

# LOOKING FORWARD

Rebuilding your life after cancer treatment

## WHAT'S NEXT? BEING MINDFUL ABOUT YOUR 'NEW NORMAL'

First in a series of 7 booklets

Your  
Practical  
Guide



"The real voyage of discovery consists not of seeking new landscapes, but in having new eyes."

*Marcel Proust*

# WELCOME

As people with cancer finish active treatment and look towards returning to daily life, it is very common that they will have questions about their recovery. There may be uncertainty about next steps. Recovering from cancer treatment isn't only about recuperation, but also about healing – physically, emotionally, and spiritually. The *Looking Forward* program offers support and resources during recovery for patients and their families.

We consider recovery as a process fundamentally based on personal experience. It was vital to us that people who have experienced recovery be part of the collaboration with healthcare professionals and researchers in developing the *Looking Forward* program. Former patients shared their perspectives, identified key priorities, and collaborated on the design and format. It is our firm belief that through their engagement this program will be a practical and relevant source of information. We are grateful to the Rossy Cancer Network, other sponsors and participants for this opportunity.

**Rosana Faria, L.Ps.**  
*Clinical Psychologist and  
Coordinator of Psychosocial  
Oncology, St. Mary's Hospital*

**Susan Law, PhD**  
*Principal scientist,  
St. Mary's  
Research Centre*

The Rossy Cancer Network (RCN) is a partnership of McGill University's Faculty of Medicine and its affiliated teaching hospitals: the McGill University Health Centre, the Jewish General Hospital and St. Mary's Hospital Center. Launched in 2012 thanks to a transformative gift from the Rossy Family Foundation, the RCN is a 10-year initiative to improve quality across the continuum of cancer care for patients in the McGill-affiliated hospitals.

Among the RCN's key priorities is improving the patient experience throughout their cancer journey. The *Looking Forward* initiative addresses the transition to survivorship after treatment – a crucial moment in a patient's cancer journey and one where more support is often required. The RCN is proud to support of this initiative which provides much needed information and assistance to cancer patients who are adjusting to the 'new normal' in their lives following treatment.

**Dr. Ari Meguerditchian,**  
*Cancer Quality & Innovation  
Program Lead, RCN*

**Dr. Wilson H. Miller,**  
*Clinical Lead, RCN*



# ACKNOWLEDGEMENTS

The *Looking Forward* initiative would not have been possible without the patience, advice and support of patient collaborators who were research partners on this project. Special thanks to Monique Ferland, Laurie Hendren, George Michaels, Danielle Potas, and Givette Volet for their feedback and invaluable insight. Thank you to the health professional members of the *Looking Forward* research team: Rosana Faria (Clinical Psychologist in Oncology, St. Mary's Hospital), Susan Law (Principal Scientist, St. Mary's Research Centre), Tarek Hijal (Radiation Oncologist, MUHC), and Joan Zidulka (Oncologist, St. Mary's Hospital). Thanks also to Mona Magalhaes (Project Coordinator) and Maud Mazaniello (Bilingual Communications Specialist). Sincere thanks to Linda Tracey for her editing and layout expertise in the production of the booklets, and to Céline Bailey for editing the French version. We are grateful to Joel Montanez and William Langlais for their professional and technical expertise in the production of the introductory video.

We owe a debt of gratitude to the patients who shared with us their experiences of treatment and life after treatment, and who worked with healthcare team professionals and the research team to select the topics included in the booklets. We feel honoured to have heard your stories. A special thanks to the health professionals for sharing their experiences of caring for people with cancer.

And finally, we give our heartfelt thanks to the oncology professionals who supported the development of materials and offered their expert advice in the following chapters: Karine Gimmig (Cancer Care, SMHC), Marc Hamel (Psycho-social Oncology, MUHC), Sandra Grant (Cancer Care, SMHC), Maria Milioto (Centres d'Évaluation et de Réadaptation), Filomena Novello (Physiotherapy, SMHC), Janet Steinberg (Cancer Care, SMHC), Mei-Lin Yee (Hope and Cope) and Joan Zidulka (General Oncology, St. Mary's Hospital).

This work would not have been possible without the generous financial support from the Rossy Cancer Network, the Canadian Institutes of Health Research, and the User's Committee of St. Mary's Hospital Center. Special thanks to St. Mary's Hospital Foundation for their ongoing support for research, education, and healthcare services.



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# MEET THE EXPERTS



## **Rosana Faria, Psychologist**

Rosana Faria is a clinical psychologist and coordinator of psycho-social oncology at St. Mary's Hospital. Her research interests are in finding ways to improve patient experiences and psycho-social health outcomes for people with cancer.



## **Janet Steinberg, Psychotherapist**

Janet Steinberg holds a Master's degree in Social Work from McGill University, as well as a post-graduate certificate in Couple and Family Therapy. She works at St. Mary's Hospital with patients and families affected by cancer, and also has a private practice where she offers individual, couple and family counseling.



## **Maria Milioto, Physiotherapist**

Maria Milioto is a physiotherapist and an expert in interdisciplinary and occupational rehabilitation. She is co-owner and director of 6 Cliniques d'Évaluation et de Réadaptation in Montreal, and is also a member of the administrative council of Coalition Priorité Cancer au Québec.



## **Tarek Hijal, Radiation Oncologist**

Dr. Hijal is a radiation oncologist at the McGill University Health Centre. His clinical interests include breast cancer, colorectal cancer and hematologic malignancies. His research mainly focuses on decreasing treatment durations in breast cancer radiotherapy.



## **Joan Zidulka, Oncologist**

Dr. Zidulka is a hematologist-oncologist at St. Mary's Hospital and an associate professor in the Departments of Medicine and Oncology at McGill University. As a community-based oncologist she works with all the common solid and hematological tumors.



### **Mei-Lin Yee, Patient Rights Advocate**

Mei-Lin Yee has worked as a lawyer in administrative law and in human resources management for almost 30 years. As a result of her own cancer diagnosis, Mei-Lin now actively volunteers as a patient rights advocate, where she is able to use her personal and professional experience to their fullest.



### **Sandra Grant, Dietitian**

Sandra Grant is a graduate of the Faculty of Science at McGill University where she majored in Dietetics and Human Nutrition. She has worked at St. Mary's Hospital for over 15 years and now specializes in cancer care.



### **Karine Gimmig, Pivot Nurse**

Karine Gimmig received her nursing degree from the Université de Montréal. She has worked as a pivot nurse in cancer care, specializing in breast cancer and palliative care, at St. Mary's Hospital since 2012.



### **Nancy Moscato, Social Worker**

Nancy Moscato is a clinical social worker. She has been working at the McGill University Health Centre for over 15 years, the past 5 years in radio-oncology. Nancy provides resources, support and psycho-social care to patients, families and caregivers throughout the illness continuum and the recovery process.



### **Marc Hamel, Psychologist**

Dr. Hamel is the clinical director of the psycho-social oncology program at the McGill University Health Centre, and provides psychological services to oncology patients and their families. His research interests include screening for distress, anxiety and depression, the fear of recurrence, and coping.

## chapter 1

"When you bring peace to your past, you can move forward to your future"

*Author unknown*

# 1. WHAT'S NEXT: BEING MINDFUL ABOUT YOUR 'NEW NORMAL'

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### IDENTIFYING AND UNDERSTANDING YOUR NEEDS

Starting your recovery

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## SECTION II.

### GETTING TO KNOW YOUR 'NEW NORMAL'

The self-assessment

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### PRACTICAL QUESTIONNAIRE

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## SECTION IV.

### YOUR ROADMAP

Find all the information you need

23

You have finished treatment and are entering the recovery phase.

**Recovery is a period of transition.** It is a time when you can reflect on everything that you've gone through, and prepare yourself to move from that stage of your life to the new chapter that is before you. While you were in treatment, you were probably mostly focused on getting yourself through that challenging time; but now you can turn your attention to regaining strength and healing yourself.



NADIA, recovering from breast cancer, age 59

"When we are in treatment, we just think about surviving. The healing process starts when we finish the treatment."

It is often assumed that after cancer treatment, people return to their life as it was before; however, this is not always the case. The experience of cancer treatment can affect the mind and body beyond treating the disease. Some people recover quite easily. Others may find it more challenging to return to everyday life, as they don't feel that they are the same person that they were before, emotionally or physically. There are many reasons for all of these feelings and everyone's experience is unique; but at the centre is the idea that having had cancer can cause changes in a person, which can also affect their life in general. That is why people often refer to life after treatment as the 'new normal'.

**Time is important in the healing process**, for the mind and the body. Although it can be difficult to be patient with the process, it is important to understand that the range of emotions can be all over the place, and it is all normal. Some people feel a roller coaster of emotions, from relief and excitement for the future, to feeling anxious and angry that they are in this situation. People also talk about feeling disoriented at first because their lives are no longer structured by medical appointments, treatments and tests. Physical effects from treatment can add another layer of challenges to the recovery phase. As with emotional effects, physical effects have a large range, depending on the treatment you received, and can vary widely from person to person.



AMELIA, recovering from breast cancer, age 49

"I kind of felt lost and like I had been thrown on some deserted island. I felt my whole life was really upside down. It was just like a complete unknown."

It is not unusual to feel that you do not have a clear path, or a plan of where to begin, for your recovery. During your treatment you were likely surrounded by your medical team who advised you every step of the way; but now many of the choices and decisions will be up to you. The goal of the *Looking Forward* kit is to help you prepare a plan — a road map — to discover what is important for you in your recovery, and to offer information, tips and strategies on how to address your needs and concerns. The information presented in the *Looking Forward* kit was prepared with the advice of people who have gone through cancer treatment and recovery, as well as health professionals who care for people throughout their experience. We hope it will help you.

These booklets do not provide an in-depth assessment of any particular type of cancer; you must always seek professional help to aid you in your recovery.

# SECTION I. IDENTIFYING AND UNDERSTANDING YOUR NEEDS DURING RECOVERY

## WHERE TO START?

During your recovery, it can be helpful to take the time to understand where you feel you are now physically, emotionally and socially, what has changed for you, and how to adapt to these changes as part of your current life.

**Recovery is a process;** it does not all happen from one day to the next. Taking the time to reflect on the current state of your health, wellbeing, and personal relationships can be a good place to start in order to move forward. Some people would like to leave their cancer experience behind, but this is not an easy thing to do. All of our experiences are continually shaping and reshaping us, and our present and future lives. They become part of who we are. By acknowledging the changes that have occurred because of your treatment experience, you can begin to find ways to connect your before and after worlds in the most helpful way for you. It is important not to ignore what has happened regarding your cancer experience when you are planning how you want to live your life going forward.



The changes that you identify may be very small, or they may lead to a major shift in the way you live your life. Understanding where you are now in terms of your experience and its effects, can help you regain a sense of control over your life. This is important because during your recovery it will be mostly your own choices and decisions that will determine what your recovery will look like. Thinking about what you need to do for yourself to recover, and what is possible for you to do, and then taking the steps forward towards these goals can be very empowering. You are the best person to know what you need.

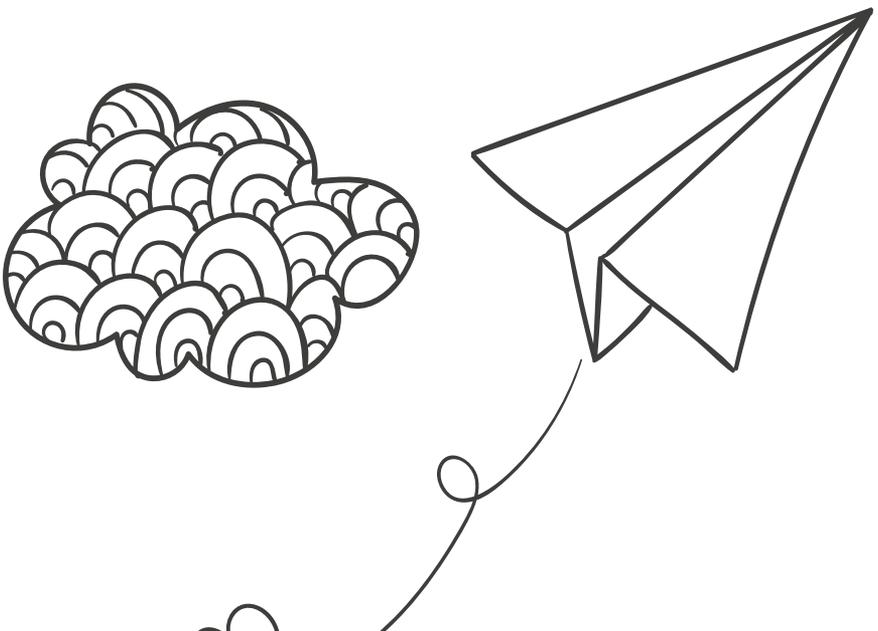
**Section II** will go into more detail about the things you may want to consider during recovery, as you look forward to what is next for you.

**Section III** includes a practical questionnaire to help guide you through this process.



"Our life pathway reflects how our choices were made; how the results of our choices were incorporated and how changes were embraced; then, just then, we can have stories to tell about our life experience."

- Rosana Faria, psychologist



## SECTION II.

# GETTING TO KNOW YOUR 'NEW NORMAL'

## THE SELF-ASSESSMENT

**Understanding and awareness** are two important tools when you approach self-assessment. How you combine the effects of your treatment experience with your life in recovery and beyond will be unique to you; however, there are some basic steps that anyone can use to explore their feelings a bit more deeply.

In this section, you will be introduced to the idea of assessing yourself. This is like taking a survey of what's going on with your body and your emotions. The assessment is divided into 3 parts: your physical wellbeing, your thoughts and emotions, and your relationships with the people in your life. In each part, some things or ideas will be proposed for you to think about.

### YOUR PHYSICAL WELLBEING

With time, your body will recover from treatment. It is important to give yourself this time and to be aware of what your body is telling you as you recover. Physical recovery does not only mean that the body heals; it also means accepting any physical changes that you may have, and being able to move forward with your life.

Many people who have experienced cancer feel physically different, whether it is visible to other people (such as the loss of a limb), or not (such as with fatigue or pain). You may feel you have been betrayed by your body, or perhaps you have feelings of guilt because you didn't lead a healthy lifestyle before your diagnosis. It is hard to understand the real randomness of cancer – it is more helpful at this stage to think about how your body handled the treatment, and how you can take care of it going forward. Take the time to listen to your body and pay attention to how you have been feeling physically since you began recovery.

Some things to consider are:

- Level of fatigue
- Level of pain
- Appetite
- Mobility issues (ability to move around)
- Level of energy
- Any concerns with your body

**TAKE SOME NOTES:** Since beginning my recovery, physically I feel...

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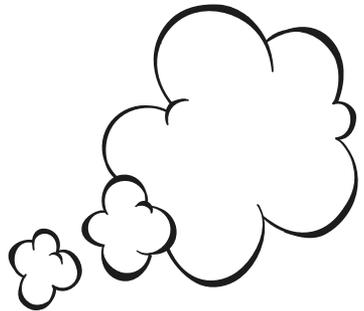
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## YOUR EMOTIONAL AND SPIRITUAL WELLBEING

After treatment you may be feeling a variety of emotions, such as:

- Relief
- Loneliness
- Joy
- Happiness
- Anger
- Sadness
- Depressed feelings
- Gratitude
- Fear
- Love
- Excitement about the future
- Stress





## YOUR RELATIONSHIPS AND SOCIAL LIFE

Your relationships with your partner, family, friends and work colleagues may have changed since you were diagnosed and in treatment.

Relationships with significant others may have been either strengthened or challenged by the experience of diagnosis and treatment. It is possible that in recovery you will want to spend time reconnecting with your partner, or working through the emotions that both of you may be dealing with at this time.

Some people find that they received tremendous support from some of the people in their life, and surprisingly little support from others, which can affect relationships. The end of treatment can also change some of your social relationships because you as a person may have changed. The role that others expect you to play, or the way they expect you to be, may not be the same as what feels right for you at this time.

For example, a supervisor at work may expect you to go back to your job with the same motivation as you had before, but your goals may be different now. Or, friends may believe that since you are in recovery there is no need to talk about your cancer experience anymore. Your family members may be looking forward to you getting back to daily life, or they may be afraid that you are too fragile to get back to daily life and take on the role that you had before treatment. It can be helpful to think about how your relationships are affecting your recovery and which ones are important for you to work on.

**TAKE SOME NOTES:** About my relationships with my partner, family, friends and/or colleagues, I feel...

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# SECTION III. PRACTICAL QUESTIONNAIRE TO IDENTIFY YOUR NEEDS

Now that you have taken the time to think about your experience, you may have some ideas about what areas of your life you would like to focus on during your recovery. This section includes a questionnaire with practical questions that will help you prepare a kind of road map to recovery, by highlighting the areas where you may need more information, guidance and/or help. **We invite you to complete this questionnaire, and then consult the chart on page 22 that will show you where you can find the information that you are looking for in the booklets.**

We wish you all the best for your recovery!

CHECK THE STATEMENTS THAT RELATE TO YOUR PRESENT EXPERIENCE:

## About your physical condition:



FATIGUE IS AFFECTING MY DAILY LIFE	>	<input type="checkbox"/>
I'M NOT SLEEPING WELL	>	<input type="checkbox"/>
IT'S A CHALLENGE FOR ME TO CONCENTRATE ON THINGS FOR A PERIOD OF TIME	>	<input type="checkbox"/>
I'M HAVING TROUBLE REMEMBERING THINGS	>	<input type="checkbox"/>
I'M EXPERIENCING PAIN SINCE MY TREATMENT	>	<input type="checkbox"/>
I'M EXPERIENCING TINGLING, NUMBING SENSATIONS IN MY HANDS OR FEET	>	<input type="checkbox"/>

MY SENSE OF TASTE HAS CHANGED



I HAVE SOME DISCOMFORT IN MY MOUTH/TEETH



I AM CONCERNED ABOUT MY WEIGHT GAIN OR LOSS



I AM EXPERIENCING LOSS OF CONTROL OF BOWEL OR BLADDER FUNCTION



I'M INTERESTED IN LEARNING ABOUT HOW I CAN MANAGE MY POST-TREATMENT SIDE EFFECTS WITH HEALTHY LIVING



I'D LIKE SOME TIPS ON HOW TO SPEAK EFFECTIVELY WITH MY HEALTHCARE TEAM ABOUT MY SIDE EFFECTS



I'M INTERESTED IN LEARNING ABOUT COMPLEMENTARY THERAPIES AND HOW THEY MAY HELP MANAGE MY SIDE EFFECTS



I WOULD LIKE TO KNOW MORE ABOUT HOW NUTRITION AND AN ACTIVE LIFESTYLE CAN HELP ME RECOVER AND LIVE WELL



I WONDER WHAT TYPES OF FOODS I SHOULD EAT TO HELP MANAGE MY WEIGHT GAIN OR WEIGHT LOSS



I WOULD LIKE SOME NUTRITION TIPS FOR MANAGING SIDE EFFECTS



I NEED TO IDENTIFY WHAT TYPES OF EXERCISES OR PHYSICAL TRAINING I CAN DO



I HAVE SOME QUESTIONS ABOUT  
SEXUALITY AND INTIMACY



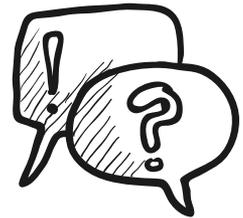
I'D LIKE TO KNOW WHERE I CAN FIND  
INFORMATION ABOUT REHABILITATION  
SERVICES



I WOULD LIKE TO KNOW HOW TO SEARCH  
FOR RELIABLE INFORMATION ABOUT  
MY ILLNESS AND RECOVERY



**About your emotional/spiritual wellbeing:**



I WOULD LIKE TO KNOW MORE ABOUT THE  
ACTIVITIES I CAN DO THAT CAN HELP  
IMPROVE MY EMOTIONAL WELLBEING



I THINK FATIGUE IS AFFECTING MY MOOD



I HAVE CONCERNS ABOUT THE CANCER  
COMING BACK



I FEEL DOWN AND UNABLE TO SHAKE OFF  
MY SADNESS. AM I DEPRESSED?



MY EMOTIONS ARE INTERFERING WITH  
MOVING FORWARD IN MY RECOVERY



ANGER IS SHOWING UP IN MY LIFE



I AM FEELING MORE ANXIOUS THAN USUAL >

I THINK I NEED SOMEONE TO TALK TO ABOUT WHAT I AM GOING THROUGH, BUT I'M NOT SURE WHERE TO START >



### About your relationships and work:

I WOULD LIKE TO KNOW MORE ABOUT THE THINGS I SHOULD CONSIDER WHEN I AM PLANNING MY GRADUAL RETURN TO WORK >

I'D LIKE SOME TIPS ON HOW TO ADDRESS MY WORK GAP IN MY CV OR WHEN TALKING TO A POTENTIAL EMPLOYER >

I WOULD LIKE TO UNDERSTAND WHAT MY RIGHTS ARE REGARDING REQUESTING REASONABLE ACCOMMODATION FROM MY EMPLOYER >

I WOULD LIKE TO KNOW IF I HAVE TO TELL A POTENTIAL EMPLOYER ABOUT MY ILLNESS >

I WOULD LIKE SOME ADVICE ABOUT HOW TO TALK TO MY EMPLOYER AND WORK COLLEAGUES ABOUT MY CANCER EXPERIENCE >

I WILL BE LOOKING FOR A NEW JOB AND I WOULD LIKE SOME TIPS AND STRATEGIES THAT WILL HELP ME >

I AM THINKING ABOUT CHANGING MY JOB OR CAREER AND WOULD LIKE SOME ADVICE ON HOW I SHOULD START AND WHAT I SHOULD CONSIDER >

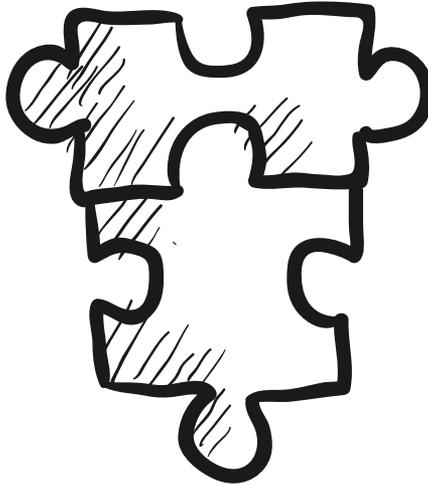
I HAVE DECIDED NOT TO RETURN TO WORK,  
OR I CAN NO LONGER WORK.  
WHAT SHOULD I BE CONSIDERING? >

I THINK THE PEOPLE WHO CARED FOR ME DURING  
MY TREATMENT COULD USE SOME SUPPORT AND  
ADVICE NOW THAT I AM IN RECOVERY >

I WOULD LIKE SOME ADVICE ON DATING AND  
SOCIALIZING NOW THAT I HAVE COMPLETED  
TREATMENT >

I FEEL LIKE A DIFFERENT PERSON NOW, BUT I'M  
NOT SURE EXACTLY HOW OR WHY THIS IS SO >

MY CANCER EXPERIENCE HAS CHANGED MY  
RELATIONSHIP WITH MY PARTNER, FAMILY,  
AND/OR FRIENDS >

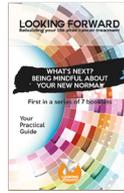


**CONSULT THE CHART ON THE  
FOLLOWING PAGE THAT WILL INDICATE  
THE CHAPTER WITH **THE INFORMATION**  
**YOU ARE LOOKING FOR****

## GO TO CHAPTER 1

WHAT'S NEXT? BEING MINDFUL ABOUT YOUR 'NEW NORMAL'

IF YOU CHECKED OFF ANY  
BOX IN THIS COLOUR >



## GO TO CHAPTER 2

SIDE EFFECTS & THEIR SYMPTOMS

IF YOU CHECKED OFF ANY  
BOX IN THIS COLOUR >



## GO TO CHAPTER 3

EMOTIONS, FEARS AND RELATIONSHIPS

IF YOU CHECKED OFF ANY  
BOX IN THIS COLOUR >



## GO TO CHAPTER 4

REGAINING FUNCTION

IF YOU CHECKED OFF ANY  
BOX IN THIS COLOUR >



## GO TO CHAPTER 5

BACK TO WORK

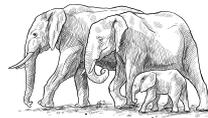
IF YOU CHECKED OFF ANY  
BOX IN THIS COLOUR >



## GO TO CHAPTER 6

FAMILY CAREGIVER SUPPORT

IF YOU CHECKED OFF ANY  
BOX IN THIS COLOUR >



## GO TO CHAPTER 7

RELIABLE INFORMATION

IF YOU CHECKED OFF ANY  
BOX IN THIS COLOUR >



# SECTION IV. YOUR ROADMAP



- Chapter 1.** What's next? Being mindful about your 'new normal'
- Chapter 2.** What to expect after treatment? Managing side effects and their symptoms
- Chapter 3.** Emotions, fears and relationships
- Chapter 4.** Regaining function. Promoting and maintaining health
- Chapter 5.** Back to work
- Chapter 6.** Family caregiver support
- Chapter 7.** Where to find reliable information?

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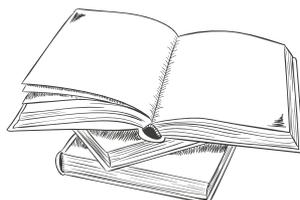
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The *Looking Forward* kit is for information purposes only and is not intended to replace the advice of qualified healthcare providers.

The information included here is offered for your education and guidance, and should always be considered in conjunction with your personal situation and medical condition. Readers should not delay seeking or disregard professional medical advice because of information encountered in this kit. This information is intended to help prepare you to address challenges you may have during your recovery, and to create a plan, set realistic goals, and be able to discuss them with your healthcare team, as well as with family and friends.

All care has been taken to ensure that the information contained here is accurate and based on current evidence at the time of publication. Please note that we are not responsible for the quality of the services or information provided by other organizations listed in the booklet. We do not endorse any particular service, product, treatment or therapy. If the website you are accessing is no longer active, please use the bolded part of the address and then search the particular topic you want. Some of the URLs (website addresses) included in this booklet may change as organizations update their information.

The names of patients have been changed to protect their privacy.



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# LOOKING FORWARD

Rebuilding your life after cancer treatment



## WHAT'S NEXT?

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SIDE EFFECTS AND THEIR SYMPTOMS

3

EMOTIONS, FEARS, AND RELATIONSHIPS

4

REGAINING FUNCTION

5

BACK TO WORK

6

FAMILY CAREGIVER SUPPORT

7

RELIABLE INFORMATION

