



**MITOLINKS**  
**The Adult Metabolic Diseases Clinic**  
**Mitochondrial Disease**  
**Support Group Newsletter**

**‘Preparing for Death: A Guide for Patients, Family and Friends’**

Preparing for your own or a loved one’s death is not easy. Feeling overwhelmed, frightened or emotionally drained is common. Family members may be reluctant to bring up the subject and patients may have difficulty expressing their wishes. Either scenario results in putting off important and necessary decisions.

For everyone, preparing for the inevitable day ensures that you have a say in what will happen as your health status changes.

**How to Begin?**

You may have been told to ‘get your affairs in order’. What does this mean? For some patients this may be a way of indicating their death is imminent, (although it is very hard to predict when death will occur). For most patients, ‘getting your affairs in order’ reflects a general statement that, as with all of us, it is time to think about what your wishes are and spend some time seeing to the legal documents that put those wishes into place.



**Make it Legal – Wills and Estate Planning**

***If you have not already done so, drafting a will is a good place to start***

A will is a document which states what you want done with the assets that you own when you die. These assets typically consist of real estate, money, investments, and personal or household belongings that you own. You can change your will at any time and it has no legal effect until you die.

### ***A will doesn't deal with certain assets***

A joint bank account or house owned jointly with a partner will be owned by the joint survivor.

### ***Name a person or company to be the "executor"***

The executor is responsible for:

- Safeguarding the estate
- Gathering up your assets
- Paying your debts (including income taxes)
- Dividing what remains of your estate among the beneficiaries (the people named in your will to receive a share of your estate)



### ***If you have minor children, appoint a guardian in your will***

Deciding who will care for your children after your death can be a difficult decision. Deciding who will care for your children, who may also have mitochondrial disease, can be heartbreaking.

The very sad reality, for many patients with mitochondrial disease, is that multiple family members may be affected. For many parents choosing a family member as guardian may not be possible. In addition, families who have always cared for a child with mitochondrial disease at home may, as their own health deteriorates, need to consider placement of their child in a group home or other managed care arrangement.

If you are a parent (guardian) of minor children, the new **Family Law Act** (which came into effect in March, 2013) allows you to appoint someone else to be the child's guardian in your will. Also, if you are terminally ill or facing a permanent mental incapacity, you can appoint a "standby guardian" who will continue to be the child's guardian after your death (unless you state differently in your will).

It's especially important that you name a guardian if you are a single parent. For parents who are separated or divorced it is best to make a legal agreement on a guardian together. It's important to consider the parenting responsibilities you have and ensure you include those responsibilities as part of the guardian appointment in your will.

A court may choose to appoint a different guardian if this is in the child's best interest. A court will also take into consideration the wishes of any child over the age of 12. Check with an older child to determine what their wishes may be before choosing a guardian.

Generally, a guardian doesn't have any rights to look after a minor's property – they can only receive and hold a minor child's property or money if it is less than \$10,000. You should appoint a trustee to manage a minor child's inheritance.

### *What is estate planning?*

Estate planning comprises strategies and measures you can take so that you can minimize the tax consequences and other costs that come when you transfer assets to your beneficiaries. An experienced lawyer will be able to assist you with estate planning.

### *References*

Information from this section is provided by the **Government of BC Website on Wills and Estate Planning**. Please see this site for further information on wills and estate planning, how to hire a lawyer, what information to gather before seeing a lawyer, probate and additional important information.

*For assistance: see the Government of BC website link:*

<http://www2.gov.bc.ca/gov/topic.page?id=B81B636B25654623A3CA94A6EF2CF F37>



### **Advance Care Planning**

There may come a time when, due to illness, you are incapable of expressing your treatment wishes to your health care provider. To prepare for such an eventuality, everyone in BC has been encouraged to prepare an Advance Care Plan. An **Advance Care Plan** is a written summary of your wishes or instructions to guide a substitute decision maker (who is someone you name in your Advance Care Plan; if you do not name someone, legislation assumes it will be a close family member such as a spouse, adult child, parent, etc.).

### *Steps to Creating your Advance Care Plan*

1. Download the BC Advance Care Planning Guide: **'Expressing my Wishes for Future Health Care Treatment'**:  
<http://www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf>
2. Have a conversation with your family about your wishes.
3. Decide what health care treatments you will or won't accept.
  - Consider what life support therapy you will want – like breathing machines, or a feeding tube.
  - Discuss with your family doctor a **'Do Not Resuscitate Order (DNR)'** – A decision not to attempt cardiopulmonary resuscitation (CPR) means the acceptance, without intervention, of natural death if and when it occurs and does not imply a restriction of any other potential form of treatment.

4. Gather a list of the people asked to be your **'Temporary Substitute Decision Maker'** or choose a **Representative** in a legally binding **'Representative Agreement'** who will make health care decisions on your behalf.
5. Put your Advanced Care Plan in a safe, accessible place. Keep a copy of your 'Do Not Resuscitate Order' on your refrigerator for easy access by paramedics.



### **Caring for Someone Who is Seriously Ill at Home**

Many people who are seriously ill want to be cared for in their own home. Making the decision to care for a seriously ill person at home is not easy. Being a care giver may mean helping your relative with mobility, bathing, dressing, bathroom visits, meals, and medications. Taking on the added responsibility can be rewarding, but also tiring, frustrating, distressing and isolating.

Caring for a seriously ill person and taking care of your own health is essential. However, mitochondrial disease can affect several family members, which can make caring for yourself and others an overwhelming challenge.

If you plan to care for a loved one at home, plan ahead.

#### ***Things to consider:***

- Are you entitled to assistance in the home or will you need to pay for assistance? Can you afford to pay for extra help around the house?
- Who will do the shopping, housework, and see to other errands if you are caring for your family member? Can they be left alone while you do these chores?
- Do you have other family members that you are caring for (especially children)? Who will look after them while you are caring for your loved one?
- Do you or your loved one have a pet that will need to be cared for?
- Will you have access to respite care?
- Is mobility and safety an issue? Has your home been assessed by an Occupational Therapist for mobility and safety? (An OT assessment can make suggestions for safety adjustments).
- Are there stairs that your loved one will need to navigate, or, if they need to use a wheel chair can they get in and out of the bathroom.
- How about in and out of your home, do you need a ramp?
- Will you need assistance transporting your loved one to appointments?

- Will your loved one need assistance with taking meals or their medications?
- What is the plan if your loved one's symptoms start to deteriorate, how will you manage at home?
- How will you cope with your loved one's pain or distressing symptoms?
- How will you provide emotional support? Who will support you?

***Useful resources:***

Regular Family Doctor  
 Community Nursing Service  
 Home Care Services  
 Palliative Liaison Nurse  
 Social Worker  
 Local Pharmacist  
 Physiotherapist  
 Occupational Therapist  
 Spiritual Care  
 Meals on Wheels

For further information see the handout '**A Time to Care: Caring for Someone Seriously Ill at Home**' available from the Adult Metabolic Diseases Clinic.

***Income Tax***

When a wage earner becomes a dependent, a number of exemptions may be claimed; e.g., increased medical costs and child care costs, etc. You may also be able to apply to Canada Revenue Agency for the Disability Tax Credit, which will allow a higher level of income tax exemptions (which can translate into less income tax owing). If your income tax liability is already low, you may be able to transfer your disability tax credit to a family member who provides you with substantial support – this could reduce your caregiver's income tax liability.

Also, the caregiver may be able to claim the mitochondrial patient as a dependent on their income tax return.

**Palliative and Hospice Care**

If care cannot be provided in the home a hospice, nursing home, or palliative care unit may be necessary. A hospice is a place for people to live until the natural end of their life. A hospice has a home-like environment.

A palliative care unit is a short stay hospital unit that provides symptom management to patients who have a life-limiting illness. The palliative care program will assist you in finding the right place for you to receive the care you need, whether at home, a hospice, or a nursing home.

## **What to do When Someone Dies**

Family members often feel numb, exhausted and confused in the first hours of grief. Yet during these early hours there are many decisions to be made. Planning ahead is helpful.

If death is expected at home, talk to your family doctor or community health nurse ahead of time about what to do when death occurs. Keep a list of people to contact at the time of death, including:

- Family Doctor
- Community Health Nurse
- Lawyer
- Spiritual leader/clergyman
- Funeral director
- Executor or next of kin

If death is expected to occur in a hospice or nursing home ask the facility to assist you with planning.

### ***Once a loved one has died, official notification is necessary***

If a person dies in British Columbia, the death must be registered with the Vital Statistics Agency. Please see the attached link with information on this process.  
<https://www.vs.gov.bc.ca/death/howto.html>

At this time, you will also want to notify credit card companies and banks where your loved one had accounts. Medical Services Plan and the Motor Vehicle Office should also be notified. They may need a copy of the official 'Death Certificate'.

Ask your lawyer or executor to assist you in checking all debts and installment plans. There may be insurance clauses that will cancel them. Consult with creditors to ask for more time to meet payments if there is a delay until the grant of probate or letters of administration.

### ***Survivor Benefits***

You may also want to check if you are eligible for survivor benefits and apply for them immediately. Check the Canada Pension Plan Office, see link below:  
<http://www.servicecanada.gc.ca/eng/services/pensions/after-death.shtml>

### ***Income Tax***

When a wage-earner dies a tax form must be filed for that person. Even if they had no taxable income that year, a tax return must be filed to inform Revenue Canada of the death.

### ***Arranging a funeral***

It will be the family's responsibility to contact a funeral home after death has occurred. Discuss ahead of time what requirements the funeral home may have.



### **At the Time of Death**

A number of physical, emotional and spiritual changes occur as your loved one enters the final stages of life. These changes are normal and natural.

Some changes to expect may include:

- Congestion: your loved one may develop gurgling sounds coming from the chest. This is caused by mucous that normally would be cleared if your loved one were more alert. Sometimes raising the head of the bed or turning your loved one to the side may help. Suctioning usually is not helpful and can be uncomfortable.
- Breathing changes: a person's regular breathing pattern may change, becoming more irregular and shallow. These changes are very common and indicate a decrease in circulation to the part of the brain that controls breathing. Sometimes morphine is prescribed to help treat shortness of breath.
- Colour changes: your loved one's arms and legs may become cold, hot or discoloured. This is a natural change indicating the circulation is conserving to support the vital organs.
- Confusion: your loved one may seem confused about time, place and the identity of people around him/her. Sometimes there may be a cause that can be treated, such as, changes to medication. But in many cases this is a natural process of dying.
- Food and fluid decrease: at the end of life your loved one may have a decrease in appetite and thirst. The body does not need much energy at this time and the digestive system cannot process much food or fluids. Do not force food or fluids. When the body does not desire food or fluids it is

not necessary to start an IV or feeding tube; as this may lead to fluid overload, lung congestion, and discomfort. You can keep your loved one's mouth moist with ice chips or popsicles if swallowing is not impaired.

- Urine output: this will decrease and may become concentrated and tea-coloured. This is due to the decrease in fluids and circulation through the kidneys. Sometimes your loved one may need to have a catheter inserted. Your home care or hospice nurse can assess for this need.
- Sleeping: your loved one may spend a lot more time sleeping or seem uncommunicative. This is a normal change.
- Restlessness: some people may seem more restless or agitated. They may appear to pull at the bed-sheets or their clothing. This may be due to the decrease in circulation to the brain. If you feel this may be related to discomfort ask the nursing staff to assess your loved one.
- Emotional: some people may wish to renew or heal significant relationships. Sometimes a loved one may try to 'hold on'. If this is a concern it is okay to reassure them that they can 'let go'. Tears are a natural part of saying goodbye, it is not necessary to hide your own emotions or for your loved one to hide theirs.
- Spiritual: visits with friends, family, spiritual or religious leaders may be very important for your loved one. Talking about their life, the people they have loved, events of significance, and saying goodbye is an important process in preparing for death.
- Decreased socialization: wishing to be alone 'with their own thoughts' is natural for many people. Having visitors or keeping up with conversations can be difficult. If talking or following a conversation seems overwhelming, sit next to your loved one and read a book or listen to music.

### ***Death occurs when***

Breathing ceases

Heartbeat ceases

The person is no longer able to be roused. Their eyelids may be partially open and their mouth may fall open. They may still be warm to the touch.

You may wish to stay with your loved one. Spend as much time as you like. Some people have spiritual or cultural traditions that are done after death. If your loved one is in a hospice or palliative care facility discuss what these practices are with the staff ahead of time.

## **Grief**

The death of a loved one can be life-transforming. The grief process is the journey between how things were and how they will be. Grief is a natural process. Each person experiences grief in their own way and with their own timetable. You may feel very different from your normal self. You may feel intense pain or emotions. This is natural. Emotions may come in waves. The most insignificant thing may set them off. You may have good days and bad days.

Take time to grieve and be gentle with yourself. Try to keep to a normal routine, but allow “time off” to take care of yourself. Likely you will need short periods of “time off” each day to take care of your grieving and then return to your normal routine. Let friends and family help you. There is no timeline for grief. Do not be swayed by other’s expectations. Over time the intense pain and emotions will subside. Life goes on. If you have concerns seek a professional grief counselor.

### ***Children and grief***

Children look to adults in their lives to learn how to grieve. They are sensitive to the moods and behaviour of others. They may be frightened and unsure how to express themselves. Children, with mitochondrial disease, who have lost a sibling or parent with mitochondrial disease, may have overwhelming fears of their own death. It is important to let them talk about their loss, thoughts, and anxieties. Children will express themselves differently depending on their age and experiences. Significant changes in behaviour may require the assistance of a professional grief counselor.

For a list of things grieving children want to know see the **OurHouse Grief Support Centre** link below: [http://www.ourhouse-grief.org/wp-content/grief\\_pages/ten\\_things\\_children\\_want\\_u\\_to\\_know.pdf](http://www.ourhouse-grief.org/wp-content/grief_pages/ten_things_children_want_u_to_know.pdf)

“Preparing Children for Loss” a booklet available from Vancouver Coastal Health Adult Metabolic Diseases Clinic

MitoAction also provides some useful links to support resource websites and material geared to siblings:

<http://www.mitoaction.org/files/caringforwholefamily.pdf>

### ***Pets***

Pets are sensitive to mood and emotions and experience loss too. Like humans, animals (especially dogs) may respond to the loss of their master in different ways. Some may exhibit signs of physical sadness; others may exhibit negative behaviour changes. This may lead to a loss in appetite, lowered water intake, sluggish response to humans and other pets, a loss of interest in play or physical activity, and even a mournful howl. The symptoms can also increase gradually over weeks or months. They may try to stick to routines associated with their

master, like going to the door at a certain time of the day. Maintaining a normal routine is best. If you have concerns visit your veterinarian.

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Making plans for a loved one's care and death is not easy. This guide was created to help assist you and your family to make decisions and plan ahead. It is not intended as a complete guide, but merely to act as a starting point for discussion. Where necessary, seek professional or legal assistance. Engage the assistance of your local community health nurse, hospice and palliative care unit in making plans for your loved one's care and death.

***My heart has joined the Thousand, for my friend stopped running today.”  
– Richard Adams, Watership Down***