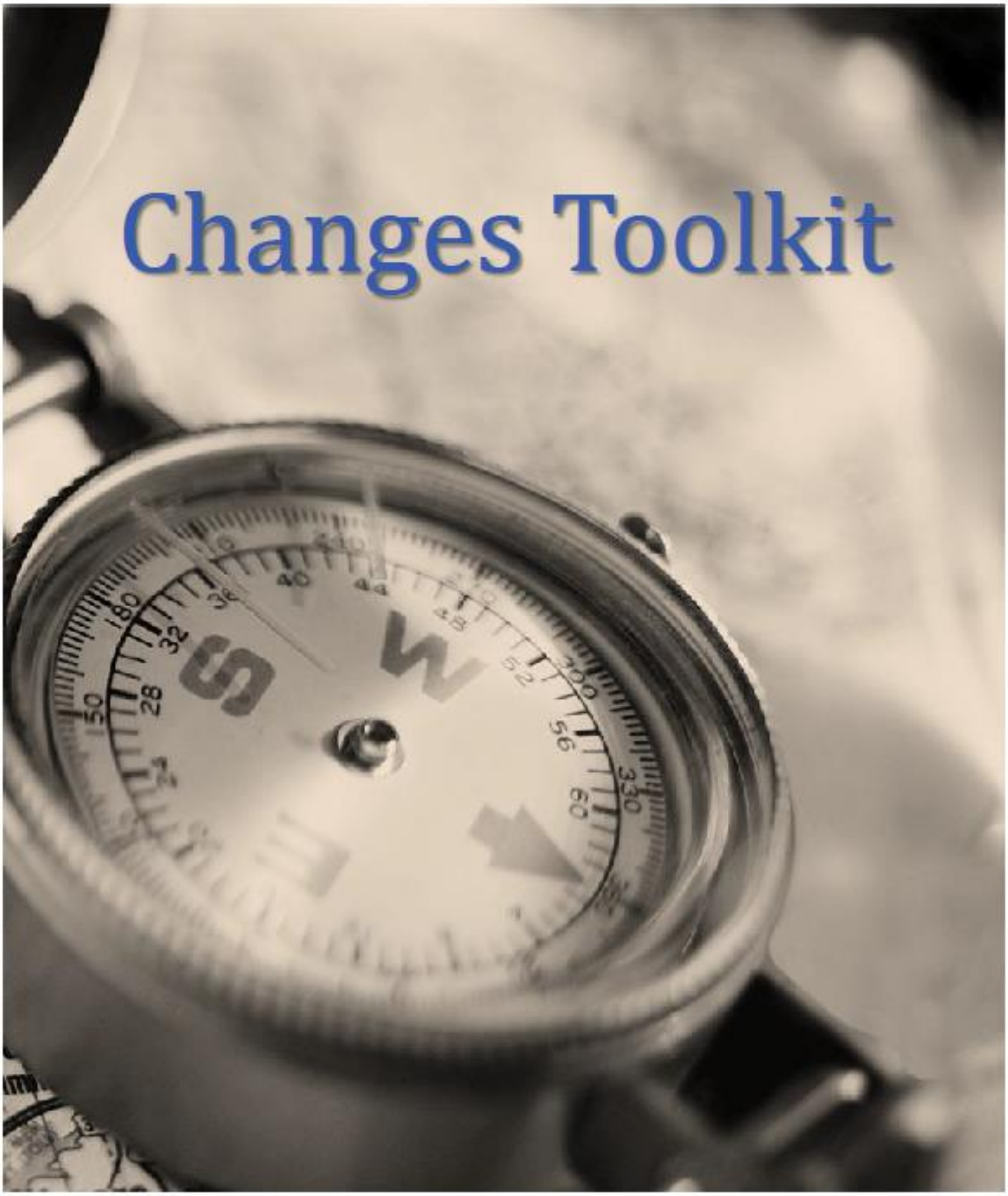
Changes Toolkit



CIHR IRSC

Alberta Health Services

UNIVERSITY OF ALBERTA
FACULTY OF NURSING

RURAL
PALLIATIVE
CARE

Introduction

This book is about life changes. It is meant to help you prepare for possible changes, and to connect you with services in your community. It has suggestions and information about resources to help you. It is based on what people receiving palliative care, their families, and health care providers have told us.

This book can be used as you wish, by you and those close to you.

You may choose to use different sections of this tool depending on what you feel you need. There is no need to complete any of the sections. It is up to you. There is a section in the folder to store what you want to share with others. You are free to add or remove what you want from the folder and the book. Make it your own. We hope that this will help you.

Table of Contents

Section 1: Thoughts & Wishes

This section is about your thoughts and wishes. Each activity starts with a brief guide, but it is your choice how you do the activities.

You can keep these pages private or share them with others. That is up to you.

What helps me?

Guide: Think about the things that help you and give you strength.

- Begin to write a list of things below that give you strength
- If needed, someone else can help you write the list
- Or you might take pictures of what gives you strength

What helps me?

What helps me?

What helps me?

My story

Guide: Write your story, or have someone help you.

- Your story can include major events or changes in your life
- Pictures can also be part of this story

What you should know about me

Guide: List things you would like to share with your family members and close friends.

- You might include memories or personal stories
- You might list some things you like or dislike
- This may be in words or pictures

What you should know about me

What you should know about me

What you should know about me

My goals of care

Guide: Write your thoughts about the goals of the care you wish to receive.

- Think about changes you may experience
- Think about whether others need to care for you
- What type of care would you want?
- What do you value that would influence your care?
- Discuss this with others

Your health care professional will want more detailed information, but this is for you to begin thinking about now.

Who speaks for me (when I can’t)?

Guide: Choose one person or more than one person who will talk for you to your family, friends, and health care professionals.

- Write below their name or names, and their phone numbers, so others will know
- Tell them what you want shared with others
- Tell them what you want them to tell the doctors and nurses and other health providers
- Let this person or persons know when they are to speak for you
- Information on personal directives, or living wills, can be found in the Resources section in this folder

Guide: Write what will give you hope today. Identifying hope is a positive exercise you can do every day.

- Think of what will give you hope today
- Think of one big or small thing you would like to finish today (this may be something like choosing a song you want to listen to)

You may also wish to view the *Living with Hope* video by going to http://www.nurs.ualberta.ca/livingwithhope/ and clicking on “view online” to view the film online.

Section 2: Common Changes to Expect

This section is **information** about what you might experience. People receiving palliative care and their families said they had changes in their lives. You may or may not have these changes.

- Environment – Home & Hospital
- Roles/Relationships – Caregivers & Family
- Daily Activities – Everyday Tasks
- Physical and Mental Health – Illness Effects

Please contact your professional health care provider for more information about your specific situation.

What are possible environmental changes?

Changes in the environment include changes in the home environment during illness and changes of location from home to hospital and long-term care.

What types of environmental changes are there?

- Moving to a new city or town
- Changing the home environment to be suitable for your comfort
- Visitors – visits from friends, family, nurses, etc. affecting the household.
- Confinement to the home
- Home to hospital or professional care – moving from home to the hospital or to a professional care giving setting
- Moving in – with a family member or friend (or having someone move in with you) to provide needed care and support

Examples from others who have experienced environmental changes:

> *"She [my wife] was an outdoor person so naturally it was a big change but she did accept it and of course her condition was making her realize that she…couldn't be outdoors."*

> *"Her [my wife's] condition was changing so rapidly…But she was able to remain at home for as long as possible…um…She probably should have been in the hospital a lot sooner than she was…but that was her decision…she could remain at home for as long as possible."*

What does it mean to have physical and mental health changes?

Changes in physical and mental health can occur during the illness. This can include symptoms of the illness or side effects from medications.

What types of physical and mental health changes are there?

- Pain
- Fatigue
- Nausea
- Loss of weight and/or appetite
- Feeling confused, dealing with memory trouble, or reactions to medications
- Bloating, swelling
- Incontinence, constipation
- Seeing, speaking, hearing, thinking, eating, and mobility difficulties
- Anxiety, sadness, and fear
- Changes in hope

Examples from others who have experienced physical and mental health changes:

> *"And I think like the rapid change in her [my wife's] condition, the weight loss, the jaundice, the diabetes, um, her incontinence, you know…that really…I, I think that really bothered her…"*

> *"Oh yeah, that changes, that's definite because you don't do very much. You aren't strong enough. Nope. You aren't very strong."*

What are possible changes in activities of daily living?

Changes in activities of daily living can happen. They include changes in chores, eating habits, diet, career, etc. This can include anything that affects or alters the way you are used to living.

What types of changes occur in the activities of daily living?

- Needing more help from others
- Appetite and enjoyment of food
- Career – ability to work
- Stopping work or volunteering activities
- Sleeping difficulties
- Hobbies, leisure activities

Examples from others who have experienced these changes:

> *"I can't hardly peel a cucumber. I can hardly wash the dishes once in a while. My husband does it most of the time."*
>
> *"Um…the things I miss most are working in the yard, I love working in the yard. Looking after a garden. Keeping my home as clean as possible. Doing all my work that I should do. I miss cooking, I love to cook. I miss it…"*

What are possible changes in relationships and/or roles?

Changes in roles and relationships often happen as the illness progresses and you may need more help with activities of daily living.

What types of changes occur in the relationships/roles?

- Feelings of being alone
- Changes in who does the chores and caregiving
- Relationship bonds may grow stronger (or sometimes be weakened) as a result of illness
- Loss of job – losing relationships with co-workers or jobs

Examples from others who have experienced these changes:

> *"I really just felt like a nurse myself...That, that was how I felt. I mean, I used to work as a nurse's aide in a nursing home...and I do have some...you know, knowledge...of that kind of thing...But all of a sudden the relationship of husband/wife was gone and it was nurse and patient for me...That was our, a big change."*
>
> *"Our family got a little bit closer, they cared for me more..."*
>
> *"You are always used to helping out, and now they've got to help you."*

Section 3: Contacts

This section helps you to create a personal contact list. Lists of phone numbers for organizations you may wish to contact are included in the folder.

Guide: Write contact information of people you may wish to contact during your changes. These can include community resources. For example: Family doctor, nurse practitioner, home care nurse, financial advisor, lawyer, community center, spiritual support, grocer who will deliver food, pharmacist, friends and family.

Name	**Contact information**
Family Doctor:	
Nurse Practitioner:	
Home Care Provider:	
Pharmacist:	
Spiritual Support:	

Name	Contact information

Name	Contact information

Section 4: Calendar

This section contains a calendar to help you manage your appointments.

Month:

Sunday	**Monday**	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Notes:**

Month:

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Notes:

Section 5: Frequently Asked Questions

Persons receiving palliative care and their family members have asked questions about the changes they experienced. In this section the most common questions are listed with answers from a national group of experts on palliative and end of life care. We hope these are helpful to you.

You will have many other questions that are not listed here. For any questions contact whoever locally knows you best or contact your palliative care provider. It is important that you always ask questions to get the information you need. Information may help you make decisions as you experience changes. The resources included in this folder may also help you find the best place for answers.

1. What is palliative care?

   Hospice palliative care is whole-person health care that aims to relieve suffering and improve the quality of living and dying. The services offered in palliative care programs differ depending upon where you are.

2. What services does palliative care provide?

   Hospice palliative care strives to help patients and families:

   - address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
   - prepare for and manage self-determined life closure and the dying process
   - cope with loss and grief during the illness and bereavement.

3. What is respite care?

   Respite care is a break, a chance to do something for yourself, to get away from the demands placed on you. There are many forms of respite care: Family or friends can give you a hand, or you may be able to find a volunteer through your local place of worship or community centre. In-home respite programs bring trained individuals into your home to provide care. Depending on the program, the worker may provide companionship, assistance with personal care (bathing, dressing), help with housework, etc. Some long-term care facilities have respite beds.

To find where and how you can get respite, contact your visiting home care nurse or your doctor to get more information.

4. <u>If a service I require is not available, how do I access this service?</u>

   Call your local palliative care provider.

5. <u>How do I find information about disease and the symptoms I should expect?</u>

   Contact your family doctor or visiting home care nurse about getting information and ask first for their suggestions to how you can get information.

6. <u>Is there a list of contact names and numbers of people who may be of help to me?</u>

   There are some contact names and numbers listed in the folder.

7. Are there books or internet resources available that would be of help to me?

   There are some books and websites which may be of help in the folder.

8. If I have any questions about my treatment plan who can I call?

   You should call your family doctor if you have questions about treatment. Your doctor will be able to tell you what is best or who to consult.

9. If I need to talk to a doctor or any other health care professional, what should I do?

   If reaching your doctor is difficult, call your visiting home care nurse for assistance.

10. How do I find information on medications?

    You should consult locally with the pharmacist first. Pharmacies have information packages for each medication. See the Resources included in this folder for websites offering drug information.

11. How do I obtain copies of tests or procedures I have had?

You have the right to ask for your records and test results. Before each test ask the person doing the test or procedures for a copy. If you forget, your oncologist or family doctor will have a copy.

12. What appointments or tests should I expect?

The primary goal of appointments and tests is to make sure you are comfortable. Tests are ordered in response to a new symptom you may have, or a change in your condition. Sometimes it is to monitor or prevent a problem. It’s natural to wonder what is coming around the corner and care will be changing now. When tests are ordered it is important to ask: “Do I have a new problem?” “What are my health care goals and will that test help me meet those goals?” Contact your local palliative care provider for more information.

13. Is counselling available?

Your visiting home care nurse will be able to help you with this information. If it is not available to you through home care then you may be able to pay for it privately if it is available in your community. Call your local palliative care provider.

14. Are there support groups available?

Your visiting home care nurse can help you with this question, and there will be information through your health region. Call your local palliative care provider.

15. Can I still make choices/decisions best suited for me?

Yes: It is very important that you still make choices and decisions that are best for you. You may wish to involve family, close friends and advisors in your decision-making process. Your doctor, nurse and other healthcare providers will also assist you as required.

Questions family and friends may have

1. Is there someone to help care for my family member at home, or do I have to do it all alone?

   Your visiting home care nurse can help you with this question. Usually there is someone on the healthcare team available to help, but asking friends and family is a good idea too.

2. If I do not know how to do something for my family member, is there anyone available to teach me and show me?

   Your visiting home care nurse is available to teach and show you how to care for your family member. There are resources for caregivers included in the folder.

3. What do I do if I cannot control my family member's pain or any other symptoms?

   Call your palliative home care nurse or family doctor right away. Do not wait for symptoms to become severe.

4. Why does my family member have no appetite and not like the food he/she once used to?

   Often people with serious illness have no appetite for many different reasons. For example the disease and the medications change what we like or don’t like. Contact your palliative care provider to get more information specific to your family member.

5. Is there someone to help me communicate with my family member through this process?

   Communication can be difficult at times. The most important thing is to keep trying. Contact your palliative care provider for more help.

6. Who do I contact if I need support for myself as I care for my family member?

   There may be many sources of personal and professional support available in your circle of family and friends and in your local community. Contact your palliative care provider to discuss your needs and concerns.

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Resources

These resources contain information about organizations, websites, books, and other things that may help you every day.

Use resources as you wish. Feel free to make copies.

Websites

Alzheimer Society
http://www.alzheimer.ca

The Alzheimer Society of Canada identifies, develops and facilitates national priorities that enable its members to effectively alleviate the personal and social consequences of Alzheimer's and related diseases, promotes research and leads the search for a cure. On this website you will find facts, causes, myths, statistics, support groups and treatment options.

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

The Canadian Cancer Society is a national, community based organization of volunteers, whose mission is the eradication of cancer and the enhancement of the quality of life of people living with cancer. On their website you will find information regarding cancer and programs and services. They have a toll free number that you can use to talk with an expert and get specific information on your type of cancer. Toll free number: 1-888-939-3333.

Canadian Hospice and Palliative Care Association
http://www.chpca.net/

The Canadian Hospice Palliative Care Association (CHPCA) offers leadership in the pursuit of excellence in care for persons approaching death so that the burdens of suffering, loneliness and grief are lessened. You will find a list of palliative care programs in different provinces and resources.

Caregiver Network
http://www.caregiver.ca

The goal of the Caregiver Network is to be a national single information source to make life as a caregiver easier. You will find information and resources for caregiving and chat rooms to talk with other caregivers

Colorectal Cancer Association of Canada
http://www.colorectal-cancer.ca/

The Colorectal Cancer Association of Canada (CCAC) is dedicated to increasing awareness of colorectal cancer, supporting patients, and advocating for population-based screening and timely access to effective treatments. Here you will find facts, risk factors and symptoms, treatment options, latest research, and support groups.

Family Caregiver
http://www.thefamilycaregiver.com/

The Family Caregiver website contains province-specific resources, as well as easy-to-read articles on topics of interest. It is designed by caregivers to help other caregivers on a wide range of topics including taking care of your family member as well as yourself.

Google Maps
http://maps.google.com/

Use Google maps to find directions to doctors' offices, pharmacies, and other places you need to know. It's helpful to include the name of the town/city, as well as the name of the specific place you want to go to.

Health Canada: Drug Products
http://www.hc-sc.gc.ca

The Drug Products site at Health Canada provides information on drugs approved for use in Canada. Go to the Health Canada website (use link above). Click on: (1) English, (2) Drugs and Health Products (on the left side), (3) Drug Products, (4) Drug Product Database, (5) Access the Drug Product Database.

Health Canada: Natural Health Products
http://www.hc-sc.gc.ca

The Natural Health Products site at Health Canada provides information on "herbal" or other natural products. Go to the Health Canada website (use link above). Click on: (1) English, (2) Drugs and Health Products (on the left side), (3) Natural Health Products, (4) Licensed Natural Health Products Database.

Heart and Stroke Foundation
http://www.heartandstroke.ca

The Heart and Stroke Foundation, a volunteer-based health charity, leads in eliminating heart disease and stroke and reducing their impact through the advancement of research and its application, the promotion of healthy living, and advocacy. On this website you will find health information about heart disease, stroke and healthy living, as well as multicultural resources.

Lung Association
http://www.lung.ca

The Lung Association works at the national, provincial and community levels to improve and promote lung health. They focus on chronic lung disease like asthma and COPD, infectious diseases like TB, flu, and pneumonia, and breathing disorders like sleep apnea. They provide reliable and trusted information to both citizens and governments, and advocate for improvements when lung disease patients are getting inadequate care.

Lung Cancer Canada
http://www.lungcancercanada.ca/

Lung Cancer Canada is the only charity whose sole mission is to raise awareness, provide patient focused information and offer peer support to everyone touched by lung cancer. On this website you will find a resource information center where you will find answers to your questions about lung cancer.

Medline Plus (U.S.)
http://www.nlm.nih.gov/medlineplus/

Medline Plus contains information on a wide range of diseases, medications, and other health topics. Some information is available in multiple languages or in multiple formats (e.g. text, video, and interactive tutorial).

National Cancer Institute (U.S.)
http://www.cancer.gov/

The National Cancer Institute provides a wide range of information on cancer, provided in various formats such as printable fact sheets and videos. Click on "Cancer Topics" near the top of the page for information on specific types of cancer, treatment options, help for living with cancer, and more.

Speak Up
http://www.advancecareplanning.ca/

The Canadian Hospice Palliative Care Association runs this website to help people to "Start a conversation about end-of-life care." It contains information about advance care planning, living wills, and how to talk about these topics with people close to you.

Virtual Hospice
http://www.virtualhospice.ca

The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers and educators. You will be able to access information on symptoms and how to manage them, as well as other resources. There is a section for patients and another for family caregivers.

Brochures

Caring Connections Brochures from the National Hospice and Palliative Care Organization (US). These three brochures are available from http://www.caringinfo.org/

- Artificial Nutrition (Food) and Hydration (Fluids) at the End of Life
- Managing Your Pain
- Using Narcotics Safely

There are many other brochures and information sheets that may be of help to you. Ask your health care provider for recommendations.

Video

Living with Hope

You can view the Living with Hope video by going to http://www.nurs.ualberta.ca/livingwithhope/ and clicking on "view online" then clicking the "play" arrow to view the film online.

Books

The three books below are available from CHPCA (www.chpca.net) and are free of charge to caregivers. To order, call 1-800-668-2785, ext 221.

- **A Caregivers Guide: A Handbook about End-of-Life Care**
  This guide helps caregivers understand the journey

their loved ones are on, to be effective members of the palliative care team, and to provide physical, spiritual and emotional support. (174 pages. Item #0632E.)

- **Living Lessons - A Guide for Caregivers**
  This guide will help family caregivers with the tools they need to care for their dying loved one. (62 pages. Item # 0603(1)E.)
- **Influencing Change: A Patient and Caregiver Advocacy Guide**
  This guide helps Canadians dealing with end-of-life health care issues. It explains clearly how the health care system works, and offers advice on what kinds of questions to ask. (Booklet. Item # 0712(1)E.)

There are many other books that may be of help to you. Ask your health care provider for recommendations.

Alberta Contacts

Guide: This is a list of important contacts in Alberta.

Name	Contact information
The Support Network: 24 hour support lines	
Community Services (information and referrals)	211
Distress Line	780-482-HELP (4357)
Health Link	
Edmonton	780-408-LINK (5465)
Elsewhere in Alberta	1-866-408-LINK
24 hour support numbers	
Alberta Mental Health - Help Line	1-877-303-2642
Salvation Army - Adult Crisis Line	780-429-0230
Edmonton Bereavement Center	780-454-1231
Alberta Health Services: Seniors Health	
Community Care Access	780-496-1300
Alberta Caregiver College - Support for Caregivers of Older Adults	www.caregivercollege.org/scoa/
Alberta Hospice Palliative Care Association	403-206-9938
Alberta Caregivers Association	1-877-453-5088 www.albertacaregivers.org

Canada Contacts

Guide: This is a list of important contacts in Canada.

Name	**Contact information**
National Support Programs:	
Disability Benefits – Canada Pension Plan (CPP)	1-800-277-9914
Survivor Benefits – Canada Pension Plan (CPP)	1-800-277-9914
Income Tax	1-800-959-8281
Employment Insurance – Special Benefits	1-800-206-7218
Veterans Affairs Canada (VAC)	1-866-522-2111
Community Supports:	
The Kinsmen Foundation	1-877-777-8979
Canadian Cancer Society	1-877-977-4673
Amyotrophic Lateral Sclerosis Society of Canada	1-800-267-4257
Multiple Sclerosis Society of Canada	1-800-268-7582
Kidney Foundation of Canada	1-800-461-9063
Canadian Paraplegic Association (CPA)	1-613-723-1913
Canadian Hospice Palliative Care Association	1-800-668-2785
Virtual Hospice	www.virtualhospice.ca

My Important Health Information

The purpose of this record is to have important documents in a place that you can grab quickly and take with you if you need to see a doctor or go to the hospital. If you want you can include your information in this plastic folder. The following are suggestions that you may wish to include:

- a short summary of your medical history
- an updated list of your medications
- a copy of your most recent test results
- a copy of your Advance Directive (Living Will) and a list of who also has a copy
- a list of doctors, nurse practitioners, home care nurses and other healthcare or community professionals who are caring for you
- answers to questions that you are frequently asked by health care providers. We have provided a guide for you to use for this called “They keep asking me....”

“They keep asking me...”

Guide: Write down the questions that health care providers often ask you, along with the answers. If you wish, you may show these pages to each new provider you meet.

You might include questions like: What care services are you currently receiving? Do you have a personal directive (living will) or health care proxy?

Question:

Answer:

Question:

Answer:

Question:

Answer:

Question:

Answer:

Question:

Answer: