

*NAVIGATING THE "END-OF-LIFE"
JOURNEY*

**A Reference Resource for
"Planning and Coping"**

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CORDOVA BAY UNITED CHURCH
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*An Important Preliminary Note to the Reader of this
Introductory Resource to Help you:
Plan for, and Cope with, End-of -Life Events*

Cordova Bay United Church pastoral care group has developed a practical resource to support those facing the imminent death of a loved one. This package of information is meant to provide you with *administrative* support. Its original purpose was to help people set down essential plans, intentions, and documents well in advance of their need. However, it quickly became apparent that most people first encounter this crisis when a death has already occurred, action is critical, and few or no plans exist. This document now anticipates both kinds of needs, and therefore is relevant to everyone.

When facing an imminent or recent death, we are thrown into a highly charged emotional state. Unfortunately, it is often then that we are also faced with pressing requirements, both practical and bureaucratic. Family members, in a state of acute grief, may not know where to start. They will be called upon to make critical medical, legal, and other end of life decisions with minimal preparation or time.

There are steps that should have been taken in advance of a death, but now, either functionally or legally, must be dealt with immediately following a death. Many other tasks, though less urgent, comprise a large "to do" list.

This guide has been researched from a number of BC Government and community sites available on-line. It introduces you to what Advance Care Planning entails, and a checklist of important documents that will be needed; offices/agencies that must be notified, how to clarify your intentions, and much more.

It is a daunting task to consider what needs to be done and where to find the appropriate information. Rev. Winston Stokes, as a member of the Caring Ministry, has researched and assembled a package of information that will help the process go more smoothly for you, your family, and its representatives.

The following compendium provides you with introductory information, as well maps the links to the relevant website for every topic. It does not provide legal advice, but it raises awareness of the professionals, such as your minister, lawyer, and financial manager, who will guide you as appropriate in their area of expertise.

We trust that you will find this information supportive and helpful, as, and when, needed.

NAVIGATING THE END-OF-LIFE JOURNEY: A Reference Resource for Planning and Coping

-- Compiled by Cordova Bay United Church

A very long time ago, the writer of Ecclesiastes wrote, “*For everything there is a season*” (Eccles 3:1), and he headed his list with, “*a time to be born, and a time to die.*” Yes, we all die – and when that happens, there are many stages, roles, and necessary responsibilities that come with it. Since these can put a lot of stress on your loved ones, you are encouraged to spell out, well in advance, your wishes and intentions, for others to implement.

This document has been developed to make it as easy as possible for both you and your loved ones to navigate the end-of-life maze. It will help you to reflect on, and organize, your wishes; whether yours is a long life moving toward its natural close, or you are suddenly and randomly overwhelmed by mishap or medical crisis. Once thought out and written down, your foresight will be a valuable guide for those handling your affairs, both in knowing your wishes and priorities; and in coping with all that needs to be done following your death.

In that context, it is vital to remember that while there will be many legal and public tasks imposed by others, or by custom, they do not outweigh the emotional needs of caring for deeply traumatized and grieving hearts.

The category of tasks imposed legally or customarily is supported by many professionals, each with their own specialty, who can assist in navigating the legal and public aspects of the end-of-life landscape. The material provided here is intended to make an initial consultation with them less daunting and more productive. A traditional *Last Will and Testament*, and *Designated Power of Attorney*, are only the beginning of the list. Equally as pressing are matters of notification of death, obituary, interment, and a Celebration of life. For those affiliated with a faith community, a helpful first step is a consult with your pastor.

An important impetus for the gathering and introducing this material is that not having a plan may have lifelong consequences, particularly for your loved ones. If you have not prepared a plan, nor designated and legally authorized someone to act on your behalf, provincially mandated protocols take precedence over personal wishes. Complying with these directives can be a time consuming, emotionally

distressing, and expensive process. Familiarity with the intent of these constraints is of special relevance to blended, fragmented, or non-traditional family units.

There are also an array of deeply personal aspects and tasks to consider as death approaches. They may include, but are not limited to, providing for your daily care during prolonged incapacity; traumatic medical crises that demand urgent treatment decisions, honouring intimate last wishes, and winding down your life's footprint.

Essential and pressing tasks soak up a lot of time and energy, but, in spite of them, there will still be the weight of the grieving itself. While it may be pushed away for a time, it is not to be neglected or dismissed amid all the busyness. Being rushed and overwhelmed by practicalities will not make grieving any easier once the busyness is past. This guide has been carefully researched to provide the relevant information when needed, so that there will be as much time and energy as possible to attend to both the external tasks, and the wholeness of the grieving heart.

Before going further, it is important to note that every reader of this guide will bring to it their own unique circumstances and reality. For example, on the one hand, you may be exploring issues and options for your own end-of-life planning, seeking to minimize the bereavement stresses placed on the loved ones who will be charged with looking after your affairs. On the other, you may be the one who is newly bereaved, or anticipating a bereavement, and are urgently looking for tools to help you cope with the end-of-life tasks that will soon come to you uninvited. The first is here called "Advance Planning", while the second is denoted as "Crisis Coping". This document is organized into these two distinct Sections, so that you may turn first to whichever phase is your reality today.

The toolkit begins with a detailed advance planning guide called "My Voice". It invites you, and guides you step by step, to prepare your own plan, by which you will be better armed to cope during moments of urgency and uncertainty. Most importantly, with this advance preparation, your family can focus more of their compassion and energy on grieving for, and honoring, your life.

"My Voice" is discussed in Section I. However, if you are handling the affairs of someone who has recently passed without any written guidance, you may prefer to go directly to Section II. Nevertheless, you are encouraged to orient yourself by reading the first half of "My Voice", as it explains what will be expected of you as you work through the process, including options and documentation.

The commentary which follows this introduction is a guide to online public resources that will help you organize your thinking and give you a vocabulary that you can take into any public seminar or professional office.

Two primary public sources have been utilized in preparing this package: the BC Government's "End of Life" Websites, and Hospice Victoria. These by no means cover the whole scope of what is available, but they do cover the essentials: legal compliance, personal affairs, remembrance, grieving, and common topics of concern. Specifically, they include lists of documents, checklists, worksheets, and contact points for more information; suitable for anyone preparing for, anticipating, living through, or recovering from, an end-of-life journey.

This introduction includes a brief synopsis of each resource, covering all the key phases of the journey. At the end of each synopsis is the URL link to the full online text. If you have a digital copy of this summary, those weblinks should be "live", just double-click on them. (***If you have a printed copy of this guide, just paste the links into your web browser.*). For those who wish to browse for themselves, the BC Government material can be directly accessed through their homepage: **www2.gov.bc.ca/afterdeath**. (*If you prefer, you can also go to their alternate site: <http://www2.gov.bc.ca/content/health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care>, which is organized around community care resources.*)

There are two sections and five parts to this overview:

Section I: PLANNING

A. My Advance Plan

Section II: COPING

B. Imperative Decisions and Actions

C. Picking Up the Pieces

D. Victoria Hospice Services and Resources

E. APPENDIX: Information for when there is a Death at Home

Before diving into the details, here are a few tips to facilitate navigating this package. Firstly, each document is semi-autonomous, with its own extensive cross-references to the other sections and links. Please do not think it necessary to explore all of them.

Secondly, the “Imperative Decisions and Actions” section concludes with a workbook which gathers the scope and essence of most of these actions into one place, complete with cues on their importance and urgency, plus a page for your own progress notes. It can serve as the foundation for your “action plan”.

Finally, the “Appendix” dealing with a death at home is only included, as information, for those of you who may be present at one, to explain why and when certified professionals must immediately attend, to ensure that the death is handled in accordance with all legislated standards.

Section I: PLANNING

A. My Advance Plan

Timing: Start now, update anytime, and revise when there is any major change in personal circumstances.

This section occurs as the first item of the Ministry of Health package, because any action usually unfolds better, and with less stress, if you have in mind a plan for it. Thus, in anticipation of our death, let us make it as easy as possible for our families, caregivers, and executors to determine our wishes and necessities well in advance. However, notwithstanding our best intentions, we all know that life often surprises us, and does not unfold according to either our intentions or expectations.

Hence, you may be coming to these resources already confronted by an unexpected or pending death, for which little or no advance preparation has been made. If so, you may be coming in an acute state of distress and urgency, and all your priorities will be focused on simply coping. This package has anticipated that possibility, and, if that is your need, you are encouraged to skip directly to Section II, which is entirely focused on immediate practical actions and tools. Once you have completed your navigation of the current crisis, we think you will keenly understand why it is important not to leave your affairs in a similar state. At that point we encourage you to come back to Section I and begin framing your own Advance Plan.

Even at the best of times, end-of-life planning is difficult; it requires you to face profound and pivotal questions well before you may feel in the mood to do so. Furthermore, there is no mandatory qualification course in the subject. Even though death and its consequences may happen at any time, most people are not familiar with the concepts, options, and terminology of this process, which involves technical and legal questions, and will prod you to make emotionally demanding, and legally consequential, choices. As a particular case in point, do you know what a “Temporary Substitute Decision Maker (TSDM)” is, and why having one may be legally important?

Even if you do not complete all the steps, it is always better to have some guidance for those who must eventually make these choices, and a partial plan is better than none, in case a catastrophic event or illness occurs. Incidentally, this terrain becomes much less frightening once you have taken a ‘dry run’ across it; much, much less frightening than having it catch you unawares.

Everyone is encouraged to begin imagining an Advance Plan that suits them; it can always be updated or redrafted as life unfolds. But just as important is having these essential tools close to hand, in case lightning strikes, and there is no plan.

1. “MY VOICE” – An Advance Care Planning Guide

The BC Ministry of Health Guide, entitled “My Voice”, is for framing a plan to ensure that your end-of-life values and wishes are implemented, according to your written directions, by those who provide your care, and those who will make any difficult or urgent decisions that may arise. An Advance Plan is actually composed of three parts: (i) a planning process wherein a capable adult’s wishes are clarified, shared with trusted family or friends, and documented well in advance, in anticipation of a time when that person may not be able to make decisions for themselves; (ii) an “Advance Care Plan” document for the benefit of a “Temporary Substitute Decision Maker” who is authorized to be contacted for guidance by the physician in the case of life and death emergency; and (iii) an “Advance Care Directive”, which authorizes the physician to act, if necessary, without consultation, solely on the basis of priorities and preferences set out in the directive.

Given the unknowable, and often urgent, nature of circumstances which may result in incapacity, clear guidance will allow caregivers to come as near as possible to respecting your wishes. Circumstances may change, but it is much easier to update than to start from scratch when you are stressed by uncertainty and urgency. Even a partial plan is a far better insurance policy than having nothing. Unfortunately, examples of the latter case abound.

The “My Voice” Planning Guide has two distinct sections. The first lays out a rationale, and options, for developing the Advance Care Plan which conveys your wishes and emphasizes your values. A copy of this document should be placed, at minimum, in the hands of your family physician, caregiver, and if relevant, on your Medical Chart. Copies should also reside with a member of your family, your lawyer, power of attorney, and your “Temporary Substitute Decision Maker (TSDM).” All of the above should be aware of its existence and location.

The second part of “My Voice” deals with Advance Care planning and action options, including the framing of an Advance Care directive, if desired, and options regarding personal and legal representation. It is an actual workbook, firstly citing sample real situations, and the reasons for choosing among a palette of either temporary or enduring legal representatives; and, secondly, encouraging you to do your own homework before consulting any legal or medical

professional. The second half includes all the forms and directions by which you can even prepare your own Plan, should you wish to do so.

The “My Voice Planning Guide” can be accessed, downloaded, or printed, via the following link:

<https://www2.gov.bc.ca/assets/gov/people/seniors/health-safety/pdf/myvoice-advancecareplanningguide.pdf>

Section II: COPING

B. The Important and Urgent Decisions and Actions that Fall to Family, Friends, or a legal Representative at the time of Death

Timing: The “Start” button for these tasks is pushed by the legal pronouncement that the person is “Deceased”, at which point someone must step up to carry the baton in navigating both the tasks and traumas of the end of a life.

The following section introduces four components of a package of resources from the Ministry of Health, dealing with the full scope of after-death essentials, and best practices. At the end it includes a section on “Common Definitions and Terms,” which can be referred to at any time to add clarity and comprehension.

1. “After a Death: When Someone Dies”

This topic addresses the need for what may best be called, “A Roadmap for Action”. What do I need to know, what do I need to do, whom do I need to contact? This resource is not a workbook; it is a survey of all that needs, or may need, to be done, both the actions and the terminology. It lays out the landscape of what must and what may be done, and establishes a supporting cast of resources you may want to consult. Please review it before going to the “Checklist and Workbook” resource, which is a very functional, practical, adaptable, and user-friendly ‘to do’ list.

<https://www2.gov.bc.ca/gov/content/life-events/death/after-death/first-steps>

2. “After a Death: Who to Notify”

This is an expansion of the previous link, with an emphasis on who must be legally notified regarding passports, licenses, and sundry other official documents, as well as other entities which may not immediately come to mind. It is a good cross-check with the workbook which follows.

<https://www2.gov.bc.ca/gov/content/life-events/death/after-death/who-to-notify>

3. “After Death Checklist and Workbook”

This checklist lays out all the key tasks, and the people and agencies you need to contact, complete with phone numbers, addresses, and a guide to urgency and priority. It includes a place for notes, callbacks, follow-up action plans, and a place to check which tasks are relevant, and which are not. If you are a spouse, next-of-kin, or person designated as the legal agent for the deceased, this will be the one most practical and comprehensive pathway to peace of mind, and a reassurance that you have not missed something.

https://www2.gov.bc.ca/assets/gov/birth-adoption-death-marriage-and-divorce/deaths/after-a-death/after_death_checklist.pdf

4. “Plan a Funeral, Celebration of Life, or Memorial Event”

This resource is broader than it sounds. It covers a whole landscape of how the identity, persona, and remains of the deceased will be honoured and celebrated. It is worth scanning for aspects and options that you might have overlooked. It is best used by someone who is comfortable online, as it has a number of embedded associated links. These are much more comprehensive, and too extensive to include here in detail. For those who are part of a faith community and have a pastor, this should be your first point of contact, as they will usually offer assistance and/or a service template.

<https://www2.gov.bc.ca/gov/content/life-events/death/after-death/plan-a-funeral-or-memorial>

5. “After Death: Common Definitions and Terms”

We all have a common parlance and working definitions for most of these terms, but for clarity and precision, they are laid out here for reference purposes with more formal and precise definitions.

<https://www2.gov.bc.ca/gov/content/life-events/death/after-death/definitions>

C.Picking Up the Pieces

Timing: From an imminent death until grieving is integrated with ongoing life.

1. “After a Death: Get Support when Someone Dies”

While this resource does not delve into specific topics, it does focus on a wide-ranging menu of links to generic bereavement resources in the public sector. A more focused emphasis on navigating the bereavement journey, from shared community events to personal grieving, including anticipatory grief, and intense occasions of non-traditional -- and publicly unsupported -- grieving, may be found in the Victoria Hospice Sections. Unique to this “After a Death” section is the introduction of a variety of financial supports and survivor benefits which, though not widely known, are available to those coping with bereavement, including special groups like Indigenous Persons and Military Veterans.

<https://www2.gov.bc.ca/gov/content/life-events/death/after-death/get-support>

2. “After a Death: Manage Wills and Estates”

This helpful little guide is a shorthand guide to not procrastinating over what you need to know about a Will or Estate. Essentially, it looks back to what guidance, legal or otherwise, may have been provided in the advance planning phase, including setting the stage for dispersing the estate, whether or not a full probate is required.

<https://www2.gov.bc.ca/gov/content/life-events/death/after-death/wills-estates>

D. Victoria Hospice Services and Resources

Timing: From anticipation of the end of a life, through death, grief and bereavement.

The Practice and Issues of End-of-Life Caregiving; by loved ones, outside caregivers, and professionals

1. “Preparing for Death: A Guide for Caregivers”

A simple, descriptive narrative of the signs and progressive stages of one who is approaching death, wherever it may be taking place. Of help and reassurance to those who watch, support, and wait, giving small gestures of comfort, emotional presence, and support during the last stages of the journey.

<https://victoriahospice.org/resources/how-to/>

2. “Here for You and Your loved Ones”

The Victoria Hospice website, largely focusing on the nature and value of registering those with terminal illness with Victoria Hospice, whether its services might be extended to home care, or climaxed with admission to the Hospice Inpatient Facility at the Royal Jubilee Hospital.

<https://victoriahospice.org/how-we-can-help/compassionate-care/>

3. Bereavement and Recovery; reflecting on the journey, and constructing a new future

There is a wide palette of support services offered by Victoria Hospice to bereaved families and individuals, either spreading over an extended time of readjustment, or with professional counselling and short-term interventions at scheduled hospice events, for those coping with loss. Services cover the full scope of individual counselling, support groups, workshops, and extended support by volunteers.

Access to this range of services is self-directed -- you choose. In general, bereavement is not best handled with a “stiff upper lip,” which usually only extends both the duration and the depth of the loss experience. No one web link suffices to capture the range of hospice possibilities, but familiarity with this

website may save precious time, and peace of mind, when it is most in short supply. These bereavement supports are open to anyone who is grieving a death, and without cost.

<https://victoriahospice.org/how-we-can-help/bereavement-services/>>

E.APPENDIX: (For Information Only)

“Joint Protocol for Expected/Planned Home Deaths in British Columbia”

Attached, for information only, is the BC protocol for handling deaths at home. This is explicitly for the guidance of professionals, a number of which will be involved in handling the medical, physical, and legal aspects of bringing the circumstances of the death into conformity with standard coroner practice in the handling of deaths. It, emphatically, is not intended to sanction actionable steps to be taken by community caregivers or next of kin. However, for anyone who anticipates being closely involved with a death at home, it makes for helpful background reading. It helps caregivers and family to be cognizant of what is necessary and desirable, and how to interact with professionals who, at the crucial moment, must be brought into the process. *(Please note: This appendix is only included here because it is also posted on the Ministry of Health website, along with the other resources referenced above.)*

https://www2.gov.bc.ca/assets/gov/health-safety/home-community-care/care-options-and-cost/expectedplanned-home-deaths/expected_home_death.pdf

F.END NOTE

To conclude this resource package where it began, the essence of this introduction and overview is to encourage you to have an awareness, and preferably a plan, which will minimize family stress when tough end-of-life questions are encountered. It will introduce you to resources and tools that can assure you that your wishes and concerns are important, and that your efforts will be both constructive and effective.

Both as an incentive, and an aid, to building that unique personal strategy, an action page is appended to this document. Entitled “My Action Page”, it is divided into three sections. The first is for noting the most significant references and resources you have uncovered in this exploration, as well as “Notes to Myself”.

The second is called: “Questions I Have: both old and new.” You will have many questions, some of which will have been spawned here, but not answered. These will lead you to other resources and professionals who you otherwise might not have encountered, or even considered.

The final, and crucial, section is called: “Contacts and Priorities for Action”. Once your priorities, resources, family values, and professional contacts begin to coalesce together, your plan will be well underway.

Thenceforth, the helm will again be yours, but now you will not be sailing alone. You have access to both a crew and a compass, ready to help you navigate your way through your end-of-life journey!

My “Navigating the End-of-Life Journey” Action Page:

A. References, Resources, and “Notes to Myself”:

B. Questions I have; both old and new:

C. Contacts and Priorities for Action:

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