

An illustration of two people, a man and a woman, looking out over a landscape of purple mountains. The man is in the foreground, wearing a blue jacket, and the woman is behind him, wearing a white shirt and a green headscarf. The sky is yellow with a few clouds and butterflies. The foreground has some green grass and flowers.

# CALM

*for caregivers*

an illustrated workbook for caregivers  
of patients with advanced cancer







We wish to acknowledge that this workbook was created on the traditional territory of many nations including the Mississaugas of the Credit, the Anishnabeg, the Chippewa, the Haudenosaunee and the Wendat peoples. It is now home to many diverse First Nations, Inuit and Métis peoples. We also acknowledge that Toronto is covered by Treaty 13 with the Mississaugas of the Credit. We are grateful for the opportunity to work on this land.

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Printed in Toronto.

# **CALM for Caregivers**

An Illustrated Workbook for  
Caregivers of Patients with  
Advanced Cancer

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# Acknowledgments

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Many individuals have contributed at various stages to the development of this workbook.

The theoretical framework, content topics, and general approach are based on the brief, semi-structured psychotherapeutic intervention Managing Cancer and Living Meaningfully (CALM), designed specifically for patients with advanced cancer and their family caregivers.

CALM was developed by Dr. Gary Rodin and Dr. Sarah Hales and shaped by the valuable input of many clinical and research collaborators. CALM was adapted into material for a self-directed online intervention that served as a foundation for this workbook.

We would like to acknowledge the input of the many individuals who helped to develop that original online material including clinician advisors (Dr. Froukje DeVries, Loreto Fernandez, Dr. Lindsay Hurlburt, Dr. Ebru Kaya, Dr. Chana Korenblum, Dr. Jenny Lau, Dr. Andrew Matthew, Kelly McGuigan, Dhara Moddel, Dr. Pamela Mosher, Patricia Murphy-Kane, Ashley Patterson, Dr. Christian Schulz-Quach, Dr.

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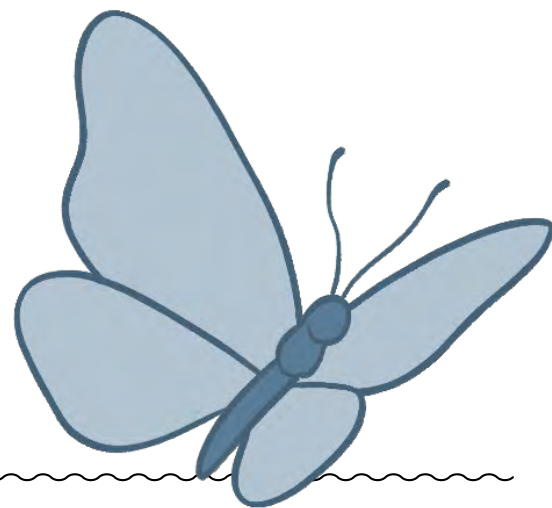
As the workbook continued to be developed, we gained invaluable insight through draft reviews and focus groups with family caregivers from UHN Patient Partners.

This final version of this workbook was created by Dr. Rinat Nissim, Dr. Sarah Hales, and research coordinator Karley Wulf. Content was illustrated and designed by Emily Huang, a biomedical communications graduate student (MScBMC) at the University of Toronto, who was supervised under Dr. Shelley Wall, associate director and associate professor at the MScBMC program.

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# Introduction

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All of us may have different roles in life, as family members, friends, partners, professionals, etc. These roles may fulfill us in different ways. Some we may take on by choice and some not.

The role of a caregiver sometimes comes suddenly and sometimes gradually. It may be a role we take on naturally without much thought, or it may be one that we resist or struggle to adjust to. Depending on different life circumstances, caregiving duties may be shared but often the burden falls mostly on one family member.

Most of the roles we have in our lives come with training, whether formal (schooling, on the job experience, etc.) or informal (learning through experience or watching others) but most of us do not have the opportunity to be trained for the role of a caregiver.

The purpose of this workbook is to support caregivers of people with advanced cancer. Through research into caregiver experiences, and through years of working with caregivers in 1:1 therapy and clinical settings, it has become clear that caregivers need and deserve support for the unique situations they face. Unfortunately, up until now there have been limited resources to support caregivers, and research shows that caregivers can often be reluctant to reach out for help resulting in underutilization of support services. This workbook has been designed to provide caregivers with a self-paced, 'choose your own path' approach to support for the emotional and practical challenges of cancer, allowing

caregivers to be in control of their experience, accessing the information they want, when they are ready.

Of note, we recognize that the close support around someone with cancer can include spouses, relatives, and/or friends. Throughout this workbook we use the word "family" to include anyone in the close circle around the individual with cancer.

## Managing Cancer and Living Meaningfully (CALM)

CALM for Caregivers is based on components of CALM therapy ("Managing Cancer and Living Meaningfully"). Developed in Canada and used in many countries around the world, CALM is focused not only on the practical challenges of cancer, but also the range of emotions that may be experienced and how to manage them, as well as common challenges to identity, relationships, meaning, and planning that may arise during this time.

This workbook begins with a primer on emotions and then explores four CALM domains: 1) symptom management and relationships with healthcare providers; 2) changes in self and relationships with close others; 3) sense of meaning and purpose; and 4) mortality and future-oriented concerns. Each section has a different focus, but



you will notice some similarities throughout. We start each section by highlighting what you can expect, and then information will be presented with real caregiver stories to illustrate the material and reflective exercises woven throughout to help connect what you are reading to your life experiences and circumstances.

The stories are based on real situations. For this reason, names and other personal information may have been changed to protect privacy. You may relate to these stories or you may not. Each story is meant to provide an example, relevant to the particular domain or topic, but is not intended to represent all experiences. For some people, learning through someone else's story can be helpful and allow for deeper insights into their own story and experience. If this is not beneficial for you, we have tried to ensure that the reflective exercises which typically follow can still be completed from your own perspective.

## How to Use this Workbook

This workbook is meant for you to use in any way that benefits you.

The various sections of this workbook have no intended order and can be worked through in many ways. You should feel free to decide what content interests you and focus your attention there. It can be helpful initially to familiarize yourself with all the content of this workbook, even if a topic or exercise is not of interest/importance now. Reviewing the content now will help you recall and return to it later.

For individuals who prefer to navigate the workbook by jumping from section to section, simply note that some information may be introduced in previous section, so you may need to flip back to the to familiarize yourself with a strategy or concept. However, this should not deter you from freely navigating the workbook as you prefer.

Many people may prefer to use this workbook with the support of a therapist or mental health professional. Bringing difficult topics or emotions to a session with a professional can help support your understanding and the process of self-reflection but is not required.

## Additional Supports to Consider

This workbook is not intended as a substitute for professional support. When navigating a challenging time, looking for professional help can be beneficial. If you feel you need more support, consider contacting your family doctor who may be able to connect you with mental health resources in your community. The cancer treatment centre may also offer counseling and support that can help you. If you feel you could benefit from speaking with a mental health-care professional, let the treatment team know. Asking to be referred to a social worker can often be a good starting point to tap into the support you need.

If you need immediate support, or if you have thoughts of hurting yourself or someone else, dial 911 or go to your nearest emergency room. There is help available to you.

