair care may also be available in your communities.
2. Check with your church, community centre, or local service clubs to learn about volunteer and support services.
3. One great advantage to living in a rural community is the closeness that often exists between people. This can be a very valuable resource. As one rural caregiver said, "don't isolate yourself more than the situation already does".
4. Staying in touch with friends and neighbours is important, even if you can only manage it for brief periods. Talking to others may help you to feel less alone and therefore, cope better.
5. Get out to community events as often as you can. Both you and your loved one (if they are well enough to go with you) will benefit from socializing and the change of scene.
6. Talk to your therapist or Client Care Coordinator about linking up with another person who has gone through a similar experience. Having a telephone buddy can be an excellent way to avoid loneliness.

MANAGING CARE AT HOME

In addition to therapy, nursing and placement coordination services, the Community Care Access Centre also provides personal support services to families who require assistance with day to day care of their loved ones.

Your Client Care Coordinator will discuss your need for personal support services to help you identify how the personal support worker can best assist you.

Personal support workers can help with:

- personal care (e.g. dressing, feeding, toileting, bathing, transfers);
- essential housekeeping (e.g. cleaning that maintains a safe environment, laundry, meal preparation, personal errands) which frees up your time and allows you to provide personal care.

If it is determined by you and your Client Care Coordinator that this is required, then the personal support worker can assist you with things such as running the household or supervising your loved one while you participate in another task.

Personal support services can be started in the home in consultation with your Client Care Coordinator. They may be at varying times of the day, or days of the week. You will have input as to how this service can best fit your needs.

Currently, the personal support worker is visiting you on:

day (s) _____, at time(s) _____.

If these times are not suitable, call your Client Care Coordinator. Remember it is generally best if you can keep these times the same over the next few days. This will help establish a routine and make things easier when planning other appointments. It is also helpful to identify the types of tasks the personal support worker can assist you and your loved one with.

During the time that the personal support worker visits, I hope to:

As your loved ones or your needs change, it is important to communicate those to your Client Care Coordinator. Your Client Care Coordinator's name is: _____, and he/she can be reached at: _____, extension _____.

In case of terminal illness, where there is a strong desire to remain at home or when the care needs become complex, you will need to work closely with your Client Care Coordinator as he or she can help access more help (private insurance benefits, resources such as Hospice, or private pay care). There are some situations where the care needs are so complex and the available resources are just not enough to meet the needs and your loved one will require admission to a hospital or a hospice facility.

DEVELOPING A CRISIS PLAN

A crisis plan is a back-up plan that takes effect if you are unable to care for your loved one. It may be needed because:

- you become ill;
- other responsibilities demand your attention;
- you need a break from your caregiving obligations;
- there is a personal emergency;
- you are having difficulty managing needs;
- you are unable to get to the care receiver due to unforeseen circumstances such as bad weather or car trouble.

Your back-up plan will help you think about what you can do when unexpected situations arise. A well thought out plan will help to decrease your stress and anxiety during a crisis and identify who your supports are and how they can be reached. It will also allow you to consider details you may not have time to think about later.

Develop your plan (below) with your loved one and discuss it with your emergency contacts and supports.

MY CRISIS PLAN

Name of family doctor: _____

Name of Client Care Coordinator: _____

Emergency contacts & supports:

Name: _____ Relationship: _____ Phone #: _____

Name: _____ Relationship: _____ Phone #: _____

Name: _____ Relationship: _____ Phone #: _____

Important facts that my key supports need to know:

Date to review and update plan with key supports:

FINANCIAL CHALLENGES

As a result of the caregiver's health issues, there may have been a loss of income. You may also have needed to reduce your hours at work to be a caregiver. In addition, health situations can result in increased medical costs. Managing your financial resources at this time can become more critical.

Managing your finances may be a new experience for you. There are a few things you should consider as you take on this task. Ask yourself:

- What are my current sources of income?
- Is my loved one eligible for the Canada Pension Plan (CPP), Disability Pension and Family Benefits?
- Am I familiar with the full coverage of extended work benefits, group benefits plan, or private insurance?
- Am I aware of all the banking information that I will need such as account numbers, investment information, safety deposit boxes, and what the monthly payments are?

As a means to assist families, there are sources of funding you may be eligible to receive for items such as special equipment, medical supplies, and home modifications. Talk to your therapist or Client Care Coordinator for information.

Each funding agency has its own eligibility criteria and application procedures.

Possible funding sources for the purchase of assistive equipment and/or home renovations are:

- Assistive Devices Program (ADP)
- Canadian Paraplegic Association (CPA)
- Churches
- CMHC - Housing Assistance for Seniors' Independence (HASI)
- CMHC - Residential Rehabilitation Assistance Program (RRAP)
- Community Service Club
- Department of Veterans Affairs (DVA)
- March of Dimes
- Multiple Sclerosis (MS) Society
- Municipal Social Services
- Muscular Dystrophy (MD) Association
- Ontario Disability Support Program (ODSP)
- Personal savings and bank loans
- Trillium Drug Plan
- War Amps

You may also want to consult with an accountant to know what tax benefits you are eligible for and what receipts to save.

THINGS FAMILY AND FRIENDS CAN DO FOR YOU

- Listening is the most important thing you can do for a caregiver.
- Give the caregiver a break by offering to stay with their loved one.
- Invite the caregiver to go out.
- Offer specific help, such as shopping, yard work, or banking.
- Don't give advice unless it is asked for.
- Be supportive of decisions the caregiver makes.

(Put out by the "Caregivers' Voice" in Bracebridge, Ontario.)

COMMUNITY RESOURCES

There are many community services that you may access to assist you with various aspects of your life. Here is a list of the types of services/resources that may be available in your community. Knowing what kinds of services are available can ease the confusion and frustration many people experience.

Information & Referral Service through the North Simcoe Muskoka Community Care Access Centre (CCAC) in partnership with 211. Search the North Simcoe Muskoka Community Information Database at:

www.NorthSimcoeMuskoka.info

- Financial assistance
- In-home foot and hair care
- In-home nursing services
- In-home therapy services (i.e. occupational therapy, physiotherapy, social work, speech/language therapy, dietary services)
- Legal assistance
- Meal preparation
- Outdoor home maintenance
- Personal support services
- Prescription of special equipment such as wheelchairs, stair lifts, walkers
- Recreational facilities
- Respite
- Social Clubs
- Support and information from national organizations related to a disease group such as stroke, multiple sclerosis, Alzheimer Society
- Support groups and information sessions
- Transportation
- Volunteer services

For specific information about any particular services, speak with your Client Care Coordinator.

TEN TIMELY TIPS FOR CAREGIVERS

1. Get help with tasks and chores early on in the illness - your loved one will get used to having other people around the home.
2. Involve other members of your family from the beginning of the illness - even if you are the only one who sees the changes which are taking place - pass these on as information only - not as a debating issue.
3. Access all the information you can about the illness and educate yourself as much as possible about its progression - disease-specific organizations, your doctor, and the public library, for example, are sources of information.
4. Recognize and learn to accept that anger, anxiety and guilt are normal feelings given the situation you are experiencing - they come not only from being tired but also from the losses you are experiencing.
5. Join a support group as soon as you can - you do not need to be alone on this journey.
6. Every change in your loved one means more adaptation and change for you - acknowledge that this gives you the right to feel off-balance some days.
7. Forgive yourself for not being perfect. Caring for someone with a chronic or terminal illness turns your life inside out.
8. Make friends with your family physician and ask for time to speak with her/him alone - if you need to do so.
9. Get regular physical check-ups, eat a balanced diet and try to take time out to express sadness, anger and helplessness. Accept yourself for being human and try to do at least one thing that you enjoy every day.
10. Take one day at a time while planning for the future. Good planning means getting to know and implementing any legal and financial considerations, facility placement issues, or palliative care, and be KIND TO YOURSELF.

By: Dorothy Orr, Caregiver Coach (re: dementia) and adapted for all family caregivers by the Family Caregivers' Network Society.

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North Simcoe Muskoka Local
Health Integration Network

Réseau local d'intégration
des services de santé de
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