Care at Home











An Organizational Tool for Family Caregivers



CARE AT HOME: AN ORGANIZATIONAL TOOL FOR FAMILY CAREGIVERS

This Care at Home workbook has been developed to help caregivers to be organized and empowered. Your role as a caregiver is important to the well-being of your loved one. You may find the caregiving 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. Key to being successful in your role as caregiver is understanding that caregiving is a process, not an event. And, it is never easy.

This Care at Home workbook aims to simplify the many responsibilities and process involved in caregiving. It's goal is to help point caregivers in the right direction and to give caregivers a sense of empowerment and control over their journey. The workbook is filled with checklists, worksheets and forms designed to make your caregiving responsibilities a little more manageable. You will find checklists to help you determine how much assistance your loved one needs; tools to help you plan; and worksheets to help you organize and keep track of your loved one's important paperwork. As circumstances change, caregivers may find themselves taking on responsibilities in many areas, including arranging for medical treatment, managing medications; paying bills; managing financial affairs; and handling legal, housing, and insurance matters. The sheer number of tasks that caregivers perform can be overwhelming. That is where this Care At Home Workbook comes in. Write in it. Take notes in it. Use it to keep information as you move through the caregiving process. Those caregivers who make a point of becoming educated and organized will be happier and healthier. You will also be a more effective caregiver.

THE CARE AT HOME WORKBOOK IS DESIGNED TO:

- Provide practical information about caregiving.
- Educate caregivers about community resources.
- Support caregivers in their vital role.
- Help caregivers navigate the system.
- Organize caregivers around health, financial and legal matters.
- Reach caregivers in remote communities and throughout the E.K.

NOW YOU ARE A CAREGIVER. YOU ARE NOT ALONE.





"With Organization, Comes Empowerment"

Lynda Peterson

This section includes:

- Information on how to educate yourself about caregiving.
- Information about the perspective of the person receiving care.
- Form to record general information and contacts
- Form to record the location of personal documents
- Space to note dates and changes.



HOW TO EDUCATE YOURSELF ABOUT CAREGIVING

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

- How the person you will be a caregiver for is changing.
- What their needs will be when they return home after a diagnosis or hospital stay.
- 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 effective 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?
- What the lasting effects of the illness will be?
- What changes may occur due to the illness/condition?

Ask to sit in on meetings with care providers about the care plan. This is an excellent way to gain information on progress of the care recipients condition and the treatment plans of the professional 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.

MOST IMPORTANTLY

Become an expert on your situation.

Educate yourself: find out what is available in your community.

Become active: advocate for you and your loved one's rights.

Be organized: know where and how to find important information

Speak with other caregivers. Do not wait to seek support as a last resort.



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.
- Fear of becoming dependent and a burden to the family.
- Sadness from a changed self image.
- Fear that old friends will distance themselves.
- Anger and frustration towards their condition (which at times can 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 can adjust to their new situation. As a caregiver, you can 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.



General Information

Name:	Preferred Name:		
Address:			
Home Phone:	Cell/Other:		
Date of Birth:	Birth Place:		
Social Insurance Number:	Medical Care Card:		
Family Doctor:	Phone Number:		
Doctor Address:			
	Blood Type:		
Extended Health Insurance:			
	Policy Holder:		
Allergies:			
Pharmacy:	Phone Number:		
Emergency Contacts:			
1	Phone:		
2			
3			

General Contacts

Name (family, friends, etc.)	Relation	Contact Info



Location of Personal Documents

Document		Where It's Kept
Birth Certificate		
Adoption Certificate	YES O NO O	
Passport	YES NO	
Marriage Certificate	YES O NO O	
Divorce/Separation Papers	YES O NO O	
Employment Records	YES O NO O	
Veterans/Military Records	YES O NO O	
Care Card		
Organ Donor Card	YES O NO O	
Will	YES O NO O	
Medical Instruction Papers	YES O NO O	
Power of Attorney Papers	YES O NO O	
Funeral Home	YES O NO O	
Plot Internment Papers	YES O NO O	



Date	Notes





"Organization is the foundation of all things" **Edmund Burke**

This section includes:

Form to record current medical conditions
Form to record current medications
Form to monitor daily living assessment
Form to record caregiver notes and changes



ADVANCE CARE PLANNING

What do you need to know?

Advance care planning is making a plan for your future health care while you're still able to make health care decisions for yourself. Even if you're doing well now, it's a good idea to prepare in case you're badly hurt or develop a serious illness. As long as you can still make your own decisions, your advance care plan won't be used. You can say "yes" or "no" or change your mind about treatment, including changing or cancelling your advance care plan at any time.

It can be hard to think and talk about the end of your life but it's best to do these things before you're in a crisis. Talk with your loved ones and your health professionals about the kinds of care you do or don't want to have, such as when to consider, continue or abandon life-support measures. Don't assume that they know what you want.

An advance care plan helps to make sure that your wishes are respected because your loved ones and doctors can use the information in your advance care plan to make treatment choices for you, if you can't make them for yourself. Having a plan eases the burden on your family so that they don't have to decide what is best for you. If you've done an advance care plan, share it with your loved ones and your doctor. Your plans will do no good if no one knows about them.

What do you need to do?

Learn about the options available to you in British Columbia outlined in the My Voice: Expressing My Wishes for Future Health Care guide. These include:

- 1. Complete an Advance Directive which can give legally binding instructions directly to doctors about treatments you would refuse, as well as guidance about your wishes for care. A frank discussion with your doctor is very important as you create this plan so that he/she can write medical orders for care that honor your wishes.
- 2. Complete a Representation Agreement which names the person(s) you wish to be your substitute decision maker. Talk openly with the person(s) you choose, so they can fulfill their responsibility to make decisions, which follow your instruction or wishes.
- 3. Discuss your plan with your loved ones and/or write down your wishes or instructions clearly. This way you can rely on any of your loved ones to follow your plan in their role as Temporary Substitute Decision Maker(s) if selected by your doctors to make health care decisions on your behalf.
- 4. If you don't discuss your wishes or write down your instructions, you can still be assured that your doctors and loved ones will make health care treatment decisions, which they believe are in your best interest and you will receive excellent and medically appropriate care.

Other resources:

There are several resources that can help you start the conversation about advance care planning. You can talk to your doctor in person about getting a copy of the My Voice document. You can also download a copy online and read about advance care planning on the following sites:

https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning https://www.interiorhealth.ca/YourCare/PalliativeCare/ToughDecisions/Pages/Advance-Care-Planning.aspx



Current Medical Conditions

Condition	Date of Onset	Treating Physician	Treatment Plan / Medications

Allergies

Allergies/Sensitivities	Treatment



Current Medications

Date Last u	pdated:			

Name (and what it's for)	Date Prescribed	Dose	Frequency/ Time of Day
Notes:			



Daily Living Assessment

Activity	Ability	Notes
Walking/Getting Around		
Getting In and Out of Chairs		
Getting In and Out of Bed		
Maintaining Balance		
Use of Bathroom and Shower/Bathtub		
Personal Hygiene		
Grooming/Getting Dressed		
Taking Medication		
Transportation		
Shopping/Running Errands		
Managing Finances/Bill Paying		
Preparing Meals		
Housecleaning/Laundry		
Home Maintenance		
Using the Telephone		
Making Appointments		
Vision		
Hearing		
Speech		
Cognition/Memory		
Decision Making		
Asking for Help		



Caregiver's Notes

Use copies of this form to monitor daily changes and help with communication among care providers

		Day/Date: _			
Caregiver Name/Co	mpany:				
SPECIAL CHANGES	or RED FLAGS				
#0.00					
FOOD	AMOUNT	TIME	COMMENT		
ACTIVITIES	DURATION	TIME	COMMENT		
MEDICATION(S)	DOSE	TIME	COMMENT		
ENERGY LEVELS					
PAIN/DISCOMFORT	PAIN/DISCOMFORT LEVELS				
SLEEP PATTERNS					
	<u> </u>				
OTHER COMMENTS	5				



Date	Notes





"Stop waiting for the perfect time to get organized. Take this moment and make some progress"

Heidi Leonard

This section includes:

- Form to record the location of financial documents
- Form to record legal and estate information
- Space to add notes and dates of importance



Location of Financial Documents

DOCUMENT		WHERE IT'S KEPT
Bank Accounts		
Credit Cards	YES O NO O	
Financial Planning	YES O NO O	
Bank/Stock Certificates	YES O NO O	
Pension Plans	YES O NO O	
Insurance Policies	YES O NO O	
Extended Health Care	YES O NO O	
Property Deeds/Real Estate	YES O NO O	
Social Insurance Card		
Security PINs/Passwords	YES O NO O	
Income Tax Returns		
Safety Deposit Boxes	YES O NO O	
Utility Statements		
Mortgage Information	YES O NO O	
Liabilities/Debts	YES O NO O	



Legal & Estate Information

	Name/Address	Phone	Email
Power of Attorney For Finances			
Will Executor			
Health Care Representative			

	Name/ Address	Phone	Email
Lawyer			
Accountant			
Financial Advisor			
Insurance Advisor			



Date	Notes





This section includes:

- Information and caregiver self care
- A caregiver bill of rights
- Form to record appointments, dates and questions
- Form to record other community resources.



CAREGIVER SELF CARE: CARING FOR YOU

The care you give to yourself is the care you give to your loved one.

1. Learn about the disease your loved one has.

Find out about what is happening now and what will happen in the future with this disease. The more you know the more you will be able to plan.

2. Use community resources.

The more you let these services help you, the less you have to do. There are places to get help.

- Your local area agencies (Better at Home, Dinners at Home, snow removal services).
- Support groups for caregivers.
- Adult day programs or home support.

3. Get organized.

Find out where important documents are kept. Gather important contact information. Think ahead and plan for legal and financial matters that may be important.

4. Take a break from caregiving.

Take a walk, meet a friend for lunch. Everyone needs to get out of the house once in a while. Do something not related to caregiving.

5. Get support.

Attend a support group, have a friend you can call to let off steam and complain. Depression is treatable. Talk to your doctor about it or seek counselling.

6. Practice communication and behavior management skills.

This will make the caregiving easier. Learn how to do this by taking a class, or reading how to on the web. The right way is not always intuitive.

7. Relax.

Read a good book, meditate, take a walk, garden, knit. Take advantage of any down time.

8. Take care of your health.

Go to the doctor, get routine exams and flu shots, get enough sleep and try to eat well.

9. Ask for and accept help when offered.

No one can do this alone.

10. Forgive yourself - often.

You cannot be the perfect caregiver, all day, every day.



A CAREGIVER'S BILL OF RIGHTS I HAVE THE RIGHT.....

- **1. To take care of myself.** This is not an act of selfishness. It will give me the capability to take better care of my loved one.
- **2. To seek** help from others even though my loved one may object. I recognize the limits of my own endurance and strength.
- **3. To maintain** facets of my own life that do not include the person I care for, just as I would do if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do something just for myself.
- **4. To get angry**, be depressed and express other difficult feelings occasionally.
- **5. To reject** any attempt by my loved one (either conscious or unconscious) to manipulate me through quilt, anger or depression.
- **6. To receive** consideration, affection, forgiveness and acceptance for what I do from my loved one for as long as I offer these qualities in return.
- **7. To take** pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.
- **8. To protect** my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
- **9. To expect and demand** that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.



Appointment Form

Date:	Time:	
Who With:	Location:	
Reason for Appointment:		
1. Question for Health Care Provider	Answer	
2. Question	Answer	
3. Question	Answer	
4. Question	Answer	
5. Question	Answer	
Blood Work/Tests: Follow Up Appointments:		



Other Community Resources

Organization & Contact Name	Services Provided	Contact Information



"It is not the load that breaks you down. It's the way you carry it."

— Lena Horne, singer 2016

About the Caregiver Network for East Kootenay Seniors

The Caregivers Network for East Kootenay Seniors recognizes that caring for seniors can be challenging and hard work. Recognizing this challenge, our not-for profit organization strives to provide support for caregivers of seniors with higher complex needs who live in the East Kootenay. The Caregivers Network has been serving and supporting caregivers for over 15 years through our toll free telephone support line, in person support visits, telephone check in's, educational opportunities, and our support groups for caregivers in six of the largest communities throughout the East Kootenay region. The Caregivers Network for East Kootenay Seniors believes that emotional support, information about community resources and help to navigate the system are essential to a caregiver's well-being.

Contact us





Toll Free: 1-877-489-0803 Office: 1-250-489-0802

Email: info@caregiversnetworkek.com Website: www.caregivernetworkek.com



Tobi Johnston M.A., M.S.W., R.S.W, is the Executive Director of the Caregivers Network for East Kootenay Seniors and a pioneer in the field of caregiver mental health and wellness. Her speciality and focus is creating therapeutic tools for family caregivers to assist them in caring for aging loved ones. She is the author of Care At Home: An Organizational Tool for Family Caregivers and the Caregivers Self-Care Workbook. Her most recent publication is the Caregiver Coloring Book and the Practice of Mindfulness.



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