

PALLIATIVE AND END-OF-LIFE CARE: A CAREGIVER'S JOURNEY

1 The shock

I feel powerless.
If something happens to me,
who will help my mother?

I feel frustrated
that I can't do
anything to
improve my loved
one's condition.

I consider
myself
responsible
for my child;
it's my duty
to show that
I am strong.

If I leave
my loved one
under the care
of others,
I feel guilty.

I fulfill my loved one's
needs before
satisfying my own.

I am afraid to
hurt my loved
one when
administering
medication
(for example
injections) and
that he will be
angry.

I think I can
manage my loved
one's end of life,
but I don't know
what to expect.

I cared for my spouse, but now,
who will take care of me?

I am no longer
able to tolerate
my loved one's
suffering alone
at home.

2 The ups and downs

3 The end of your loved one's life and grief



Different emotional states

- You ask questions about the illness: Internet searches, acquaintances, etc.
- You are concerned or confused.
- You isolate yourself because of the uncertainty surrounding your loved one's health.
- You wonder about the steps to come.
- You must adapt to your new reality and learn to live with the consequences associated with this illness.



How to deal

- Speak with resource people and look for information on the Internet.
- Analyze and validate any information you are given and discuss it with your loved one.
- Accept the services that are available (ex.: on-call team, CLSC at-home support team) and call upon them for reassurance and help during difficult periods.
- Request help for legal and financial aspects, if necessary.
- Explore your loved one's wishes while respecting his rhythm and paying attention to your own needs.
- Discuss pre-admission for palliative care homes, if applicable.

- You must manage the difficult moments that arise as part of your daily life.
- You must adapt to the many changes and prepare for the steps to come.
- You feel alone to deal with all the tasks and formalities.
- You try to fulfill your loved one's needs as you continue to see to your daily obligations.
- Participate in the administering of care, welcome health professionals into your home, and do not hesitate to ask questions.
- Manage appointments, accompany your loved one for his appointments, and inform your patient navigator of any changes so that the doctor is quickly made aware of any results (tests, swabs, samples).
- Manage medication.
- Make a list of what may be helpful so that you can openly inform others and make clear requests.

Consult the *Support Guide for Caregivers | Palliative and end-of-life accompaniment*
Visit santeestrie.qc.ca > *Care and Services* section

- You are tired.
- You are given a great deal of information.
- You must make many decisions and follow several steps (notary, palliative care home, medication, etc.).
- Gather information and respect your loved one's end-of-life choices.
- Stay alert to detect the breaking point in your loved one's condition and call the 24-hour on-call service, if necessary.
- Be involved and help the team responsible for your loved one's care prepare for the transfer towards his end-of-life location or for arrangements required for at-home end-of-life.
- Accompany your loved one to his chosen end-of-life location (if not at home).
- Accompany your loved one in his last moments and surround yourself with those who can support you (friends, family, healthcare workers).
- Participate in bereavement follow-up meetings (1 or 2 meetings possible) with your patient navigator. Do not hesitate to ask other resources for support (palliative care home, funeral home, family doctor, etc.).