

***Being diagnosed with a terminal illness will have a significant psychological and social impact on you and your loved ones. It will be important for you to consider these issues as you are developing strategies to assist you.***

***It is important to get emotional, social and spiritual support as you progress in your illness. It is also imperative that you consider the financial and support issues you may need as your illness progresses. This pamphlet is intended to give you information and guidance on what to expect and some tools to assist you to cope with the future.***

***Just as a palliative care should be introduced at the beginning of a life-threatening diagnosis, financial discussions should also begin early in the treatment process. This will ease the burden for the family and you down the road.***

During our working lives we spend time saving and dreaming of retirement. After we retire, we may start thinking about our estate and how to provide for our loved ones after we are gone.

**One thing we do not do, is plan for our care when we will be needing care.**

If you have been diagnosed with a terminal illness, the last thing you want to think about is your last months leading up to your dying time. While you are feeling well, however, this is the best time to start planning how you want to be cared for during your last months.

**We hope that this booklet will help you with that planning process.**

## **Path of terminal illness**

Regardless of diagnosis, there is a predictable course of increasing care needs as time passes when you have a terminal illness. Generally speaking people with terminal illness become more frail with time. As they become more frail, they need more help with day to day activities.

Interventions such as chemotherapy or treatment of reversible illness can slow down the process of frailty, but still, we can anticipate as treatments go on, people inevitably become more frail. We measure people's performance with time and this gives us a good indication of what they need for care. We term this '**Palliative Performance Status (PPS)**' in the medical world, but for better understanding we'll call it **Battery Power**

<b>PPS (Battery Power)</b>	<b>Performance</b>	<b>Care needs</b>	<b>Prognosis</b>
<b>100%</b>	Normal functioning, at work full time, normal energy	None	Months-years
<b>90%</b>	Working full time but less energy	None	Months-years
<b>80%</b>	Working part time and less energy, energy to do heavy chores	None	Months-years
<b>70%</b>	Not working but can do most chores	Heavy chores such as wood splitting, house maintenance	Month-years
<b>60%</b>	Can still do light housework, cooking	Grocery shopping, laundry, banking, gardening	Months-year
<b>50%</b>	Can not do any housework but can mobilize and dress independently. Not leaving the home much	Preparing food, all house cleaning, laundry, help with showering	Weeks-months
<b>40%</b>	Cannot mobilize independently, not leaving home	24 hour care help with medications	Weeks to months
<b>30%</b>	Bedbound but eating and drinking small amounts	24 hour care help with medications	2-4 weeks
<b>20%</b>	Not eating and drinking but still awake	24 hour care medications administered by others	1-2 weeks
<b>10%</b>	Unable to wake up	24 hour care medications administered by others	1-7 days

## **The Current Reality**

Currently, the public healthcare system cannot provide 24 hour care at home. Depending on where you live and your access to resources, you may be able to access 1-4 hours of public funded health care when your BATTERY POWER is 40% but this depends on current resources.

Once people are at a Battery Power of 30-40% they may be candidates for residential care or hospice placement, however, not all communities have residential care or hospices. The default for those who have care needs that cannot be provided for at home is to move them to hospital for their dying time.

Many people rely on family members or friends for support. If only 1 or 2 family members are caring for a person for 24 hours a day for a month or two - this can cause the caregivers to burn out and then be unable to care properly for their loved one. This places a great burden of guilt on family. Canadian studies show that 70-90% of personal end of life care is provided by family members.

For those who want to stay at home and be cared for in their own home, it is possible; however, it takes planning and open conversation between family members. Will your family member be able to dress you, bathe you and toilet you? Will your family member be capable of giving medications - including injectable medications at end of life to keep you comfortable? Will your family member be capable of providing care day and night without a break?

So how does one find others to help care for them? What is the cost? Let's take each performance status and discuss.

## **Battery Power 70-80%**

At this point you may not have the energy to work, but you still have energy to do mostly everything. This is a great time to start planning! Don't wait until you don't have the energy to do all the work. Now is the time to take stock of your financial resources and predict costs. If you have cancer, the rate of decline is generally much more predictable than if you have COPD, heart failure, liver failure, dementia or other illnesses. With these illnesses, some people will stabilize at a Battery Power of 40-50% for many months (sometimes years!). In this case, these individuals are much better considering a complex care home if they don't have family who can support those care needs for that period of time.

For those with cancer, the rate of decline can slow or even stabilize for a period of time with chemotherapy. Planning still has to occur as sometimes when chemotherapy stops working the disease can progress very rapidly and not give time for preparation.

### **Explore your supports:**

Who in your friends and family are willing to commit to the following?

- 1) Driving you to appointments as necessary
- 2) Helping you with groceries
- 3) Helping you with gardening/snow removal
- 4) Helping you with maintenance and chores
- 5) Helping you with caring for another family member who needs care?

### **Plan for future care:**

If you think that you will need 24 hour care for up to 2 months (sometimes a lot less, sometimes more) you can predict the cost:

Private care through a private nursing company \$40-80/hour (lower rates for support workers and higher rates for licensed nurses) = \$60,000 - \$100,000 for 2 months of 24 hour care. Costs are tax deductible.

Hiring your own workers (CSW/LPN) at \$30-40/hr = \$43,000 - \$60,000 for two months of 24 hour care. If you do this, you have to set yourself up as an employer, have a Business Number with Revenue Canada and formally hire people to provide care. This includes providing wages and submitting payroll to Revenue Canada. The wages are tax deductible.

Often people will have family caregivers for 8-12 hour a day so hiring someone for 4- 8 hours a day to support family caregivers can run \$7,000 - \$40,000 for two months.

#### Compassionate EI benefits

Once you require care, a family member may want to provide that care for you. If that family member is working and qualifies for Employment Insurance benefits, they can apply for Compassionate EI benefits for up to 6 months of coverage. This will start at the time you need care. It can also be shared amongst family members.

EI only covers 55% of a person's earnings so often family cannot afford this pay reduction, however, you could consider topping this up to their regular pay rate. This may be less money than hiring private nursing care.

Some family members may have access to paid personal leave which would allow them to help care for you. You would want them to save this time for when you need care, not when you are relatively well.

### **Financial Resources**

***Ensuring that your finances are in order is a gift you can leave your loved ones. In today's world creating a list of your passwords for***

***Internet and social accounts and giving them to trusted loved ones will provide some assistance to them when you cannot.***

The following are suggestions about possible resources which may be available to you. You may require a financial consultant or lawyer to explore these options in depth.

### **CPP Disability**

If you have a terminal illness, you can apply for terminal illness CPP. This is a resource available to you if you have paid into CPP benefits. The wait is much shorter than applying for regular CPP.

### **Unemployment Insurance**

If you are unable to work due to terminal illness and you qualify for EI, you can apply for EI through Service Canada.

### **Long term disability**

If you have long term disability with your employer, now is the time to apply for this.

### **Extended Health Benefits**

If you have extended health benefits through your employer or through your pension, you may qualify for money to cover nursing care and equipment. Call your provider to see if nursing care is covered and how much. You should have the required forms sent to you so you can have them available when you are closer to requiring nursing care.

### **Veteran's Affairs**

If you are a Veteran, you may qualify for extended medical benefits. Now is the time to inquire as to whether this will cover nursing care and how much. Have them send you all the required forms so you have the resources on hand when you are closer to requiring care.

### **Life Insurance**

Many Life Insurance companies are willing to give you an advance on your life insurance if you have a terminal illness. You can use this

money to pay for nursing care when you need it. Call your life insurance providers. Check to see if you have life insurance connected to your mortgage or credit cards as well.

### **Critical Illness Insurance**

Many people have Critical Illness Insurance. Now would be the time to apply for the money, once you are diagnosed with a terminal illness.

### **Long-term Care Insurance**

If you have paid into this insurance policy, contact your provider to see if you qualify for nursing care at home in the case of terminal illness.

### **Line of Credit**

Many people have a significant asset in their home. You can talk to your financial advisor or banker. Many banks will give you a line of credit based on the amount of equity you have in your home. This money is available to you when you need it. **You pay interest only on the money that you use.** If you don't use any money from it, there is generally no charge.

Once you start using your line of credit, you are required to pay the interest on the amount owing. Interest payments are often achievable, even on reduced income. After death, the money you used in the line of credit can be paid off by your estate. If you have another person living in your home and the estate doesn't have the money to pay off the line of credit, the home can be mortgaged again to absorb the line of credit. Make sure that anyone who will be living in the home after your death has their name on the Title - or that your Will is clear about the disposition of the home after your death.

### **Deferring ongoing payments**

Look into whether you qualify to have your property tax deferred. You can also see if your bank or credit card companies can lower payments or temporarily freeze payments.



## **RRSP /RRIF**

There is never a penalty for accessing your RRSP or RRIF at any age - you can withdraw it at any time but it is regarded as taxable income. When you file your tax return you withdrew from your RRSP, all your income is added and the actual amount of tax owing is calculated. Remember that private nursing care, medical equipment and medications are tax deductible, so that the tax liability for paying for care may be quite low. This can be said about withdrawing RRSP monies to pay for medical costs for a spouse or dependent.

## **Pharmacare Deductible**

Every year, you must pay for your prescription medications until you reach your deductible, if you do not have third party medical insurance. Your deductible is calculated based on your last tax return.

Sometimes this is a big financial burden if you have expensive medications and you're not working. If you call Pharmacare and explain that your income has been reduced significantly, then they may reduce your deductible based on your estimated income.

Many drugs that are designed to prevent illness are very expensive, such as blood pressure medications or cholesterol medications. Ask your doctor if these medications are necessary for your care if you are suffering from a terminal illness.

## **Palliative Benefits**

This is a benefit program for people with terminal illness in their **last 6 months of life**. It will cover many medications used for pain and symptom control in people with terminal illness. Many expensive medications used for treatment of epilepsy and COPD and other diseases are not covered by this benefit program. Coverage of other medications not covered by palliative benefits is dependent on the Fair Pharmacare program.

## **Advanced Care Planning**

Who are the people that know you best? Who do you trust with finances? Who do you trust to make healthcare decisions *on your behalf, that you would want?*

Now is the time to make sure you have:

- 1) A current Will
- 2) Make sure that titles of property, ownership of vehicles, recreational property and vehicles and bank accounts are in joint names (unless you want these distributed in your Will. Joint ownership will prevent delay in someone accessing these assets. Otherwise they will have to wait until the Will is probated which can take up to a year)
- 3) Enduring POA - this allows someone to do your financials on your behalf (you don't have to be mentally incapacitated for someone to act on your behalf with an Enduring Power of Attorney)
- 4) Health Representation Agreement - naming 1 or 2 individuals who understand your goals and beliefs and can make health decisions on your behalf based on what you would want (not what they would want).
- 5) Make a list of your accounts and passwords and keep with your Will for the executor of your estate, or give to your POA.

## **Planning for child guardianship**

In today's world, our families are often very complex. Many blended families exist with parents caring for their own biological children, or their spouse's children by another marriage. If you have under aged children, ***it is essential that you have a legal document which outlines guardianship when you die.*** It is essential that this is done as soon as possible. Children should understand who will care for them when you die.

If you die and you have a blended family, the biological mother/father of your child/children will have custody of them - regardless of their appropriateness as a parent. If your children do not have a biological or

legally adoptive parent, then they may become Crown Wards and the Ministry of Family and Children will have to be involved in placing your child/children. This is extremely traumatic for the child. Grandparents or siblings have been burdened with long court battles for custody of children.

### **Planning your notification of death**

Many people take the time to create a summary of their family, careers, hobbies and other important things in their lives. This greatly helps those who will be writing your obituary.

Who will take responsibility for notifying government agencies, employers, family and friends of your death? Make this an easy task by creating a list of people to contact with their contact information.

Who will send notification of your death to your email contacts? Google and Facebook have tools which allow you to plan for this. Facebook has rolled out “legacy contact”. You can choose a Facebook friend as a “legacy contact” who will have the ability to create a memorial post and pin it indefinitely to the top of your timeline. Other options allow you to totally delete your account upon notification of your death.

Google has an “Inactive Account Manager tool” which you set an amount of time (3,6,9,12 months) and one month before that deadline if your account has been inactive, you will receive an alert. If at the end of the time you have set you have not re-entered your account, Google will notify your ‘trusted contacts’ you have given and you can share your data with them. Google can also delete your account (and all other accounts associated with it) if you choose that option.

### **No CPR order**

If you have a terminal illness and your heart stops, this is a life-ending event. An attempt at CPR will not reverse dying, but can cause a great deal of suffering, both for the patient and the family. It is important

to have a 'No CPR' order in your home, available to healthcare professionals, such as ambulance attendants.

## **Medical Orders for Scope of Treatment**

The Medical Order for Scope of Treatment (MOST) is a medical order signed by a doctor which outlines your wishes. In some jurisdictions it is called a POST or physician order for scope of treatment. It is a record of a conversation you, or your decision maker, have had with your physician. The physician then documents the best level of intervention based on that conversation. You change this level of intervention depending on where you are in your disease process. You need to talk to your doctor when you want this change.

The MOST describes what kind of medical care you want, given your current medical state. It describes interventions you want or don't want. It gives doctors direction of what to do if you can't speak for yourself.

**MOST M1** - Supportive care, symptom management and comfort measures only.

Care is for physical, psychological and spiritual preparation for an expected or imminent death. Do not transfer to higher level of care unless to address comfort measures that cannot be met in current location. Allow for natural death.

**MOST M2** - Medical treatment within current location of care, excluding critical care intervention, SPR and intubation. Transfer to higher level of care if patient's medical treatment needs cannot be met in a current location. Goals of care and interventions are for cure or control of symptoms of illness. No critical care interventions.

**MOST M3** - Medical treatments including transfer to higher level of care, excluding critical care interventions, CPR and intubation.

Medical treatments are for cure or control of symptoms of illness. Transfer to a higher level of care may occur if required for diagnostics and treatment.

**C0** - Critical care interventions excluding CPR and intubation.

Patient is expected to benefit from and is accepting of any appropriate investigations and interventions that can be offered excluding CPR and intubation.

**C1** - Same as C0 but with intubation and ventilator

**C2** - Same as C0 but with intubation, ventilator and CPR

Most patients with a terminal illness opt for M3 if they are undergoing life prolonging treatments, such as chemotherapy, dialysis, surgery, total parenteral nutrition and other interventions

Most patients with a terminal illness opt for M2 if they want antibiotics or fluids or transfusions or surgery or radiation for symptom control only.

Patients who do not want any life prolonging interventions opt for M1.

## **Battery Power of 60%**

At this point you may require help with grocery shopping, gardening and heavier chores. If you don't have the family and friends who can offer help with these, you can see if your community has a volunteer service which can provide for this.

Call your local senior's program and see what resources may be available in your community. Even if you are not a senior, you may be able to access the resources if you have a terminal illness.

### **Explore your supports:**

Who in your friends and family are willing to commit to the following?

- 1) Laundry
- 2) Cooking meals
- 3) Household chores
- 4) Groceries
- 5) Banking
- 6) Checking up on you daily

If you don't have these supports, you may hire someone in your community to help you at this time. Try finding a housekeeper who may help you with meals as well.

It is important to have someone who has your Enduring Power of Attorney. This allows your representative to do your financial work - banking, paying bills, etc on your behalf. It does NOT give them the ability to make healthcare decisions for you.

Now is that time to complete any paperwork in anticipation for requiring nursing care, such as extended health benefits.

## **Battery Power 50%**

Now is the time to access those resources for nursing care. At this point you are needing help with simple things - showering, dressing, food preparation. In 2-4 weeks you may be not able to be independently mobile and need help with all personal care. This is a time to prepare for the next stage.

### **Explore your supports:**

Who in your friends and family are willing to commit to the following?

- 1) Personal care, toileting and hygiene
- 2) Available 24 hours a day
- 3) Available to help with medications

Now is the time to start planning to have nursing care in place. If you have no money for private nursing care, you must connect with your family doctor or palliative care team to arrange for public care to help support your caregivers in providing care for you. If you live alone, you need to connect with your family doctor and palliative care team about planning a move to a facility which would provide 24 hour nursing care.

If you have finances available for private nursing care, now is the time to arrange for that care to be in place and available when you are unable to care for yourself.

## **Funeral Arrangements**

If you have not done so already, this is a good time to arrange how your body will be treated after you die. This is a time to explore different funeral homes and the services they offer. Most offer services from collection of the body, embalming, viewing, cremation and burial, services and receptions. There are a myriad of options for all the above

and the cost varies significantly with the services provided. Exploring these options now, instead of leaving the decisions to family, is very helpful.

### **Medical Assistance in Dying (MAiD)**

Medical Assistance in Dying is a program that is offered in Canada. This is euthanasia for persons who feel that their terminal disease is causing irremediable suffering. Patients who feel they want to access euthanasia must complete a patient assessment form (available on the internet from your province). Completion of this form must be done in the presence of 2 adult witnesses who are not related to you, beneficiaries of your estate, caregivers, care providers or administrators of residential care homes. You can withdraw your request at any time. There is currently no expiry date from the time you complete your patient request form.

After you complete the form, you must have a physician fill out a physician assessment form. After this, your physician must refer you to another physician for a second opinion, and often this physician is the one to provide euthanasia at a mutually convenient time.

### **Battery Power 40%**

At this time you will be unable to mobilize without assistance and be dependent on others for assistance 24 hours a day. This is a period of time where your caregivers need maximum support to prevent burnout. If you have access to private nursing care, usually 4 hours 2-3 times a week is needed to help family cope with the increased care.

### **Explore your supports:**

Who in your friends and family are willing to commit to the following?

- 1) Bed care



## 2) Medication administration - sometimes injectable medications

In 2-4 weeks you may be completely bed bound where you will require bedcare.

Sometimes the unexpected happens. When you are quite frail, you are at high risk to die at any time from a fall or infection or complication of your disease. It is important to have an **Expected Death In The Home (EDITH) form**. In the case that you do die at home, this form allows your caregiver to call your funeral home to collect you. There is no need to involve ambulance services, coroner or police. Ask your physician or palliative team about having this form on hand.

## **Battery Power 30%**

At this time you do not have the energy to get up out of bed and you are spending most of your time sleeping. You require complete bedcare, toileting in bed and may have a catheter in the bladder to drain urine so you don't have to use a commode. You may have to wear an adult diaper and all bowel care is done in bed. You are still able to eat small amounts and swallow medications.

This is a challenging time for caregivers and if you have capacity for private care, hiring care for 4-8 hours a day allows your caregivers respite and helps them to continue to support your care at home.

If you have no caregivers, you can use private care but will require 24 hour, around-the-clock care at this time.

If you can't afford private care, you will have to move into a facility that can provide 24 hour care. If there is no hospice facility, often this will mean moving into hospital.

## **Battery Power 20%**

At this time you are spending most of your time asleep and don't have the energy to swallow food or fluids. Your time spent at this stage is only 1-2 weeks. You will require 24 hour care as above, however, your caregivers may be required, with the support of your palliative home care team, to give you your medications by injection. We do this by placing a 'butterfly cannula' - a plastic line under the skin and administer medications with syringes we attach to the line.

Medications are often given every 4 hours around the clock. This is a time where 8 hours of additional care to allow your caregivers time to rest is very important.

## **Battery Power 10%**

At this time you are unable to wake up at all. Your time spent at this stage is only days before you die. You will need the same care as above but preparations for your passing now being done.

You will need total care and unable to direct your care. If you have requested MAiD, you cannot give consent for this to be done, unless you have already booked a time for MAiD and signed a Waiver of Consent form, then your substitute decision maker gives the 'go ahead' for the procedure to be done.