

Self-Assessment, Reflection and Self-Care

The months and weeks before death offer an opportunity to look back and understand what our life has been about. It can be a time of gaining wisdom about the meaning of life or spirituality, of discovering and understanding our strengths, of learning to accept love and caring from others. It can also be a time to make peace and heal difficult relationships. Dying is a great mystery, and maintaining our curiosity and willingness to learn about it can help people can make the experience a valuable and important part of living. However, it is also a time of change, loss and grief.

This part of the binder provides some information about **what to expect** during this time at an emotional, spiritual and practical level. You will find **self-assessment tools** for both patients and family members and caregivers, along with several **reflection exercises** that offer you an opportunity to stop in the midst of all that is going on and reflect on how you are doing, what questions you may have, or what things you may want to say to those who care about you. You can use the space provided to make notes, or you might prefer to think privately about the statements and questions. There are a number of ideas to help you with **stress reduction, relaxation and caring for yourself**. There is also a list of **question prompts** to help you talk to your care team.

If you would like **professional support** at this time, talk to your family physician or Home and Community Care nurse, or ask the nurse to request a visit from a Victoria Hospice counsellor.

For the patient

Reflection

Take a moment to complete the following statements.

The most important things to me right now are

I find joy in

I am hoping for

Things I want my family to know – for example, about my care, how I'm doing, my thoughts and feelings, what's important to me

Patient self-assessment

For each item, please indicate how much of a problem or concern these have been for you in the last few days.

	Not a problem	A slight problem	A problem	A major problem	An overwhelming problem
1. Not being able to carry out tasks associated with daily living (e.g., washing myself, getting dressed)	1	2	3	4	5
2. Not being able to attend to my bodily functions independently (e.g., needing assistance with toileting-related activities)	1	2	3	4	5
3. Experiencing physically distressing symptoms (e.g., pain, shortness of breath, nausea)	1	2	3	4	5
4. Feeling that how I look to others has changed significantly	1	2	3	4	5
5. Feeling depressed	1	2	3	4	5
6. Feeling anxious	1	2	3	4	5
7. Feeling uncertain about my health and health care	1	2	3	4	5
8. Worrying about my future	1	2	3	4	5
9. Not being able to think clearly	1	2	3	4	5
10. Not being able to continue with my usual routines	1	2	3	4	5
11. Feeling like I am no longer who I was	1	2	3	4	5
12. Not feeling worthwhile or valued	1	2	3	4	5
13. Not being able to carry out important roles (e.g., spouse, parent)	1	2	3	4	5
14. Feeling that life no longer has meaning or purpose	1	2	3	4	5
15. Feeling that I have not made a meaningful and/or lasting contribution in my life	1	2	3	4	5
16. Feeling that I have “unfinished business” (e.g., things that I have yet to say or do, or that feel incomplete)	1	2	3	4	5
17. Concern that my spiritual life is not meaningful	1	2	3	4	5
18. Feeling that I am a burden to others	1	2	3	4	5
19. Feeling that I don’t have control over my life	1	2	3	4	5
20. Feeling that my health and care needs have reduced my privacy	1	2	3	4	5
21. Not feeling supported by my community of friends and family	1	2	3	4	5
22. Not feeling supported by my health care providers	1	2	3	4	5
23. Feeling like I am no longer able to mentally cope with the challenges to my health	1	2	3	4	5
24. Not being able to accept the way things are	1	2	3	4	5
25. Not being treated with respect or understanding by others	1	2	3	4	5

Used with permission: Chochinov HM, Hassard T, McClement S, Hack T, Kristjanson LJ, Harlos M, Sinclair S, Murray A. The patient dignity inventory: a novel way of measuring dignity-related distress in palliative care. *J Pain Symptom Manage.* Dec;36 (6):559-712008

Focus on the patient

Physical changes

As your illness progresses, you may have symptoms such as pain, nausea or shortness of breath. This likely means you also have more medications, tests or treatments to deal with. You may find that you have less energy, sleep more and are less interested in food and eating. You may find it difficult to get out of bed or walk far. You may notice various changes in how your body looks or functions. These many changes can be overwhelming and leave you feeling out of control, anxious or even frightened. You may find that this is also worrisome for your family.

Reflection

Take a moment to complete the following statements.

Things that worry me right now (my greatest fears) are

I feel overwhelmed by

I would like to talk to my family about

I would like to talk to my care team about (see the "Question prompt list" at the end of the Self-Assessment, Reflection and Self-Care section)

Life changes

At this time you may experience changing thoughts, feelings and levels of energy that affect you and those around you. As a result, you may notice that your usual activities, interests and relationships are shifting. More and more, your focus is on daily care, symptom management and planning for future care needs. Everyone is becoming more tired and stressed, and there are many changes to family roles and duties. You may find that your world is “shrinking,” as you have less energy for social interactions, or that there are more phone calls and interruptions to your daily life, with increased numbers of visitors and health professionals in your home.

In the midst of these changes and activities, it is important to take some time out for yourselves as a family and as individuals. It is okay to cancel or delay visits when you don’t have the time or energy for extra people. It is okay to need time on your own, whether for rest, exercise or hobbies.

Reflection

Think about the many changes that you and your family have experienced.

List five ways in which your focus has changed over the past months, weeks or days.

What do you miss most right now about your day-to-day life?

What are you feeling right now?

Losses

You may find that you are losing many important things in your life – independence, physical abilities and fitness, appetite, connections with colleagues and friends, hobbies, roles and so on. It may be hard to depend on others to run errands, cook and clean, and, perhaps, provide personal care (such as bathing or eating). It can be hard to see your spouse doing jobs or tasks that previously you would have done. On the other hand, you may feel relieved that you are no longer required to do some things. Whatever your reaction, it is to be expected that these losses will affect you and your family, and you may find it helpful to talk to someone. Your family physician, Home and Community Care nurse or Victoria Hospice counsellor are available for support.

Reflection

Think about recent losses in your life and how you are coping with them.

How do you express your thoughts and feelings about these losses?

How are you coping with these losses? For example, do you find you need to talk to others or do you prefer to work things through on your own?

How do your family members express their grief differently from you? Is this a problem?

Reactions

Since your diagnosis, you will have experienced many different thoughts and feelings. Anger, hope, sadness, gratitude, depression, joy, despair, fear and love are all possible, even expected. Some emotions will come and go, while others may stay with you for long periods of time. Old feelings and issues could rise to the surface again, or you may worry about the future, for yourself or your family. Your memory and concentration may be poor, and making decisions might be difficult. You may be preoccupied with thoughts about your illness or death. You may find that you are questioning your beliefs or looking for spiritual peace. You may find yourself hoping for a miracle or grieving the loss of a life's dream.

Reflection

Think about your thoughts and feelings over the past days, weeks or months.

Do you have any concerns?

What would be helpful to you now? (For example, information, help with a task, talking to someone.)

List three things your are grateful for.

Care for the spirit

With your physical symptoms addressed and a level of comfort achieved, you may find a space cleared to explore personal healing, repair and growth. You may have religious beliefs and practices that give you comfort and guidance or a particular philosophy of life that directs your exploration. Or you may have no connection with a power or life force beyond that of your everyday life. Regardless, questions around purpose and meaning of life, mortality and legacy often surface as we confront the prospect of death – our own or that of someone we love.

Reflection

As you consider the end of life:

What meaning has your life had, for you or for others? What is your legacy?

How do you think about your spirit?

Do you need to seek or offer forgiveness?

How has your faith or courage been tested over the past weeks or days?

Is there a religious or spiritual ritual that would give you comfort now?

Do you sometimes feel lonely or isolated?

Patient resilience: Strategies for self-care

Relaxation techniques¹

The following exercises have been developed to help with sleep, breathing, anxiety, pain and general relaxation. You can practise them alone or have someone read the instructions to you. It may be helpful to first practise these techniques when you are already relaxed and able to focus on the instructions. Family members may also find these helpful.

Sleep meditation (for deep relaxation)

This simple technique can prepare your body and mind for restful sleep.

- Close your eyes softly and bring your attention to your heart.
- With inner awareness on your heart, mentally feel the area around your heart and silently say, “one.”
- Now bring your attention to your left shoulder and silently say, “two.”
- Next let your attention come to your left hip. Mentally feel the hip and silently say, “three.”
- Continue through the body, bringing awareness to and mentally feeling the following parts as you count them: navel “four,” right hip “five,” right shoulder “six” ...
- Let attention come back to your heart again for “one” and so on, moving your awareness at a comfortable and relaxed pace, simply noticing and mentally feeling each part as you count it.
- Let your mind “busy” itself by slowly moving in this pattern; it will soon tire and spiral inwards to come to rest at the heart, its settling place for sleeping. As you begin to drift off, simply let go of the practice and sink into sleep.

Relief breath (for pain, stress or anxiety)

This exercise can increase feelings of safety and your ability to deal with challenging situations.

- Begin by slowing your exhale slightly by breathing out through softly pursed lips.
- Let your belly draw back and widen with each exhale.
- To inhale, close your lips and release any belly tension – this relaxing will allow the most natural in-breath possible to flow through your nostrils and into your lungs.
- Over time, gently lengthen the exhale to a count of 6 or 8, and inhale for a count of 3 or 4.
- Allow the out-breath to be intentional and complete without strain, and the in-breath to be as relaxed and effortless as possible.
- Continue for as many rounds as desired.

¹ Developed by M. Butot from C. Johnson & D. Webster, *Re-crafting a life: Solutions for chronic pain and illness* (2002, Brunner-Routledge) and K. McGonigal, *Yoga for pain relief: Simple practices to calm your mind and heal your chronic pain* (2010, New Harbinger).

Anxiety reduction breathing (in – cool, out –warm)

This technique stimulates the parasympathetic nervous system – activating the body’s natural relaxation response. It can be used when you are alone or while waiting for medication to take effect and can be practised at any time and anywhere.

- Bring your attention to the breath, just as it is, allowing your body to breathe in its own way.
- Let your attention come to your nostrils or the back of the nose, wherever the sensation of air moving is strongest and **feel the breath moving** there.
- Begin to notice the temperature difference between **in-breath (cool)** and **out-breath (warm)** and pay attention, feeling this difference for one to several minutes.
- If you like, silently repeat to yourself “in – cool, out – warm” to deepen the effect.
- Allow a few minutes for the practice to do its work, assisting your body’s own relaxation response to help distress and anxiety subside naturally.
- When you feel finished, count yourself up through five regular or deeper breaths, becoming increasingly alert and refreshed at each breath.

Eye breathing (for acute pain or anxiety)

This exercise can help separate you from feelings of pain or discomfort or from disturbing thoughts. It can be used in emergency situations and in times of acute pain or anxiety while waiting for medical interventions to take effect.

- Sit or lie as comfortably as you are able, breathing as normally as possible.
- Begin to link your eyes closing with your breathing rhythm, just as your breath is right now: **open your eyes while breathing in and allow them to close while breathing out.**
- Continue breathing, establishing a distinct rhythm all your own.
- As you inhale (eyes open) and exhale (eyes closed), you may want to imagine adding a colour to the inhale – any colour that you find soothing or healing, a colour that offers the kind of peacefulness and comfort you are looking for.
- After a while, you might consider colouring the exhale as well – any colour that represents something you want to eliminate or release.
- Continue breathing – (eyes open) breathing in that healing colour, (eyes closed) breathing out that releasing colour – for as long as needed.

Pursed-lip breathing (for shortness of breath)

Shortness of breath can be physically and emotionally anxiety-provoking and can affect your quality of life. This technique is one of the most helpful things you can do when you feel short of breath. The lip position helps keep the breathing tubes open and maintains better pressure in the air sacs in the lungs. It can reduce breathlessness, slow rapid breathing, help empty stale air out of the lungs, increase breathing volume and lengthen the exhale (which helps with anxiety). It also encourages the contraction of the abdominal muscles, moving the diaphragm up to empty the lungs more fully, allowing the fullest possible in-breath.

- **Breathe in slowly through your nose**, as though smelling something delicious. Relax your neck and shoulders as much as possible.
- Lean slightly forward and **softly, gently, s-l-o-w-l-y blow out through pursed lips**, as though cooling hot soup or using the breath to flicker a candle. Do not force the air out.
- Continue to do this for as long as needed.

5-4-3-2-1 (for deep relaxation)

This self-hypnosis technique can be used to relax in stressful situations, and to re-centre yourself. It can help with pain, sleeping, anxiety, scary thoughts and nightmares, and symptoms of post-traumatic stress. Do not use when driving, because it narrows peripheral vision.

- Find the most comfortable position you can and find something pleasant to focus your eyes on.
- Breathe normally. Your eyes can stay softly open unless you wish to close them or are using this to fall asleep. Keep your head and eyes quite still.
- Open your senses. Now name **out loud** (to deepen the effect): 5 things you see, 5 things you hear and 5 physical sensations you are aware of in your body. Notice each detail, maybe taking a breath between each one.
- Naming an item more than once or counting on your fingers is fine. If you lose count, simply begin again. If pain or discomfort is present, notice what needs to be noticed, then move on to notice other sensations.
- Now proceed to **4 sights, sounds and sensations**, and then to **3, 2 and 1 of each category**.
- Repeat the whole cycle as needed to deepen the effect.
- When you are finished, take 5 regular breaths to reorient yourself. To fall asleep, let your eyes close at any point.

For families and caregivers

Family member and caregiver self-assessment

This self-assessment tool is intended to help family members and caregivers identify aspects of their lives that are a concern or problem at the moment. If you feel overwhelmed or distressed doing this self-assessment, you may want to stop and come back to it at another time. Victoria Hospice counsellors are available to help you understand and work through whatever thoughts or feelings arise during or after completing this assessment.

Read each item and circle the number that best represents how much of a concern or problem this is **currently** in your life. You may want to complete this in one sitting or in several. You may also want to do the self-assessment more than once and notice how your answers change over time.

	Not a problem	A slight problem	A problem	A major problem	An overwhelming problem
1. Difficulty with memory or focusing my attention	1	2	3	4	5
2. Having enough information about the disease and how to provide care	1	2	3	4	5
3. Lack of understanding about palliative care services	1	2	3	4	5
4. Feeling isolated	1	2	3	4	5
5. Communication or conflict within the family	1	2	3	4	5
6. The safety of the patient	1	2	3	4	5
7. My own health	1	2	3	4	5
8. Asking others for help	1	2	3	4	5
9. Financial pressures	1	2	3	4	5
10. Having my spiritual needs met	1	2	3	4	5
11. Having opportunities to take breaks away from caregiving or from the home	1	2	3	4	5
12. Feeling that I won't be able to cope in the future	1	2	3	4	5
13. Feeling emotionally distant from the patient	1	2	3	4	5
14. Not feeling adequately supported by health care providers	1	2	3	4	5
15. Finding something to be grateful for at this time	1	2	3	4	5

Focus on family members and caregivers

Finding balance

A big challenge for family members is finding balance in caring for yourself in the midst of caring for another. You may have extra tasks and responsibilities at the moment. You are fulfilling your usual roles and chores plus those of the patient and adding on new tasks, such as organizing caregivers, picking up prescriptions, giving medications, driving to appointments, entertaining visitors and communicating with the care team. That's not to say that you don't have the interest, time or energy for pleasurable activities and moments. It may simply mean that you need to plan for or focus on these times more carefully. (See "Caregiver resilience: Strategies for self-care" later in this section.)

You may also find that you are overwhelmed at times by conflicting thoughts and feelings about this situation: you may feel great satisfaction in being able to care for the patient, yet at the same time feel resentment or anger about the demands being placed upon you. You are dealing with and grieving the many losses in your own life, as well as witnessing the losses experienced by the patient. You may feel physically and emotionally exhausted, wondering how much longer you can "do this." All of these reactions are to be expected.

And you worry that if you get sick or overly exhausted, you will not be able to give the kind of care that has become important to you. However, there may be help available from family and friends or from community services such as Victoria Hospice volunteers, home support agencies and various support programs. Talk to your Home and Community Care nurse or Victoria Hospice counsellor about available resources.

Reflection

How can you care for yourself while caring for another?

What three things would be most helpful to you at this time? Think about ways your family, friends or neighbours could support you (e.g., doing errands, practical chores or offering respite).

What would a mini-rest or break look like to you right now?

Planning for care

Uncertainty – not knowing what lies ahead – can be very unsettling or worrisome for families. You may have questions about practical things, such as hospital beds or wheelchairs, giving medications or making funeral arrangements. You may wonder how this particular disease will progress, “how long” your loved one may live, and what you can expect to see. You may wonder whether you are able to continue care at home, or whether you need to consider a bed at the Victoria Hospice Palliative Care In-patient Unit or other setting.

If you want to know about future care needs, funeral planning or financial and legal affairs,² contact your Home and Community Care nurse or Victoria Hospice counsellor. They can answer many of your questions and provide you with written information, or direct you to the appropriate resources.

Reflection

Think about what you are hoping for in the coming weeks and months.

What information would be most helpful to you at this time?

Are there things you will want to know in the future?

² Dial-A-Law (1-800-565-5297, www.dialalaw.org) and the Lawyer Referral Service (1-800-663-1919) offer information on a number of topics and can refer you to legal services if you do not have your own representative.

Communication

While your family may share many common characteristics, values and interests, each of you have unique ways of looking at and dealing with things. These differences may be appreciated and enjoyed, but they can also cause challenges when families are stressed. Dealing with the ongoing change, multiple losses and uncertainty of having someone seriously ill and dying in the family can heighten everyone's stress level. This makes it important to not only plan for self-care, but also to plan for family care. Family care starts with communication, and good communication requires time, honest discussion, respect and agreements about ways to make decisions.

While it may seem easier to deal with this situation on your own, to hide your thoughts and feelings, or to protect other family members from the worry or turmoil, this will likely not work well in the long run. When people are excluded or ill-informed, they often feel resentful and hurt, and it becomes harder to work together. Finding effective ways to communicate with one another at this time will help patient care and family relationships.

Sharing thoughts and feelings can ease one's sorrow and sense of being isolated and alone. However, for some this is not an easy conversation to have. It may help to talk first with a Victoria Hospice counsellor to plan such a conversation or to have the counsellor be present when you meet with your family, so that everyone's concerns and questions are addressed.

Involving others in tasks, information-sharing and decision-making can ease the burden and lead to more effective planning. Continuing to reminisce about the past, share pleasurable activities and discuss upcoming events can help to nurture and normalize family life.

Remember that family communication needs to include the patient!

Reflection

Consider the challenges you and your family have been facing.

Is there something important to talk to your family about (e.g., information, secrets, concerns)?

Is there an activity that your family would enjoy doing together?

Is there an upcoming decision that your family could help you with?

Feeling helpful

Sometimes family and friends wonder how to help someone who is ill. Remember, your relationships pre-date this illness and there may be activities or interests that you have shared over the years that you can continue or reminisce about now. There may be practical jobs or errands that need to be done, or it may be a time for quiet conversations and heartfelt presence. The following suggestions can help you find ways to be close and supportive:

- Touch – an embrace, gentle massage or a squeeze of the hand can be comforting and express your caring
- Humour – enjoying laughter together can bring lightness and pleasure
- Reminiscing – photos or stories are reminders of shared memories and life
- Silence – can be as comforting as conversation and require less energy
- Asking what's needed or wanted – allows the ill person to have more control
- Reading, singing, offering prayers and playing music may be pleasurable or comforting to the person and those who care for them

Caregiver resilience: Strategies for self-care

Taking good care of yourself at this time is both important and difficult. However, even small efforts can have great benefits. Consider incorporating a strategy from each of the following categories into every day. Maintaining your health will allow you to be more helpful – refreshed, renewed and restored.

Physical

- Eat properly with balanced, even if small, meals.
- Exercise (e.g., walk, swim, do yoga, do tai chi).
- Get adequate rest and sleep (e.g., put your feet up regularly).
- Consider massage, acupuncture or other complementary therapies.

Emotional

- Find ways to cope/deal with your grief and the thoughts and feelings that arise.
- Find quiet time to be alone (even five minutes is helpful).
- Plan some time away from care on a regular basis.
- Meet with a counsellor or a support group.

Social

- Meet with friends who understand what you're going through and can talk about shared interests.
- Try to stay connected with your favourite activities (e.g., golf, bridge, going for lunch).

Spiritual

- Stay connected; if you have a faith community, talk to your pastor, rabbi, priest or teacher.
- Spend time in a nurturing place (e.g., beach, sacred place, nature).
- Reflect on your beliefs and what is most important or meaningful to you now.
- Reaffirm life.

Thoughts

- Read a light or inspiring book.
- Listen to soothing music.
- Meditate, or use stress reduction exercises (see the relaxation techniques in “Patient resilience: Strategies for self-care”)
- Write in a personal journal, paint or do collage.

Reflection

Consider creating a “self list” for yourself.

Activities I want to do more of

One thing I can do for myself every day

Three things am I grateful for in my life now

One thing I can ask someone to help me with