

THE HANDBOOK OF  
CAREGIVING ESSENTIALS

PLAN

WELL

10

WAYS TO BE A

**STELLAR  
CAREGIVER**

*WITHOUT BURNING OUT*







BY CAREGIVERS  
FOR CAREGIVERS

## Fellow caregiver,

Caregiving can be so rewarding as we serve our loved ones and walk through life together. Yet, caregiving is a physically, mentally and emotionally heavy task and it can also be overwhelming at times, especially after a crisis. There are so many questions, decisions, and demands. It can be hard to know where to start. We're here to help.

As a caregiver, you may feel alone. However, there are so many of us who have gone through similar experiences and have had the same struggles. We've felt deep connection with those that we've provided care to, we've shared in poignant experiences with our loved ones, we've found meaning in being there for them during difficult parts of their lives. However, we've also felt undervalued, unappreciated, and unhappy. But we've also found ways to get our joy back, to find hope, and to cope with the daily struggles of caregiving.

I know what you are going through. I too am an active family caregiver as my mother has advanced dementia and I support her and my father in their own home still. In addition, before my mother-in-law passed away, my wife and I were active in helping her through her final stages of life. She lived till she was 96! In her last days, she was very frail and experienced increasing amounts of pain. It was one of my most significant life experiences and a real privilege to assist her in achieving a home death. For more details on that remarkable experience, [read about it on my blog here](#). In fact, my experiences as a family caregiver with my mother-in-law is the reason I started Plan Well Guide. I want to empower people – especially caregivers – to help their loved ones too.

We hope this handbook will be able to guide you through your caregiving journey. These 10 steps will be a good start. They will help you be more prepared for the task at hand, feel more yourself, and less stressed. We have also included some extra resources along the way to help you make the most of this handbook, and be best prepared for your role as caregiver.

Hope this helps, and best of luck to you and your family on this challenging but meaningful journey.

**Dr. Daren Heyland**

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## EXTRA RESOURCES

- [planwellguide.com](http://planwellguide.com) provides medical planning resources and information.
- [caregivers4change.com](http://caregivers4change.com) is a network standing up for caregivers rights.
- [Carers Canada](http://Carers Canada) is a national caregivers' coalition.
- [The Caregiver Network Inc](http://The Caregiver Network Inc) is a resource centre to help caregivers of the elderly and ill.
- [Caregivingmatters.ca](http://Caregivingmatters.ca) offers a comprehensive look at all aspects of caregiving.
- [ShareTheCare.org](http://ShareTheCare.org) strives to improve the quality of life for caregivers in need of support.
- [Stories for Caregivers](http://Stories for Caregivers) raises awareness about caregiving.

# What is a caregiver?

A family caregiver is a family member or friend of any age who provides care and support to someone living with disease, disability or frailty. As family caregivers, we are the person's closest, holistic, and involved care partner.

Our love, presence and attentiveness are essential elements in the health and wellbeing of those we care for. At the bedside, we perform many small acts of tenderness and are often able to recognize needs that may escape the attention of busy health care workers. We provide counsel to those who are still able to make their own decisions and are the substitute decision makers for those who cannot. We advocate for our loved ones and provide a precious continuity that can be lost in the shuffle of health care workers tending to multitudes of patients. We mop the brow, moisten the lips, and check the medications of our loved ones. We notice when they need to be taken for a stroll or to the bathroom or need to be turned in bed. We monitor their symptoms and well-being and tend to their spiritual and emotional needs.

What we do is often as important as any service health care professionals provide. There are moments when what we do—even our mere presence—is more important. That's why it's important that caregivers have access to the best resources, free training, advice, and communities so that we can give the best care possible for the people most important to us.

This guide is designed to help you get started as a caregiver. It outlines the questions you need to ask, resources that you will find helpful, and helpful advice from other caregivers.

*retrieved from: [caregivers4change.com/declarationfull](http://caregivers4change.com/declarationfull)*



“

There are only four kinds of people in this world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, those who will need caregivers.

”

**Rosalynn Carter**

## 1. Assess the needs of your care recipient.

Your caregiving role starts with the needs of the cared for. A good caregiving plan is always made with the wishes and goals of the person receiving the care in mind. This includes their wishes for medical care, where they want to live, the activities they want to accomplish, and any other values they have for their quality of life. Moreover, any care that you give must be given with the consent of the individual receiving the care.

With that in mind, we've attached a guide that will help you and your loved one define the care recipient's values and goals called, **[Loved One's Goal Sheet](#)**. You can use this worksheet to come up with a caregiving plan that everyone can agree on.

Identifying your loved one's goals for the future – both for caregiving purposes and in general – will help you get on the same page about what they want in life. This will assist you in creating a caregiving plan and will help you agree on priorities for the care recipient.

After their goals have been identified, you will also want to assess their needs. You will have to find a balance between needs and wants. Remember to keep all types of needs in mind, not just physical needs. Often emotional needs, social needs, and spiritual needs get overlooked. Our **[Loved One's Needs Assessment](#)** sheet on the back of this handbook has some examples of needs to get you started.

If your loved one has a medical condition, it will be important to understand as much as you can about your loved one's condition. This will give you a better overall picture of what their needs are and will help you to anticipate their future needs. Do some research about their illness, its progression, the different treatments and medications (and side effects), and what caregiving requirements they might have now, and down the road. Do research online, but also go with them to the doctor and discuss it with them. Once you have the information from your loved one's doctor, you can look for resources you might need specific for that condition. There are many great websites for caregivers dealing with dementia, Alzheimer's, and other common illnesses.



## 2. Define your caregiving role and set boundaries.

“

It is not how much you do, but how much love you put in the doing.

”

**Mother Teresa**

Caregiving is different for everyone and likely there will be more than one person involved in providing care to your family member. You get to define the caregiving role that is best for you. Decide what you are capable and willing to take on. If you are caregiving from a distance (an hour away or more) check out our tips for long-distance caregiving in the box on the right. At the back of this handbook, you will find a number of resources that will help you: [Define Your Caregiving Role & Caregiving Check-in](#).

Will you be the caregiving “team leader” for your family? If not, who will? Make a list of your resources (including time that you have) and define what tasks you will do. You do not have to do everything yourself! You can outsource to other family members, neighbours, and professional services.

To maintain your own wellness, it will be important to set boundaries and expectations early! It is much easier to establish boundaries at the start. Don't take on too much to handle over a long period of time. You need to remember to take care of yourself and your own needs before you can be an effective caregiver for someone else. For more on self-care, see [Step 9](#).

### 3 Quick tips for setting realistic boundaries:

#### 1. Learn when to say no - and prepare explanations in advance.

There will be circumstances when you are caregiving that you will have to say no. If possible, write out your responses in preparation for these situations. Sometimes people in need of care will request things that may be unreasonable, or even unsafe (for example, they may not want to eat, bathe, or clean). But if you have responses ready (and your boundaries set), then it is a lot easier to say no when you need to.

#### 2. Ask for help when you need it. (more on this on [Step 10](#))

It's okay to need help. In fact, what's not okay is to need help and not ask for it. You will only end up putting more stress on yourself, which leads to burnout and fatigue. Be realistic about what you can do, don't stretch yourself too thin. You shouldn't be sacrificing your job, home life, and relationships to be a caregiver. When you need help, talk to other family members, friends or neighbours about what you need help with, and then be specific about the jobs they could do for you. Take it a step further by putting the tasks on a sign-up sheet or schedule, and then ask friends to sign up.

#### 3. Schedule time for yourself, and your friends and family.

One way to make sure you stick to your boundaries is to treat yourself like your own patient. Schedule time for resting, eating, and taking care of yourself. Commit to setting time aside for you to take a break and enjoy yourself. And make sure you spend some time with your friends and family. You can only be a good caregiver if you are taking care of yourself properly.

## 5 Tips for long-distance caregivers:

Sometimes we don't have the luxury of living close by to our loved one in need of care. Just living one hour away is enough to make caregiving difficult. If you are a long-distance caregiver, there are still things you can do from a distance that make a big difference in the quality of life for our loved ones.

**1. Stay in touch regularly!** A phone call or video chat or even a text once a day is a great way to stay connected with your loved one from afar.

**2. Visit when you can.** Plan your visits at a good time for both you and your loved one. And schedule something fun to do that you can do together that allows you to enjoy your time spent with each other.

**3. Research local resources for your loved one.** See what is available locally for your loved one to take advantage of.

**4. Set up a personal alarm service** so that if anything happens, you will be notified immediately.

**5. Find things that you can help with from a distance.** You may be able to help schedule doctors' appointments for your loved one from home and take some stress off that way. You may also be able to coordinate other family members and their caregiving tasks. Finding safe social and leisure activities for your loved one to do may also be something you can contribute as a long-distance caregiver.



### 3. Identify local resources.

There are many caregiving resources available for you to take advantage of, from workshops, to support groups, to government programs. As you get started in your caregiving journey, we encourage you to look for what is available locally and take advantage of the opportunities to learn and be supported in your caregiving role.

#### Workshops

Workshops are an excellent resource for caregivers because they provide so many benefits. Not only do they provide education about being a caregiver, meeting needs, having difficult conversations, and what to expect from certain conditions, but they also act as a safe space for people going through similar challenges to come together.

For example, if you attend a workshop for caregiving for Alzheimer's, everyone you meet there will be going through a similar experience to you, and you can share your stories, ask questions, discuss challenges, and make connections. The emotional support from the workshop can be just as beneficial as the educational content.

Workshops are also a great way to get illness-specific knowledge, guidance, and expert advice. Research workshops that are available locally, or online, about your loved one's illness.

Websites that host free caregiving workshops:

- [caregiversalberta.ca](http://caregiversalberta.ca)
- [caregiver.org](http://caregiver.org)
- [continuingeducation.norquest.ca](http://continuingeducation.norquest.ca)
- [training.mmlearn.org](http://training.mmlearn.org)

#### Support Groups

Support groups are another great resource for caregivers. Support groups provide a way for caregivers to connect with others who are going through the same challenges and situations. Many individuals find support groups are safe places to vent, ask questions, seek advice, and get encouragement from others who have gone through what you are going through. Fortunately, there are multitudes of different support groups; some are specific to conditions, others are welcoming to all types of caregivers.

Feel free to try a few support groups out, and see where you feel supported and connected with others.

#### Government Programs

Across Canada, each province has their own resources and programs for caregivers. Research what programs and services are available near you and take advantage of as many as you can. Programs could provide extra financial support, extra care services, and more. Please see *Caregiver's Organizations by Province* and *Caregiver's Resource List* in the back of this guide for a complete list of supports and resources.

#### Federally Available Financial Supports:

- Canada Caregiver Credit
- Family Caregiver Benefit for Adults
- Compassionate Care Benefits
- Medical Expense Tax Credit
- Family Caregiver Benefit for Children
- Disability Tax Credit

#### National Organizations:

- [carerscanada.ca](http://carerscanada.ca)
- [caregivers4change.com](http://caregivers4change.com)
- [von.ca](http://von.ca)

#### For more information:

- [http://www.servicecanada.gc.ca/eng/ei/types/compassionate\\_care.shtml](http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml)
- <https://www.canada.ca/en/services/benefits/ei/caregiving.html>
- <http://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities.html>

#### Provincial Resources:

- BC: [familycaregiversbc.ca](http://familycaregiversbc.ca)
- AB: [caregiversalberta.ca](http://caregiversalberta.ca)
- SK: [saskatooncaregiver.ca](http://saskatooncaregiver.ca)
- MB: [residents.gov.mb.ca](http://residents.gov.mb.ca)
- ON: [familyservicetoronto.org](http://familyservicetoronto.org)
- QC: [lappui.org](http://lappui.org)
- NB: [www2.gnb.ca](http://www2.gnb.ca)
- NS: [caregiversns.org](http://caregiversns.org)
- PE: [healthpei.ca](http://healthpei.ca)
- NL: [seniorsnl.ca](http://seniorsnl.ca)
- YT: Yukon Crisis Line: 1-844-533-3030
- NT: NWT Helpline: 1-800-661-0844
- NU: Kamatsiaqtut Help Line: 1-800-265-3333

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## 4. Get organized.

“

Lists, charts, and all manner of organizing tools made me feel more secure that I wouldn't forget to buy or do anything regarding my husband's care.

”

**Adrienne Gruberg**

We know this part of caregiving can be overwhelming, so we've broken it down for you into simple steps.

### Organization

First, you'll want to get yourself organized. We've included several charts at the back of this handbook that will help you sort out your time, tasks you need to do, and make emergency lists. These will cover what you need to know to get started:

- **Partners in Care**
- **Schedule of daily care activities**
- **Medication chart**
- **Meal planning chart**
- **List of important contacts**

The Partners in Care list will help you organize which tasks your loved one can do, what you can do, which tasks others will help you do, and where you might need professional help. Keep your boundaries and abilities in mind when you work through this chart.

Once you have your Partners in Care list, you can create a daily schedule to help keep everybody on track. Assign tasks on a weekly basis and chart it out so you can always stay organized.

The medication chart will help you and your loved one keep track of which medications to take, their dosages, and when to take them.

The planning meal chart will help you plan ahead for meals so you can make sure the right groceries are bought and you can plan appropriate time for meal preparation.

A list of important contacts is handy to have in case you have an urgent question, or news comes up that should be shared with everyone on the caregiving team.

### Important Documents

Being a caregiver for a loved one places you in a very important position. As caregiver, it is important you know where your loved one's important documents are, in case you ever need to access their information on their behalf.

Important documents include all legal, financial, medical, and personal documents. Basically, you should consider gathering any piece of paper or file that your loved one is currently managing that would require someone else to continue or close out, if they were not able to do so themselves.

We've put together a list of the most important documents you should try and track down. Keep as many as you can in one organized file that you know the location of. The full list is at the back of this handbook, titled **Important Documents List**.

Once you have all of the important documents found, organized and filed away, keep them in one accessible location. Ensure the rest of the family also knows the location of this file.

The purpose of having a file like this is to be prepared and organized in case of a crisis. Preparing this file beforehand will reduce a lot of stress at the time of a crisis, and will ensure you are well organized to keep things in order for your loved one if you need to.

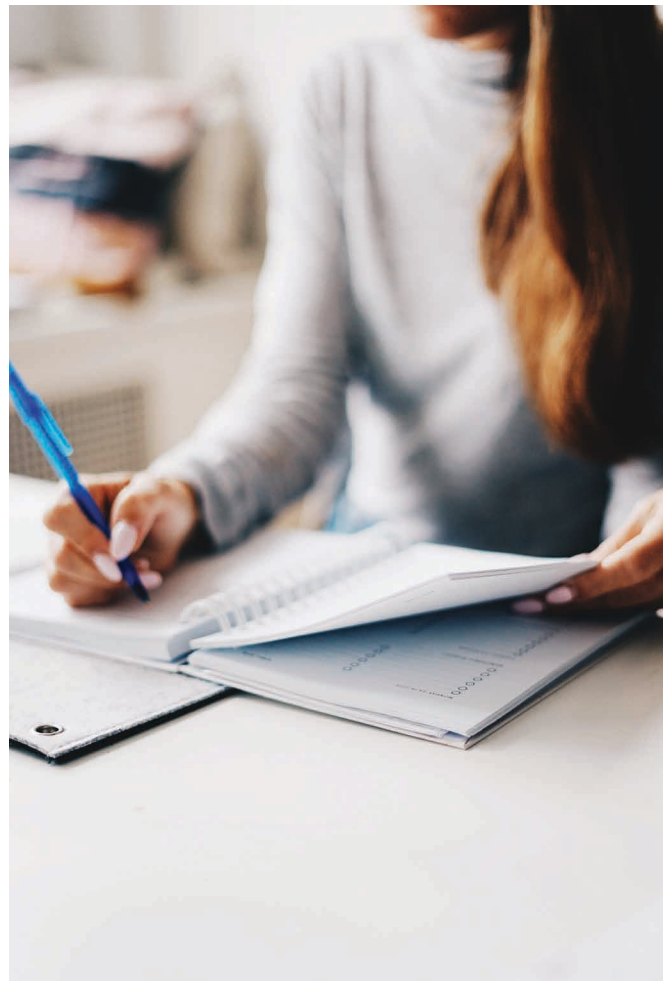


Photo by STIL on Unsplash

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## 5. Communicate your caregiving role with others.

Likely, there will be many different people that will be involved in supporting your loved one. You will want to communicate your role with them and collaborate with them, as all of them will play a part in your loved one's life. You will want to have a conversation with your friends, family, and your loved one's doctor and medical team.

### Family Conversations

When talking with family members, it helps to go into the conversation prepared. This is where your checklists from [Step 1](#) will come in handy. Make a list of topics you want to discuss (including caregiving tasks that you need help with) and take it with you, so you stay on topic.

Make sure you bring your loved one's goals and wishes for their future into the conversation. This will allow all of your family members to be on the same page when it comes to caring for your loved one.

Lastly, you will need to find any and all relevant personal documents for your loved one. If there are certain legal, medical, or financial documents you don't know the location of, you might want to bring these up in conversation as well. [Step 4](#) covers the list of essential documents.

Don't worry if you don't hit every point in one conversation. You can always circle back later. But it is important to get the ball rolling and start these conversations as early as you can.

### 8 Tips for Hard Talks

We understand that sometimes these conversations are difficult to approach or awkward with loved ones. Here's some tips to keep in mind when discussing a difficult topic:

**1. Don't assume you know what your loved ones want or need.** Let them express their needs and wants to you. It is better for them to feel a sense of control over their future and their life. Being part of the discussion about their care helps empower them.

**2. Listen, don't tell.** The harder the conversation, the more a person needs to feel heard. By creating space for them to raise their concerns and their questions, you create an environment for a more productive conversation.

**3. Be straightforward about the facts.** As important as it is to listen to your loved one, it is also important for you to be honest with them about their condition, and their future needs. Express your needs as well, and what is realistic for both you and your loved ones.

**4. Phrase your concerns as questions.** A two-way conversation is always better than a one-way conversation. By phrasing your concerns as questions, you involve the other person and allow them to contribute to the discussion.

**5. Give your loved one space to express anger or emotions.**

Difficult conversations can often get heated or emotionally charged. That's okay, let it happen. Allow your loved one to feel heard and acknowledge their feelings.

**6. Continue the conversation later, if needed.** Don't put pressure on yourself to decide everything in one conversation. It's okay to open the conversation and come back to it when people are ready.

**7. End the conversation on a positive note.** Encourage your loved one afterwards and thank them for their courage, it's not easy to talk about these things.

**8. After you have this conversation, do something fun as a family** to remember what is important. Remember you love each other, and all want what's best for everyone. Enjoy the good times you have as a family and take advantage of the time you have.

### Communicating with Medical Professionals

To the extent possible, one family member should handle conversations with all healthcare providers. Make sure at least one family member has written permission to receive medical and financial information. This person should be the only liaison between the medical team and the family.

If you are handling the conversations with the medical team, here are some tips to help you communicate effectively:

**1. Always come prepared.** Make a list of concerns and questions beforehand so you know the answers you need from the doctor. It may also be helpful to carry a list of medications and their dosages to inform the doctor, and also act as a reference for you.

**2. When talking to the doctor or pharmacist, take notes** to help you remember important things. There can be a lot of information to remember after an appointment. Medication instructions and recommendations from the doctor are things you don't want to forget.

**3. Ask the right questions.** You will want to know as much as you can about your loved one's condition, the treatment, the side effects, and what is required of you as a caregiver. Ask about the illness or condition, how it progresses, if you should see a specialist, and if it is permanent or reversible. Ask about treatments, the success rate, the duration and frequency of treatment options, the side effects of medications, and if there are any lifestyle changes that might help. If there are any tests or treatments that you don't understand, ask for clarification about what the test or medication will address.

**4. Ask the doctor about information you find online.** It's perfectly fine to do research online about illnesses, conditions, medications, etc. However, not all information online is credible or accurate. Bring it to the doctor if you are unsure about something or have any questions.

**5. For hospital visits, always bring your loved one's medical information with you.** This includes any medical history documents, their Advance Serious Illness Plan ([Step 6 Dear Doctor](#)), Goals of Care document, or personal directive document. These documents will help you answer questions and have conversations with the medical team regarding your loved one's preferred medical treatment in case they are unable to take part in that conversation themselves.



## 6. Make an Advance Serious Illness Plan.

In case your loved one's condition worsens or requires a trip to the hospital, having an Advance Serious Illness Plan (ASIP) in place will help inform you before any decisions have to be made. An ASIP is a good document to have ready to go with other medical documents if you ever need to grab them and go to the hospital.

Advance Serious Illness is preparing you and your loved one for decision making in the case of a serious illness or a medical crisis that incapacitates your loved one to make decisions for themselves. This is important because it impacts your loved one's quality of life, and quantity of life. Preparing this document in advance will save a lot of anxiety, stress, and potential guilt down the road.

You can create a free Advance Serious Illness Plan at [planwellguide.com](https://planwellguide.com). This website will educate you and your loved one about the different types of care, common types of treatment, and will help you to define your values and goals. It will also walk you through the process of creating an ASIP and a *Dear Doctor Letter*.

Remember, this document is not legally binding or set in stone. It is simply a tool that will help your loved one's family, decision-makers, and doctors understand their goals so they can make better decisions regarding medical care if your loved one is not able to.

**Visit [planwellguide.com](https://planwellguide.com) to make a plan.**

### **Why does my loved one need an Advance Serious Illness Plan?**

When people are seriously ill, they are unable to make decisions for themselves. Decision-making will fall to the legally appointed decision maker. In times of a medical crisis, making life and death decisions for a loved one can be very emotionally stressful on a decision maker. Making decisions about medical care involves taking in a lot of information, a careful evaluation of the risks, and making a decision on your loved one's behalf. That is why having an ASIP in place is beneficial. It eliminates uncertainties about your loved one's wishes and goals, and helps inform you to make decisions with more confidence.

### **Isn't an ASIP the same thing as a Power of Attorney or Personal Directive?**

No, instructional directives in a Personal Directive or Power of Attorney are only helpful when you are certain about the outcome. Unfortunately, you can never be certain about the outcome of a serious illness. An ASIP provides the opportunity for individuals to express *why* they have the values and goals that they do, which helps future decision makers evaluate whether a certain type of medical treatment is worth it or not for the individual receiving it, even when they don't know what the outcome will be.

### **What's the difference between ASIP and End of Life Planning?**

End of Life Planning is planning for death, in other words, death is a certain outcome. Advance Serious Illness Planning is more complex, because death is not certain. You are planning under uncertain circumstances, trying to make the best decision as possible without knowing what the outcome will be.





Photo by Skiathos Greece on Unsplash

## 7. Consider the best places for your loved one to live.

Most of the time, it is ideal for people to live independently at home for as long as possible. However, there often comes a time when this is just not feasible anymore – they may need more assistance at home that they cannot get very easily, they may need extra equipment, or they may be living alone and far away from family.

The best way to prevent this discussion topic from becoming a headache is to make a plan with your loved one for the future. Consider the location they are living in – are the hallways wide enough for walker and wheelchair use? Are there many stairs? How big is the yard that will need maintenance? Think about the needs your loved one will have in the future and decide if where they are living will be able to accommodate them. If not, think about the different options you could pursue at the time when you will need a change. For a list of things to consider, see the guide called **Independent Living Assessment** at the back of this handbook.

If you do think your loved one may need to move, then there are even more questions to think about. Factors like location, price, transportation, healthcare options, and degree of independence all need to be considered when choosing a place for your loved one to go.

Discussing living options with your loved one and family members can often be difficult. There are so many factors to consider. Not only do you want to respect their wishes and desires, but also the needs of yourself as a caregiver and what is practical. But no matter how hard the conversation may be, it is always better to have it in advance, instead of too late.

For help in processing these essential Aging in Place plans and other related decisions, pick up the guidebook called, "Options Open: The Guide for Mapping Your Best Aging Journey" by Sue Lantz, BA, MPA, Managing Director of Collaborative Aging at [collaborativeaging.com](http://collaborativeaging.com).

To purchase the Options Open guide or sign up for the community workshops, visit: [optionsopen.org](http://optionsopen.org).

Here are 5 tips about how to talk to your loved one about moving to assisted living :

- 1. Research some options beforehand.** Present options in a positive way, and address questions and concerns your loved one has.
- 2. Don't decide anything after only one conversation.** Keep the conversation open and come back to it from time to time.
- 3. Make sure your loved one feels heard** and take their values into consideration when making decisions.
- 4. Make contingency plans for what-if scenarios.**
- 5. Research the progression of your loved one's illness** and address future needs.

## 8. Make a Crisis Plan.

Crises and emergencies often happen without warning. Being prepared for an emergency saves so much stress, anxiety, and time. In these situations, you always want to hope for the best, but plan for the worst. That way, whatever comes, you're ready to handle it.

Some things you will want to plan for as a caregiver are:

- if you suddenly are unable to provide care,
- if your loved one has a sudden deterioration of wellness,
- disaster planning (power outages, evacuations, lock downs).

Think about each of these possibilities and what the plan would be if they were to happen.

If you are suddenly unable to provide care at the extent you are currently, have two or three people you could call to temporarily step in for you until another primary caregiver can be arranged. You may also want to set some financial resources aside in case you need to call on professional services as a temporary or permanent replacement.

Planning for medical crises can be daunting. Fortunately, there is a free resource available that will help you and your loved one define your goals and values for medical care in the case of a serious illness. [Step 6](#) covers this tool at length. This is a decision-making tool, not a legally binding document. It is a way for people to put their values on paper that will aid the decision makers when the time comes.



Being prepared for a disaster is recommended for the general population, but is even more important for caregivers and their loved ones. The [Canadian Red Cross](#) and the [Government of Canada](#) have great resources available for disaster preparation. In this guide, we've included the [Red Cross Emergency Kit](#) and a [Hospital Emergency checklist](#).

Some things you can do to prepare for an emergency situation in advance are:

- **Create an Emergency Checklist**
- **Prepare an Emergency Kit**
- **Have an Advance Serious Illness Plan**
- **Know the contents and location of the important documents folder**
- **Have contact info for POA / Agent / Substitute Decision Maker**

You will find the [emergency checklist](#) and an [emergency kit guide](#) at the back of this handbook.

### Signs that could indicate a health problem:

Keeping an eye out for signs of a problem will help you catch things early and prevent a crisis if possible. Here are some things to take note of if and when they happen:

#### Physical changes examples:

- Fever
- Pain
- Loss of appetite
- Inability to sleep
- Dizziness
- Skin irritation

#### Behavioral changes examples:

- Mood
- Attention
- Depression
- Aggression

#### Functional changes examples:

- Loss of hearing
- Worsening vision
- Less mobility
- Inability to get up from a chair

If you see any of these changes, keep track of what you see and how often you see it. Bring it to the attention of your loved one's medical professionals.

*Retrieved from: Teva*



## 9. Regularly practice self-care.

Taking care of yourself as a caregiver is one of the most crucial steps you can take in being a long-term caregiver. If you don't prioritize self-care, the care that you give to others will drain you of your energy, joy, and satisfaction. You need to be well in order for you to give effectively (and manage your own life!).

Caregiving can be exhausting and physically taxing. Caregivers often report experiencing:

- Sleep deprivation
- Poor eating habits
- Failure to exercise
- Failure to stay in bed when ill
- Postponement of, or failure to, make medical appointments for themselves

These are some of the reasons it is so vital to set boundaries as a caregiver (see [Step 2](#)). In addition to setting boundaries, there are some other things you can do to ensure you are taking care of yourself.

Check in with yourself regularly (see the self-assessment we have included at the back of this handbook). How are you feeling? What is causing you stress? How are you coping with the stress? Are you maintaining your health physically, mentally, spiritually? Another part of checking in with yourself is identifying personal barriers to wellness. Do you feel guilty when you put your needs first? Do you feel like you have to earn affection through caregiving? Learning to identify your barriers will help you overcome them and take better care of yourself.

Take steps to reduce your stress. Try not to let your stress get out of hand or to the point where you feel overwhelmed. Instead, try to take small steps every day to manage your stress and keep the levels at a tolerable level. A [Harvard Medical Study](#) suggested 5 ways to reduce stress:

**1. Have self-compassion: Be kind to yourself.** Don't succumb to your harsh inner critic, give yourself credit for the hard work you do, and give yourself time each day to take care of yourself.

**2. Focus on your breath for 10 minutes a day.** Breathing exercises are one of the simplest ways to reduce stress.

**3. Try a mind-body practice.** Practices like yoga, Tai Chi, and meditation help reduce stress, promote relaxation, and deepen the connection between mind and body. Yoga and Tai Chi also provide beneficial exercise to the body.

**4. Prioritize eating and sleeping well.** Getting enough sleep and eating well are essential to preventing caregiving burnout. Having a nightly wind-down routine before bed can help your body achieve a more restful and regular sleep. Avoiding unhealthy foods (excessive in sugar, salt and alcohol) can help decrease inflammation in the body and achieve better overall health.

**5. Remain socially connected.** Caregivers tend to withdraw and become socially isolated. But social support is crucial to a caregiver's health. Book time to unwind with friends and family, and reach out when you need to talk, or need help in your caregiving duties.

For more self-care resources, [see the back of this handbook](#).



Photo by Photoholic on Unsplash

## 10. Know when to get help.

Caregiving is a team sport. It's not only up to you to make sure your loved one is taken care of. If you are finding yourself exhausted, irritable, or unmotivated, it may be time for you to take a break and ask for help. Needing help is not a bad thing – it is 100% normal.

If you need to ask for help, here are 5 tips for you to go about it:

### 1. Explain the situation and how you're feeling.

When asking for help, it's often helpful to phrase your request starting with "I am feeling..." and then fill in the blank. Be honest about your feelings when asking for help.

### 2. Be specific with what you need.

When asking for help, have specific tasks in mind, for example, "I need a meal cooked, I need the lawn mowed, I need a night off." It's much easier for someone to offer help when they know what you need. It's also a good idea to have some specific tasks in mind for when someone offers help. That way, you know what to say and can take them up on their offer when you need to.



Photo by Patricia Prudente on Unsplash

### 3. Ask them how they would like to contribute.

If you're having difficulty recruiting helpers, ask them what they would be willing to do. Not everyone is suited for administering medication, but many are willing to help in other ways, such as walking the dog, providing occasional rides, or paying the bills.

### 4. Use technology to help where you can.

There are many applications and websites that are dedicated to helping caregivers. Use as many as you find helpful in your caregiving routine. Some apps help with scheduling jobs, others remind you when to take/give medication, and others can even coordinate meals and errands. Here's a quick list for you to check out:

- **Lotsa Helping Hands** or **CareCalendar** – free online schedulers
- **Medisafe** – medication reminder app with other features
- **CareZone** – medication reminder app with other features
- **Caring Village** – task organization and scheduling app designed specifically for family caregivers
- **Ecure21** – helps track loved one's location, mood, and health information
- **HeadSpace** – guided meditation for self-care
- **Hank** – all in one paid app that automates chores, food delivery, medications and more to help your loved one live independently

### 5. Call a family meeting.

If you're at the point where something needs to change, don't be afraid to call the family together for a discussion. It's better to make a change that makes caregiving better, than to put your health at risk by taking on too much for too long.

When you plan a meeting, make a list of the jobs you need help with and ask your family members (and friends and neighbours) who can take what, and when. You may want to sit down and re-create the job chart if you find that helpful. For helpers who cannot commit a lot, offer some options to increase flexibility and the chances of them taking on a task. At the meeting, you may also want to be as prepared as you can to answer questions and address any concerns your family members might have about caregiving. Addressing concerns will help to make caregiving less intimidating for them.

“

The greatest disease in the West today is not TB nor leprosy, it is being unwanted, unloved, and uncared for.

”

**Mother Teresa**

*And those are our 10 best tips for how to be a stellar caregiver without burning out! We wish you the best of luck on your caregiving journey and we hope you found this handbook helpful. Remember to flip through all of the extra resources in the back pages! Take care.*





Photo by Esther Ann on Unsplash



# LOVED ONE'S NEEDS ASSESSMENT

*Created by AARP Foundation*

What needs does your loved one have or will have in the future? Use this guide to identify and plan for your loved one's needs.

- Pay rent/mortgage
- Home repairs
- Ongoing maintenance
- Safety concerns
- Accessibility for disabilities
- Grocery shopping and meal preparation
- Lawn and yard care
- Pet/plant care
- Housekeeping
- Paying bills
- Keeping financial records
- Accessing public programs
- Driving decisions
- Coordinating rides
- Organization of family and professional care providers
- Bathing
- Hair, nails, skin care
- Make/accompany to doctor's appointments
- Explain medical decisions
- Keep family informed
- Coordinate visits
- Order/maintaining/paying for adaptive devices (ex: wheelchair, walker)

# LOVED ONE'S GOALS SHEET

Created by AARP Foundation

Have a conversation with your loved one about what is most important to them as they grow older. You can use the following checklist as a starting point to better understand their priorities. Start by asking them to check all those that apply and then spend some time talking about each one in a little more detail.

- To remain as independent as possible for as long as possible
- To remain healthy and active
- To remain in my own home for as long as possible
- To focus on a hobby of mine
- To work for as long as possible
- To become involved in the community
- To remain as financially independent as possible
- To take classes
- To create a safety net in the event of an emergency or crisis situation
- To start my own business
- To buy a second home
- To move closer to family
- To relocate to a smaller home
- To retire in a different place
- To travel
- To be able to help my children and grandchildren

# DEFINE YOUR CAREGIVING ROLE

*Adapted from a publication by Caregivers Nova Scotia:*

- Do I want to be a caregiver?
- How much care do I want to provide?
- How involved would I like to be in decisions about care? What does the care recipient want and need?
- What type of care do I want to provide? What are my skills and resources?
- What types of tasks am I comfortable with and able to do? What types of tasks am I not comfortable with or unable to do?
- Are there other people who can assist with care, give me a break, and support me in my work? Who are they, and how can they help?
- I live in a different town or province. Can I be a long-distance caregiver? What kind of support can I give?
- How will I feel about myself if I choose to be a caregiver?
- How will I feel about myself if I choose not to be a caregiver?



# CAREGIVING CHECK-IN

*Adapted from a publication by Caregivers Nova Scotia:*

We encourage you to:

- Understand that you, alongside healthcare providers, are an essential partner in your loved one's care.
- Recognize the value of the care you give.
- Accept that your role may be physically and emotionally challenging, but you may find unexpected rewards along the way.
- Connect with other caregivers in your community to reduce isolation, to build courage and confidence, to laugh with, and to draw strength from.
- Be proactive. A written plan will help you decide where to begin your caregiving journey.

- 
- |   |     |    |
|---|-----|----|
| ■ Do I feel confident about being/becoming a caregiver?   | Yes | No |
| ■ Have I involved family members or friends in my loved one's care?   | Yes | No |
| ■ Am I able to balance caregiving with other responsibilities?  | Yes | No |
| ■ Am I comfortable asking for or accepting help from others?  | Yes | No |
| ■ Do I understand my care recipient's health condition?   | Yes | No |
| ■ Do I have the information and skills I need for:<br>- Safe lifting, transferring, feeding, or bathing?<br>- Managing and giving medications?<br>- Programs and services that can help us?<br>- Financial and legal aspects of caregiving? | Yes | No |
| ■ Have I thought about ways to manage stress?   | Yes | No |
| ■ Do I take care of my own health by getting regular check-ups, eating well, exercising, and getting enough sleep?  | Yes | No |
| ■ Do I take time out for myself to do the things I enjoy?   | Yes | No |

If you have answered "no" to any of these questions, please see the Caregiver's Resource List for free resources. If you are well prepared and answered "yes" to many questions above, please remember to check in with yourself by reviewing these questions from time to time.

# PARTNERS IN CARE

## Resource adapted from Caregivers Nova Scotia

The Partners In Care Checklist will help you organize their care and your caregiving responsibilities, now and in the future.

What are your needs and those of your care recipient? Take an inventory of your skills and the resources available to you both. Are there things that others could do to help you in your role as caregiver or to give you a break from caregiving? What is your care recipient able to do for themselves.

Activities	Who can help	When and how often
Personal Care		
Bathing		
Dressing		
Eating/feeding		
Foot care		
Mouth care		
Toileting		
Lifting/transferring		
Help Around the House		
Light housekeeping		
Cleaning bathroom		
Cleaning floors		
Laundry		

# PARTNERS IN CARE

Resource adapted from Caregivers Nova Scotia

Activities	Who can help	When and how often
Help Around the House		
Meal planning		
Meal prep		
Yard work		
Pet/plant care		
Check mail		
Recycling and waste		
Home repairs		
Transportation/Shopping		
Accompany to appointments		
Activities/recreation		
Social appointments		
Take shopping		
Fill prescriptions		
Car maintenance		

# PARTNERS IN CARE

Resource adapted from Caregivers Nova Scotia

Activities	Who can help	When and how often
Coordinate Care		
Find out about services		
Arrange appointments		
Psycho-Social Support		
Phone call check-in		
In-person visits		
Leisure activities		
Financial/Legal Affairs		
Banking, paying bills		
Legal documents		
Income taxes		
Notes		



# IMPORTANT CONTACTS

*Resource adapted from Caregivers Nova Scotia*

Name	Number	Email / Website / Notes
Local Hospital:		
Pharmacy:		
Doctor:		
Lawyer:		
Health Insurance Provider:		
Family:		
Power of Attorney/Agent/ Substitute Decision Maker:		
Other services:		

## SCHEDULE OF DAILY CARE ACTIVITIES

[illegible]

# MEDICATION CHART

For: \_\_\_\_\_ Date: \_\_\_\_\_

Name of Medication	Dosage	When to take	How to take	Reason for Medication

Family doctor's name and telephone number: \_\_\_\_\_

Name of pharmacy and telephone number: \_\_\_\_\_

# MEAL PLANNING CHART

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Breakfast						
Snack						
Lunch						
Snack						
Dinner						
Allergies			Preferences			



# IMPORTANT DOCUMENTS LIST

Adapted from resource by Plan Well Guide

## Health Planning Documents

- Current advance serious illness plan
- Medical emergency contacts
- List of medical conditions and allergies
- Prescriptions

## Signed Legal Forms

- Will/trust
- Power of attorney for finances
- Power of attorney for personal care/personal directive

## Insurance Policies and Beneficiary Documents

- Life insurance policy
- Health insurance
- Long-term care insurance
- Disability insurance

## Financial Documents

- A list of bank accounts
- Retirement information
- Investment portfolio information
- Debt/loan information
- Most recent tax return
- RRSPs
- Credit card information
- Pension information
- Safety deposit box/home safe location and codes

## Property Documents

- Mortgage or rental information
- Deeds
- Leases
- Titles
- Home-owners' or renters' insurance policies
- Real estate rentals or other investments

## Copies of Identification Documents

- Drivers license/organ donor card
- Passport/citizenship papers
- Birth certificate
- Marriage certificate
- Divorce certificate
- Military/veteran benefit details
- Social insurance number

## Passwords

- Passwords to various personal websites
- Online payment accounts for utilities
- Online banking account information
- Home alarm system or other security

## Pre-Made Funeral Arrangements

- Receipts for pre-paid expenses (plot, casket, gravestone)
- Veteran burial benefit information
- Contact information to a specific fraternal or religious group organizing funeral or ceremony
- Personal wishes for the funeral (music played, mementos displayed, religious passages to be read)

## Letters of Instruction

- Guardian letter: how to care for your children/dependents
- Pet care plan: how to care for your pet
- List of who should receive certain sentimental items
- Practical information about running your home

## Legacy Documents

- Pre-written obituary or eulogy
- Photos for your obituary or memorial
- Ethical will
- Legacy letter to family members, friends, loved ones

And anything else you think will be helpful to those providing care!

retrieved from [planwellguide.com](http://planwellguide.com)

# INDEPENDENT LIVING ASSESSMENT

## Adapted from assessment created by Interim Healthcare

You can access the original by going to: <https://www.interimhealthcare.com/education-center/independent-living-assessment/>

Review the statements and add a tick mark in the column for each Yes or No response that applies to you. If a statement does not apply, please leave it blank. Total your score and it will give you an idea of how you are doing in preparing for your later years. This step will take about 15 minutes to complete.

### Health:

<input type="checkbox"/> I am physically active and do a variety of physical activities that I enjoy.	Yes	No
<input type="checkbox"/> I eat seven or more servings of fruit and vegetables in a day.	Yes	No
<input type="checkbox"/> I have a healthy body weight that has remained the same for the past six months.	Yes	No
<input type="checkbox"/> I schedule regular appointments for physical, vision, dental and hearing check-ups.	Yes	No
<input type="checkbox"/> I know what screening tests are recommended for my age and discuss these with my doctor.	Yes	No
<input type="checkbox"/> I do not smoke or I have a plan to quit in the future.	Yes	No
<input type="checkbox"/> If I drink alcohol, I stay below the limits suggested for adults my age.	Yes	No
<input type="checkbox"/> I avoid alcohol when taking medication, or check with a doctor or pharmacist first.	Yes	No
<input type="checkbox"/> I generally experience good mental health. I am aware of the signs and symptoms of depression/anxiety and if they continue, I will take steps to address them.	Yes	No
<input type="checkbox"/> I keep my mind active through a variety of interests and hobbies, such as reading.	Yes	No
<input type="checkbox"/> I know how to keep my bones healthy and strong, and have discussed this with my doctor or other health care professional.	Yes	No
<input type="checkbox"/> I have talked with my doctor about my preexisting medical condition and what services and supports I may need as I age.	Yes	No
<input type="checkbox"/> I am aware of my family's medical history and have talked with my doctor about what I can do now to maintain my health and how my health care needs may change as I age.	Yes	No
<input type="checkbox"/> I am aware of electronic tools, such as medication reminders and health management systems that will allow me to remain healthy.	Yes	No
<input type="checkbox"/> I have written down my wishes for care in the event I become incapable of giving my consent (I have made an Advance Serious Illness Plan).	Yes	No

## Home:

- |  |     |    |
|--|-----|----|
| ■ My home is in a location where I will not feel isolated in my later years and is close to services, friends, and family.   | Yes | No |
| ■ I have thought about current and future costs of staying in my home (e.g. mortgage or rent, condo fees, taxes, repairs, maintenance) and whether I can afford to live there as I age.                                      | Yes | No |
| ■ I can afford to pay for services (e.g. house cleaning, yard maintenance) to maintain my home, if needed.   | Yes | No |
| ■ If I find myself living alone in the future, I could manage it on my own.  | Yes | No |
| ■ I recognize safety risks in my home and have taken steps to fix them.  | Yes | No |
| ■ I have spoken to my landlord or condo board to find out if changes can be made to my current home.   | Yes | No |
| ■ The features in my home will adequately support my mobility and health needs as I age (e.g. entryways and doorways that can be accessed by a walker, bathroom walls that can support the installation of handrails, etc.). | Yes | No |
| ■ In the future, I will make changes as needed to my home to help me to age in place (e.g. night lights in the stair areas, solid handrails on both sides of the staircase, and a grab bar in the tub area).                 | Yes | No |
| ■ If my health changes and I need to use a wheelchair or another mobility device, I am prepared to modify my home to accommodate my needs (e.g. widen doorways, build a ramp, or install a walk-in bathtub).                 | Yes | No |
| ■ If I am no longer able to remain in my current home, I am aware of other available housing options in my community.  | Yes | No |
| ■ I have thought about reducing my belongings and/or moving to a smaller home.   | Yes | No |

## Transportation:

- |   |     |    |
|---|-----|----|
| ■ If I am able to continue driving, I plan to take a refresher course to maintain my skills and knowledge of the rules and regulations.                 | Yes | No |
| ■ I talk to my doctor and/or pharmacist about how my health conditions, and the medications used to manage them, can impact my ability to drive safely. | Yes | No |
| ■ I am aware of, and have access to, alternate means of transportation if needed (e.g. walk, bus, taxi, volunteer driving programs, and carpool).       | Yes | No |
| ■ I have thought about what it costs to run and maintain my own vehicle compared to the cost of other means of transportation.                          | Yes | No |
| ■ I plan to take up or increase walking or cycling as a healthy and active form of transportation.  | Yes | No |
| ■ I am aware of delivery and/or online shopping services I can use if I am not able to travel.  | Yes | No |
| ■ I have thought about my future transportation needs and would be willing to relocate so I can continue to have access to the services I need.         | Yes | No |

## Finances:

■ I am able to live comfortably within my current income.	Yes	No
■ I have money set aside for unexpected expenses such as health-related supports and major home repairs.	Yes	No
■ I have someone I trust that I can consult for financial advice when needed.	Yes	No
■ I have thought about my retirement and the kind of lifestyle I would like to have.	Yes	No
■ I have thought about the kinds of supports and services I may need to purchase as I age (e.g. cleaning, shopping, yard maintenance, and personal care support).	Yes	No
■ I know how much money is required to sustain the lifestyle I want in the future.	Yes	No
■ I plan to retire debt-free (e.g. pay off mortgage and credit cards).	Yes	No
■ I know of ways I could transition to retirement that can maintain or increase my income (e.g. work part-time, become a consultant, retire early and try a new career, or start a business on the side and keep it going post-retirement).	Yes	No
■ I plan to have my retirement income based on more than one source (e.g. personal savings, Canada Pension Plan (CPP), Registered Retirement Savings Plan (RRSP), Old Age Security (OAS), other pensions, investments and/or employment income).	Yes	No
■ If my living arrangements changed, I could manage financially.	Yes	No
■ I have a plan for who will be responsible for my financial affairs if I am not able to look after them myself (e.g. an enduring power of attorney) and have communicated my plan to those involved.	Yes	No
■ I have a will and my loved ones know where all my important documents are (e.g. will and insurance).	Yes	No

## Safety:

■ I feel safe in my home and my neighbourhood.	Yes	No
■ I know how to protect myself from fraud, abuse, and neglect (including emotional, physical and financial abuse and neglect).	Yes	No
■ I know falling is a risk, and I know what I can do to decrease this risk.	Yes	No
■ I keep my home uncluttered by removing scatter rugs and other tripping hazards.	Yes	No
■ I keep my walkway clear of snow and ice.	Yes	No
■ I had a fall recently, but I took action to decrease my risk of having another.	Yes	No
■ I have considered using a home monitoring system, personal emergency response system, or a fall detection system to help keep me safe at home.	Yes	No

## Connections:

■ I maintain good relationships with my family members.	Yes	No
■ I have family/friends I can rely on for support if needed.	Yes	No
■ I have someone I can talk to when I need to do so.	Yes	No
■ I have friends I enjoy spending time with, and I nurture the friendships I have.	Yes	No
■ I have friends who are of different ages, some of whom are younger than I am.	Yes	No
■ I enjoy connecting with people through my work and plan to work full- or part-time for as long as I am able.	Yes	No
■ I have built deeper relationships with some of my work colleagues whom I would like to stay connected with after I retire.	Yes	No
■ I have developed social networks outside of my work.	Yes	No
■ I have considered how I would like to stay connected with my community.	Yes	No
■ I may explore volunteering as a way to contribute to my community and provide social contact.	Yes	No
■ I have explored different ways of connecting with friends and family, such as Skype, Zoom, FaceTime or social media.	Yes	No

## Supports:

■ I have thought about what services and supports I may need to remain in my home in the future.	Yes	No
■ I know where to go to find information if I have questions about my care needs or community services.	Yes	No
■ I have talked to family and friends about help I may need in the future, so they can prepare accordingly.	Yes	No
■ I have thought of using devices such as a video monitoring system, medication reminders, and a personal response service to help.	Yes	No
■ As a caregiver (or if I become a caregiver in the future), I know what resources and respite services are available to help me in this role.	Yes	No
■ If I am a caregiver, I have a plan for self-care to help maintain my own health and well-being.	Yes	No

## Community:

- |   |     |    |
|---|-----|----|
| <input type="checkbox"/> I am comfortable getting around in my community and will continue to be in the future.   | Yes | No |
| <input type="checkbox"/> I feel safe in my community and know where to report concerns about how to make my community safer.  | Yes | No |
| <input type="checkbox"/> I know what programs and services (e.g. shopping, personal services, health and support services, and recreation programs) are available in my community.                            | Yes | No |
| <input type="checkbox"/> I have friends I enjoy spending time with, and I nurture the friendships I have.   | Yes | No |
| <input type="checkbox"/> There are activities in my community that interest me, and I know how to find out more about them.   | Yes | No |
| <input type="checkbox"/> In the future, I may move to another community or to another area in my community that is better designed to help older adults to live safely, enjoy good health, and stay involved. | Yes | No |

## Partner:

- |  |     |    |
|--|-----|----|
| <input type="checkbox"/> My partner and I have discussed our plans for old age and aging in place.                   | Yes | No |
| <input type="checkbox"/> We have shared our plans for what we want to be able to do financially.                     | Yes | No |
| <input type="checkbox"/> We have shared our plans for when we will retire.   | Yes | No |
| <input type="checkbox"/> We have shared our plans for what options we may explore to work part-time or in a new job. | Yes | No |
| <input type="checkbox"/> We have shared our plans for what we will do with our time.                                 | Yes | No |
| <input type="checkbox"/> We have shared our plans for what activities we can do together and separately.             | Yes | No |
| <input type="checkbox"/> We have discussed how aging or changing needs could affect our relationship.                | Yes | No |
| <input type="checkbox"/> We have shared our plans for where we want to live.   | Yes | No |
| <input type="checkbox"/> My partner and I nurture our relationship and work out any problems.                        | Yes | No |

	Yes	No
Health		
Home		
Transportation		
Finances		
Safety		
Connections		
Supports		
Community		
Partner		
<b>TOTAL</b>		

Yes responses indicate those areas of your life where you are most prepared for the future. No responses indicate areas where you need more preparation to successfully age in place. Review your No responses in each section. These are the areas you may wish to reflect upon and try to make changes.

# THE CAREGIVER'S HOSPITAL SURVIVAL KIT

by Amy Goyer

*In the past year, I've spent close to 40 overnights in the hospital with my parents, plus roughly 10 emergency room visits with them. I dislike going to hospitals ... a lot.*

*I think I've developed some sort of post-traumatic stress disorder around hospital visits. I find that I am great in the moment and deal with crises easily, but afterwards I am exhausted and when the time comes to venture off to the hospital again I tense up, feel a sense of dread, and my stomach goes into knots. Clearly, Mom and Dad don't like to go either.*

*Our ER visits have never taken less than 6 hours for us, and those lovely little cubicles aren't exactly comfy cozy. Sleep or rest in a hospital? Not hardly. It's cold, machines are beeping, vitals being taken and medicines dispensed at all hours along with blood draws, x-rays, and other tests.*

*So, how do I survive these visits? Over the past three years of intensive caregiving, I've developed my "hospital survival kit" to help keep my parents as comfortable as possible, aid in their healing, and keep myself occupied and calm as well. Thought I'd share some must-have items with you:*

- **Chargers** – They're first on the list for a reason. My iPad is loaded with movies, calming music, or favourite tunes. I also take copious notes on everything that happens during a hospital stay (doctors, medications, tests, treatments, questions, etc.) and email them to my sisters so they stay apprised. A copy of their medications list and medical history are stored on my iPad and phone. Most hospitals have free WiFi now, even in the ER, and allow use of cell phones (if you can get a signal). Facebook posts also bring lots of virtual support from friends and family on an up-to-the-minute basis and have helped me through many a tense and lonely time in the hospital.
- **Healthy snacks** – Nuts, air-popped popcorn, brown rice chips, granola, etc. The hospital cafeteria and vending machines are usually packed with unhealthy comfort food, which is sometimes necessary, but I just end up feeling worse if I eat too much of that stuff.
- **Several magazines** – For something to look at with my loved one.
- **Warm and comfy clothes** – I wear sweat pants and long sleeved shirt. No jeans. I bring warm jackets for all of us because it's always so darned cold in hospitals. My Dad's hat is a must (one of his chief complaints – his head gets cold), and a colourful shawl or throw blanket for Mom – hospital rooms are so dull. A cheerful color goes a long way.
- **Really good moisturizers** – Lip balm and Mentholatum or Vick's ointment to keep our noses moist. Good thick hand cream can be used every time we wash our hands, which is often, and is great for hand or foot massages to calm my parents.
- **Saline nose spray** – I like the Xlear brand with Xylitol. Can prevent bacteria breathed in hospital from adhering to the nasal passages. Sometimes that's not enough. When Dad started to develop sinus problems during a hospital stay I asked the doctor if I could bring in a vaporizer – no problem! Glad I asked. And don't forget good, soft tissues from home – ditch the rough and scratchy cheap ones the hospital supplies.
- **Nicely scented antibacterial hand gel** – While it's often available from wall units in hospitals, it's drying and smells nasty. I like the lavender scented gel - makes us all feel special.
- **My soft, fuzzy green blanket** – The texture is wonderful, the color is calming. Mom and Dad get lovely heated blankets and I don't hesitate to ask for them frequently.



- My own pillow – With a good cover on it and pillowcase to protect against picking up germs. They usually don't want Mom and Dad to use their own pillow in the hospital bed though.
- Mom and/or Dad's slippers and robe and a change of clothes for their homecoming. I also bring my slippers – I can stay more relaxed in their room if I wear my slippers – psychological? Perhaps. But if it works, do it. I keep an easy to wash pair just for hospital visits. Also hairbrush, ponytail holders, hair clips.
- A small flashlight – To read or find things in the room when they are asleep.
- Eye mask – For me or them. Keeps us from waking up any time someone opens the door during the night.
- A sound machine – A portable one or iPad app with calming nature sounds or white noise. It blocks out the beeping and other disturbing hospital noises.
- Room spray – A friend gave my Mom a beautiful scent when she broke her hip and it's amazing how spraying that makes us all feel better. It obliterates nasty hospital odors and aromatherapy is good for us all.
- Mom's teddy bears – She has a collection and for an extended stay I bring in a couple of them. They make her laugh and I think they are a bit comforting too. Any familiar item from home can be helpful.
- Portable CD player – For extended hospital stays when I don't have enough tunes on my iPad to last.
- Flowers – They really do brighten the room as well as our spirits. Intensive care or certain hospital units will not always allow live flowers, but will often OK silk flowers.
- Pictures – I bring tape, beautiful nature pictures, and copies of family photos. I tape them on walls or mirrors along with get well cards. Easy to take down when we get to go home. When Mom fractured her spine and couldn't stand on her own, I posted photos of her standing tall and strong as inspiration while she recovered from surgery.
- Insist on a cot or a room with built-in couch/bed – If you end up spending the night with your loved one you may not sleep much but when you do you'll sleep much better. I usually have to ask as they are rarely offered but always materialize when asked for.
- Dark chocolate – Lots of it!!!

Here's hoping your next trip to the hospital will be a bit more safe, calm and healing.

# CANADIAN RED CROSS

## EMERGENCY KIT

*Getting or making an emergency kit is a very important step in ensuring you are ready for emergencies. You should have an emergency preparedness kit in your home with enough supplies to meet the needs of your entire household for at least 3 days. It is also vital that your care recipient has an emergency kit ready for them if disaster strikes.*

*Some disasters, such as floods, wildfires, and major power outages, can create very unsafe conditions. If your safety is at risk, community officials may ask you to either take shelter at home, or evacuate to a safer place. If asked to evacuate, you may have only minutes to get what you need and leave. Having an emergency kit that you can either use at home or grab and take along will help you be prepared and get to the evacuation point quickly, if needed.*

*Building a kit doesn't have to be expensive! Here are some quick tips to help you save on costs: Before purchasing anything new, see what you already have. Don't build the entire kit all at once, start with the high priority items, then add one or two things every week. Ask family and friends for any spare items they might have that you need, and check out second-hand stores or garage sales. Buy food with a long shelf life, and avoid foods that need to be refrigerated after being opened.*

### Essential Items

- 3 days worth of drinking water (1L per person per day)
- Water for cleaning and hygiene (2L per person per day)
- Non-perishable food for each person for at least 1 day
- Manual can opener and utensils
- Essential items like medications (and copies of prescriptions), eye glasses, contacts, baby supplies, hearing aids, dentures (enough to last 3 days)
- Copies of important documents: birth and marriage certificates, passports or permanent resident cards, health cards, licenses, wills, insurance, land deeds
- Copy of emergency plan
- Crank or battery operated flashlight (with extra batteries)
- Crank or battery operated radio (with extra batteries)
- Spare keys for house/car
- First aid kit
- Extra cash in small bills and coins
- Personal hygiene items
- Cell phone, charger, power bank, extra charging cord
- Pet supplies: water, food, medication, vaccination records
- Paper and pens
- Whistle

### Additional Items to Consider

- Traditional medicines and/or portable ceremonial items that you use or want to have with you
- Traditional foods that may be difficult to find in stores
- Change of clothing and footwear for each person in your household
- Old plastic sheeting
- Scissors and a pocket knife
- Hand sanitizer
- Garbage bags and twist ties
- Toilet paper
- Multi-tool or basic tools
- Duct tape
- Sleeping bag or warm blanket for each member of your household
- Toys, games, books, deck of cards
- Paper maps

*Pack your kit in a sturdy, easy-to-carry bag. Store your kit in a clean, dry place that is easy to access in case you must evacuate quickly. Make sure everyone in your family knows where it is. Check your kit every year to make sure it's ready in case you need it, and always resupply your kit after use.*

# CAREGIVER'S ORGANIZATIONS BY PROVINCE

## British Columbia

- Family Caregivers of British Columbia (FCBC)
  - The FCBC is a very active not-for-profit society supporting caregivers in southern Vancouver Island. The society runs support groups for caregivers in Victoria, Sydney, and Salt-Spring Island, which run either weekly or monthly on a drop-in basis. You can also sign-up to join online support groups and watch their online caregiving video series, which shares short clips and tips for caregivers. Also on their website, you can find an extensive collection of resources on Vancouver Island, including community health services, home support, housing, grocery delivery, medication delivery, and meal services, among others.
  - Link: [www.familycaregiversbc.ca](http://www.familycaregiversbc.ca).

## Alberta

- Family Caregiver Centre - Alberta Health Services
  - The Family Caregiver Center operates in Calgary. It helps caregivers find accurate and up-to-date information and connect them with existing health care and community services. With supportive counseling available and monthly support groups, they also offer an understanding and supportive person to talk with. The center provides several educational opportunities including a speaker series, newsletters, and a library with books, videos, and articles for loan and regular newsletters are available.
  - Link: <https://www.albertahealthservices.ca/services/Page13155.aspx>
- Caregivers Alberta
  - Caregivers Alberta provides a number of programs and services dedicated to maintaining the health and wellness of caregivers. You can speak to a caregiver advisory who is there to listen, provide information, and help find resources and support. This association also provides workshops to help caregivers balance their own needs with the demands of their caregiving role. As well, they host community groups on a drop-in-basis to connect caregivers in the community and provide an opportunity to share experiences and resources.
  - Link: [www.caregiversalberta.ca/](http://www.caregiversalberta.ca/)

## Saskatchewan

- Caregiver Information and Support - (Saskatoon Council on Aging)
  - This caregiver center is located in Downtown Saskatoon. Professional counseling is available in-person or on the phone for caregivers who are feeling overwhelmed or not sure of their next step. The center also hosts evening seminars for caregivers. You can stop by the downtown resource center or browse for resources on their website. Online, you can find information on healthy aging, fall prevention, family communication, long distance caregiving, Alzheimer's, alternative living arrangements, and end of life.
  - Link: <http://www.saskatooncaregiver.ca/resources.html>

# CAREGIVER'S ORGANIZATIONS BY PROVINCE

## Manitoba

- Seniors Resource Network of Manitoba
  - The Seniors' Resource Network is an online gateway to seniors' information in Winnipeg and Manitoba. On the site you can find Manitoba-wide listings of senior organizations, various transportation options, meal programs, and health and housing resources among others.
  - Link: <http://www.gov.mb.ca/seniors/>
- Transportation Options Network for Senior (TONS)
  - TONS is a volunteer driven network to inform and educate Manitobans on transportation options for seniors. On their website, you can find information about public transportation options, volunteer driving programs, and taxi and ride-sharing services for people with disabilities.
  - Link: [www.tonsmb.org](http://www.tonsmb.org)
- Government of Manitoba - Resources for Residents
  - The Government of Manitoba provides a directory of resources and information available for caregivers. You can find information about a caregiver tax credit, family support services, health care services, and law, justice, and citizens' rights.
  - Link: [https://residents.gov.mb.ca/reference.html?filter\\_category=14&d=list](https://residents.gov.mb.ca/reference.html?filter_category=14&d=list)

## Ontario

- Home & Community Care
  - This site is directly through the Ontario provincial government and provides direct support around how to get help for patients and seniors who need support living at home.
  - Link: <https://www.ontario.ca/page/homecare-seniors>
- Family Service Toronto - Seniors and Caregivers Support Services
  - The Seniors and Caregivers Support Service Unit provides social work services to older people and caregivers. The unit offers counseling in English and Spanish either over the phone or in person. They also offer group work, advocacy, and education seminars on topics including memory loss, anger and guilt, how to access community resources, and others.
  - Link: [www.familyserVICEToronto.org/our-services/programs-and-services/seniors-and-caregivers/](http://www.familyserVICEToronto.org/our-services/programs-and-services/seniors-and-caregivers/)

## Quebec

- Regroupement des aidants naturels du Québec (RANQ)
  - RANQ has put together a comprehensive directory of caregiving groups, associations, and local organizations throughout the province of Quebec. On their website, you can find information about these groups, as well as two French-language guidebooks for caregivers in Quebec.
  - Link: <http://www.ranq.qc.ca/>
- L'APPUI pour les proches aidants
  - L'APPUI is a not-for-profit organiza throughout Quebec. On their website you can find a directory of resources and services in your region of Quebec. As well, you can browse articles and videos about being a caregiver, adapting to your role, caring for elderly persons, and maintaining your health and wellbeing. L'APPUI also runs a toll-free hotline for caregivers who need support, need help to find resources, or need to talk.
  - Link: <http://lappui.org/>

# CAREGIVER'S ORGANIZATIONS BY PROVINCE

## New Brunswick

- New Brunswick Health
  - Visit the government of New Brunswick's gateway for residents to find information and resources about health and basic needs.
  - Link: <http://www.gnb.ca/>
- Caregiver's Guide
  - The government of New Brunswick's social development website provides resources and information about a variety of services (including health services and social programs) available to its residents. They have also published a caregiver's guidebook that provides guidance on various aspects of caregiving, and suggests practical ways for caregivers to help improve their quality of life and that of the person for whom they are caring.
  - Link:  
[http://www2.gnb.ca/content/gnb/en/departments/social\\_development/seniors/content/caregivers\\_guide.html](http://www2.gnb.ca/content/gnb/en/departments/social_development/seniors/content/caregivers_guide.html)

## Nova Scotia

- Caregivers Nova Scotia
  - Caregivers Nova Scotia hosts support groups for caregivers in various parts of the province. All caregivers are welcome—the groups are neither age- nor disease-specific.
  - Link: <http://caregiversns.org/>
- Nova Scotia Health Authority
  - There is a helpful section on continuing care which highlights caregiver support and respite services, including information on things like adult day programs, caregiver benefit program, etc.
  - Link: <http://www.nshealth.ca/content/respite-and-caregiver-support>

## Prince Edward Island

- Health PEI
  - The Health PEI website provides information about healthcare in PEI, including a directory of hospitals, health centers, walk-in clinics, and long-term care facilities throughout the province. You can find listings of community programs and services provided throughout the province.
  - Link: <http://www.healthpei.ca>
  - You can also access help navigating the system in PEI from a patient navigator
  - Link: <https://www.princeedwardisland.ca/en/information/health-pei/patient-navigator>

## Newfoundland and Labrador

- Senior Resource Centre Caregiver Support Program
  - The senior resource center hosts a toll-free telephone line available to everyone in Newfoundland and Labrador. On their website, you can find more information on family caregiving.
  - Link: <http://seniorsnl.ca/family-friend/family-friend-support/>

## Northern Canada

- Health Canada Environmental Scan on respite care for caregivers in Canada (2003)
  - Link:  
<https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/home-continuing-care/respite-family-caregivers-environmental-scan-publicly-funded-programs-canada.html>

# CAREGIVER'S RESOURCE LIST

There are so many fantastic resources for caregivers, especially regarding self-care. We've put together a list of the best resources we've found, so you can find the right ones for you, when you need them.

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## Self-Care Resources:

- Family Caregivers BC Self-Care Booklet  
[www.familycaregiversbc.ca/wp-content/uploads/2020/04/Self-Care-Booklet.pdf](http://www.familycaregiversbc.ca/wp-content/uploads/2020/04/Self-Care-Booklet.pdf)
- Help Guide: Caregiver Stress and Burnout  
[www.helpguide.org/articles/stress/caregiver-stress-and-burnout.htm](http://www.helpguide.org/articles/stress/caregiver-stress-and-burnout.htm)
- Mayo Clinic: Stress Management  
[www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/caregiver-stress/art-20044784](http://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/caregiver-stress/art-20044784)
- Harvard Health: Self-Care for the Caregiver  
[www.health.harvard.edu/blog/self-care-for-the-caregiver-2018101715003](http://www.health.harvard.edu/blog/self-care-for-the-caregiver-2018101715003)
- Family Caregiver Alliance: Taking Care of Yourself  
[www.caregiver.org/resource/taking-care-you-self-care-family-caregivers/](http://www.caregiver.org/resource/taking-care-you-self-care-family-caregivers/)
- Caregivers Alberta resources  
[www.caregiversalberta.ca/for-caregivers/resources/printables/](http://www.caregiversalberta.ca/for-caregivers/resources/printables/)
- Teva Canada: Self-Care for Caregivers  
[www.tevacanada.com/en/canada/support-for-caregivers/self-care/](http://www.tevacanada.com/en/canada/support-for-caregivers/self-care/)

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## Other Resources:

- Canadian Virtual Hospice  
[www.virtualhospice.ca](http://www.virtualhospice.ca)
- Caregivers Out Loud Podcast  
[www.familycaregiversbc.ca/podcast/](http://www.familycaregiversbc.ca/podcast/)
- Carers Canada  
<https://www.carerscanada.ca>
- Lumino Health Caregiver Guide  
[https://luminohealth.sunlife.ca/s/caregiving-resources-for-older-adults?language=en&WT.ac=en-ca%3Adirect%3Aredirect%3Aacg\\_guide%3Aguides\\_landing\\_pg%3Aenglish](https://luminohealth.sunlife.ca/s/caregiving-resources-for-older-adults?language=en&WT.ac=en-ca%3Adirect%3Aredirect%3Aacg_guide%3Aguides_landing_pg%3Aenglish)

# CAREGIVING SELF ASSESSMENT

Created by Teva

Signs of burnout and fatigue:

■ I can't fall asleep or frequently wake up.	Never	Sometimes	Frequently	Always
■ I lack energy during the day.	Never	Sometimes	Frequently	Always
■ I eat too much or too little.	Never	Sometimes	Frequently	Always
■ I am sick more often (flus, colds, headaches).	Never	Sometimes	Frequently	Always
■ I feel impatient or I am easily agitated.	Never	Sometimes	Frequently	Always
■ I feel guilty that I am not doing enough.	Never	Sometimes	Frequently	Always
■ I have trouble concentrating on everyday tasks.	Never	Sometimes	Frequently	Always
■ I am becoming more forgetful.	Never	Sometimes	Frequently	Always
■ I stopped doing activities I used to find enjoyable.	Never	Sometimes	Frequently	Always
■ I am more socially isolated from friends and family.	Never	Sometimes	Frequently	Always
■ I feel sad or depressed.	Never	Sometimes	Frequently	Always
■ I feel anxious or worried.	Never	Sometimes	Frequently	Always
■ I have lost interest in doing things.	Never	Sometimes	Frequently	Always

If you checked "Frequently" or "Always" for any of the above, then it's time to seek help from a healthcare provider, or your local health and social service network—because you have to take care of yourself, too!

Building a support network is one of the most important ways to prevent burnout. It can be helpful to do an inventory of professional and family/friend supports that can help you with care tasks.

Get more information and resources for caregivers at [TevaCaregiver.com](https://tevacaregivers.com).

*\* Not intended as a substitute for medical advice. Please consult your doctor if you are experiencing a health problem.*



# CAREGIVING TERMS

## Activities of Daily Living (ADL)

*describes fundamental skills that are required to live independently*

## Acute

*condition that happens suddenly and severely*

## Advance Care Plan (ACP)

*planning for medical care at the end of life or for a terminal illness*

## Advance Serious Illness Plan (ASIP)

*planning for medical care in the case of serious illness or injury, where the outcome is not certain*

## Agent

*designated individual who will act and make decisions on a person's behalf*

## Allow natural death/do not resuscitate

*a legal order not to conduct CPR in the event of the heart stopping*

## Anticipatory grief

*feeling grief before a loss*

## Assistive devices/assistive technologies

*ex: wheel chairs, walkers, prosthetic devices, hearing aids, orthotic devices*

## Assisted living

*residence for people with disabilities, or those who choose not to live independently*

## Care recipient

*a person receiving caregiving services, paid or unpaid*

## Caregiver

*person (paid or unpaid) giving care and assistance to another*

## Caregiver burnout

*state of complete exhaustion due to caregiving that may lead to mental illness*

## Caregiver distress

*when a caregiver is no longer able to provide care due to severe burnout*

## Caregiver fatigue

*when a caregiver starts to feel exhaustion from caregiving activities*

## Caregiver stress

*the feeling of almost complete exhaustion from caregiving activities*

## Cardiopulmonary resuscitation (CPR)

*emergency procedure that attempts to revive someone whose heart has stopped through chest compressions and artificial ventilation*

## Chronic

*diseases that last 1 year or longer and require ongoing medical treatment*

## Comfort care

*medical care that eases pain and focuses on keeping a person comfortable*

## Comfort measures only

*designation of medical treatment that focuses primarily on maintaining comfort as a person passes, and does not intervene with life-saving measures, allowing them to die a natural death*

## Degenerative disease

*a disease resulting from cells deteriorating over time*

## Dialysis

*a treatment that cleanses the blood by filtering it through a machine*

## End of life care

*medical care administered to a patient who is dying*

## Feeding Tube

*a tube inserted into the stomach to provide nutrition when a person has difficulty eating*

## Health care provider

*individuals or institutions with a license to diagnose conditions and provide medical care, such as medication or surgery*

## Hospice care

*type of care that focuses on palliative care for patients with terminal illnesses*

## Informed consent

*when patients make a decision (and are able to) after being educated on the options, risks, and benefits of a treatment*

## Intensive Care Unit (ICU)

*the department of the hospital that provides intensive care interventions and treatments to patients with severe conditions*

## Intravenous

*administering fluids to a patient via tube inserted into the vein*

## Life support with medical interventions

*a designation for treatment that allows the patient to undergo life-saving measures of medical care*

## Mandate of incapacity

*document that enables a person to make decisions for another person if they are incapacitated (Quebec)*

## Palliative care

*medical care focused on maintaining quality of life for people suffering of a serious illness*

## Power of Attorney (POA)

*legal document that grants a person permission to make decisions on one's behalf if they are unable to make the decisions themselves*

## Prognosis

*predicting the progression of a disease or condition*

## Relapse

*deterioration of health after a temporary period of improvement*

## Remission

*when a disease appears to be becoming less severe or disappearing*

## Respite

*relief for caregivers by providing rest or a break from caregiving activities*

## Responsive behaviour

*behaviour exhibited by a person with a mental disorder, in response to something important happening in their environment*

## Side effect

*unintended outcomes of a medication, secondary to the primary function*

## Substitute decision maker

*someone who will make health care decisions for you if you're unable to speak for yourself*

## Symptoms and clinical signs

*observable effects that indicate a disease or condition*

## Terminal illness

*an disease that cannot be cured, whereby the patient is expected to die*

## Ventilator

*machine that assists a person's breathing, by pumping air in and out of the lungs*