Oncology

Passport

Québec

Oncology Passport

Santé
et Services sociaux
Québec

Produced by:
Direction des communications du ministère de la Santé et des Services sociaux du Québec

This document is available online and can be downloaded at **www.msss.gouv.qc.ca/cancer**.

It may also be ordered at **diffusion@msss.gouv.qc.ca** or by mail at:
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Masculine pronouns are used generically in this document.

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WORD OF INTRODUCTION

This is the Oncology Passport for cancer patients, designed to help guide you through the various phases of your care experience. It can help you manage your appointments, treatments, exams, and various meetings with doctors, nurses, and other healthcare professionals. It also provides information on the symptoms you may experience during treatment and can help you decide when and whom to consult about your symptoms. You can use the passport to record information about your tests, exams, symptoms, and even your medication.

Everyone living with cancer receives an oncology passport. We have designed it to make your life easier and facilitate your contact with the care providers you deal with frequently in the healthcare system. It should be your constant companion when you go to the hospital, doctor's office, CLSC, or emergency room. Show it to your care providers; they will be interested in the information it contains. You can also download the Oncology Passport at **www.msss.gouv.qc.ca/cancer**.

Cancer affects everyone differently and your Oncology Passport reflects your personal approach. It is yours to use as you see fit. Don't hesitate to share your concerns, questions, or comments with your healthcare providers.

We wish you well as your journey begins…

ACKNOWLEDGEMENTS

This Oncology Passport is the result of experiences pooled together from people living with cancer as well as nurses and other healthcare professionals who have dedicated time and energy to help meet your needs.

People living with cancer have told us that they found the Oncology Passport to be a useful and effective tool. Healthcare professionals also encouraged us to develop this handy tool for you. You only need to use it.

The Direction de la lutte contre le cancer of the Ministère de la Santé et des Services sociaux would like to thank the working group and everyone else who believed in and took part in and who want everyone living with cancer to receive the best possible care.

IMPORTANT PLEASE READ

Information provided in this booklet is for educational purposes only. It is not intended to replace the advice or guidance of a professional healthcare practitioner or as a substitute for medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

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TABLE OF CONTENTS

1 PERSONAL INFORMATION AND TELEPHONE NUMBERS

Name: _____ Telephone number: _____

Telephone number of a relative or friend to contact in the event of an emergency: _____

_____

Important telephone numbers

Oncology clinic: _____

Oncology Emergency: _____

Info-Santé: _____

24/7 service (you must register with your CLSC): _____

_____

_____

_____

2 PROFESSIONAL SUPPORT AND OTHER VALUABLE RESOURCES

The composition of your healthcare team depends on *your needs* and is designed to help you deal with your illness and make the most out of every day. Your healthcare providers work *together to* provide you with the best care and treatment. If you have any questions, don't hesitate to contact any member of your team.

The list of resources lets you see how your healthcare team is structured and what each team member does. We encourage you to enter the *names and contact information of your healthcare providers*.

HEALTHCARE TEAM	
Nurse Navigator Acts as resource person throughout the course of the disease. Assesses your resources and healthcare needs. Informs and supports you.	Name: Telephone number: Fax: Email:
Oncology clinic nurse Administers treatments. Answers your questions about your treatments and concerns.	Name: Telephone number: Fax: Email:
Oncologist Treats cancer with chemotherapy.	Name: Telephone number: Fax: Email:

Surgeon Performs surgical procedures to remove tumors.	Name: Telephone number: Fax: Email:
Radiation Oncologist Treats cancer using X-rays (radiotherapy).	Name: Telephone number: Fax: Email:
Oncology Pharmacist Prepares your chemotherapy treatment and explains it in detail. Tells you about potential side effects and how to minimize them.	Name: Telephone number: Fax: Email:
Other	Name: Telephone number: Fax: Email:

Psychosocial Resources Professionals such as social workers, psychologists, psychiatrists, spiritual-care professional, and others can provide support.	Name: Telephone number: Fax: Email:
	Name: Telephone number: Fax: Email:
Other Healthcare Professionals Other team members such as physical therapists, occupational therapists, and nutritionists can assess your physical needs and advise you on ways to improve your quality of life.	Name: Telephone number: Fax: Email:
	Name: Telephone number: Fax: Email:

Volunteer Resources	Name: Telephone number: Fax: Email:

COMMUNITY HEALTHCARE TEAM

CLSC CLSC Resource Person	Name: Telephone number: Fax: Email:
Family Physician Plays a key role in monitoring your overall health	Name: Telephone number: Fax: Email:
Pharmacist	Name: Telephone number: Fax: Email:

Palliative-Care Team	Name: Telephone number: Fax: Email:
Other	Name: Telephone number: Fax: Email:
Community Volunteer Resources	Name: Telephone number: Fax: Email:

*** At the end of active treatment, your doctors and nurses will tell you who will be in charge of follow-up.**

3 FOLLOW-UP SCHEDULE APPOINTMENTS AND EXAMS

Legend:

C	Chemotherapy	T	Blood tests
R	Radiotherapy	E	Exams
V	Visits	MD	Doctor

NUR	Nurse	NUT	Nutritionist
IPO	Pivot Nurse / Nurse navigator in Oncology	SW	Social worker
		PSYCH	Psychologist

MONTH: _____

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY

Legend:

C	Chemotherapy	T	Blood tests
R	Radiotherapy	E	Exams
V	Visits	MD	Doctor

NUR	Nurse	NUT	Nutritionist
IPO	Pivot Nurse / Nurse navigator in Oncology	SW	Social worker
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MONTH: _____

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY

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Legend:

C	Chemotherapy	T	Blood tests
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V	Visits	MD	Doctor

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MONTH: _____

MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY

FOLLOW-UP SCHEDULE

4 TREATMENT PLAN

Chemotherapy & other treatments

When you go in for treatment, ask the nurse or pharmacist to enter the names of your chemotherapy medications and other drugs in the table below. This information will be valuable should you have side effects or symptoms after your treatment.

Date of first chemotherapy treatment: _____

DATE	CHEMOTHERAPY OR OTHER TREATMENT (including medications given before and after chemotherapy)	DRUGS TO BE TAKEN AT HOME AFTER TREATMENT	COMMENTS

DATE	CHEMOTHERAPY OR OTHER TREATMENT (including medications given before and after chemotherapy)	DRUGS TO BE TAKEN AT HOME AFTER TREATMENT	COMMENTS

DATE	**CHEMOTHERAPY OR OTHER TREATMENT** (including medications given before and after chemotherapy)	**DRUGS TO BE TAKEN AT HOME AFTER TREATMENT**	COMMENTS

DATE	CHEMOTHERAPY OR OTHER TREATMENT (including medications given before and after chemotherapy)	DRUGS TO BE TAKEN AT HOME AFTER TREATMENT	COMMENTS

DATE	**CHEMOTHERAPY OR OTHER TREATMENT** (including medications given before and after chemotherapy)	**DRUGS TO BE TAKEN AT HOME AFTER TREATMENT**	**COMMENTS**

DATE	CHEMOTHERAPY OR OTHER TREATMENT (including medications given before and after chemotherapy)	DRUGS TO BE TAKEN AT HOME AFTER TREATMENT	COMMENTS

DATE	**CHEMOTHERAPY OR OTHER TREATMENT** (including medications given before and after chemotherapy)	**DRUGS TO BE TAKEN AT HOME AFTER TREATMENT**	**COMMENTS**

Radiotherapy

When you visit the radiotherapy department, ask the nurse, technician, or radiation oncologist to enter information about your radiotherapy treatment below.

Area of body treated: _____

Type of radiotherapy: ❑ External beam radiotherapy ❑ Brachytherapy

Expected number of treatments: _____

Expected duration of treatment (weeks): Start date: _____ End date: _____

DATE OR WEEK	RADIOTHERAPY TREATMENT	COMMENTS

DATE OR WEEK	RADIOTHERAPY TREATMENT	COMMENTS

DATE OR WEEK	RADIOTHERAPY TREATMENT	COMMENTS

DATE OR WEEK	RADIOTHERAPY TREATMENT	COMMENTS

DATE OR WEEK	RADIOTHERAPY TREATMENT	COMMENTS

5 WEIGHT & BLOOD TESTS

You may receive certain drugs that reduce blood-cell production. We will test your blood regularly to make sure your cell count is not low. Other tests may also be conducted

Hemoglobin: This provides information about your red blood cells' ability to carry oxygen from the lungs to the rest of the body

- If the value is too low, you may experience symptoms such as acute fatigue or weakness, dizziness, or persistent shortness of breath.

Neutrophils: White blood cells that fight infections.

- If the count is too low, you may develop an infection, which often results in fever.

Platelets: Help produce blood clots, which prevent prolonged bleeding in the event of injury.

- If the count is too low, you may bleed or bruise more than usual.

Weight: This information is used to adjust the dosage of your chemotherapy.

If you like, *you can ask for your blood-test results and record them yourself below.*

The values given in the table are for information purposes only; those at your oncology center may differ. If you have any concerns, don't hesitate to discuss them with your doctor.

Date	Weight (kg) Height (m)	Hemoglobin (120-160 g/L)	Neutrophils (2.1-6.7 X10^9/L)	Platelets (140-450 X10^9/L)	Other			

You are receiving white blood cell growth factors.

Name of medication: _____

Schedule	Dosage	Start Date	Stop Date (final dose)

You are receiving drugs to stimulate red blood cell production.

Name of medication: _____

Schedule	Dosage	Start Date	Stop Date (final dose)

You are receiving anticoagulant drug (to thin your blood and prevent clot formation).

Name of medication: _____

Schedule	Dosage	Start Date	Stop Date (final dose)

6 CENTRAL VENOUS CATHETER

Ask your nurse to indicate the type of catheter used, if any:

☐ Catheter name: _____

Date of insertion: _____

Your nurse at the oncology clinic or CLSC will regularly rinse your catheter and change the dressing according to your center's practices.

If you experience the following severe symptoms:

- **Acute shoulder pain**, or ear or neck pain
  or
- Pain or burning sensation, redness, **heat**, **swelling**, or **discharge** in the area around the point of entry of the catheter, accompanied by fever (over 38°C)

  You should:

  - Call this emergency number: _____
    or
  - Immediately go to the emergency room.

If you experience the following symptoms:

- **Pain** or **burning sensation**, **redness**, **heat**, **swelling**, or **discharge** in the area around the catheter, without fever.

  or

- The **catheter** is accidentally withdrawn, either partially or completely

You should:

- Immediately notify the nurse at your health center: _____

  or

- Call the emergency oncology number: _____

  or

- Go to the emergency room.

7 LIST OF SYMPTOMS

The treatments you receive are intended to treat the disease, but they may sometimes result in the side effects listed below. However, your healthcare team may be able to suggest ways to relieve side effects, thereby improving your quality of life.

The following is a general list of symptoms that may arise depending on the treatment you receive. If you have one or more of them, it is important that you notify your contact people as soon as possible. You already have their telephone numbers at the front of your passport. However, don't hesitate to call if you are concerned about any other symptoms or situations that may arise.

Please note that this table is only a guide. Remember that you can best assess what you are feeling. Trust your feelings. Do not stay at home and allow a situation to worsen and potentially lead to complications and/or delay your treatment.

If you have any of these symptoms but are unable to reach a healthcare provider to assess your physical condition, you must go to the emergency room.

SYMPTOM	REPORT IF…[1]	GO TO THE EMERGENCY ROOM IF…
Fever during chemotherapy or radiotherapy **treatments**	–	• Temperature over **38°C for over an hour** OR

1. During the day, contact the Oncology Clinic or telephone the oncology emergency number (phone numbers at the front of your passport). In the evening or at night, call Info-santé or any other emergency number provided by your treatment team.

SYMPTOM	REPORT IF…[1]	GO TO THE EMERGENCY ROOM IF…
		• Temperature **over 38.3°C** In both cases, do not take anti-inflammatory drugs or acetaminophen, since they could mask the fever.
Fever 6 weeks or more after treatment has ended	• Temperature over **38.3°C**	
Pain	• Known pain that is not relieved by current pain medication • New pain • Pain that keeps you from carrying out everyday activities • *Increased level* of pain	• New acute pain • Intolerable pain

SYMPTOM	REPORT IF…[1]	GO TO THE EMERGENCY ROOM IF…
Fatigue	• Persistent fatigue over several days • Fatigue that reduces your quality of life and prevents you from carrying out everyday activities • Shortness of breath after exertion	• Extreme sudden fatigue with chest pain, palpitations (sensation of increased heartbeat), or both
Shortness of breath (difficulty breathing)	• Difficulty breathing • Out of breath more easily than usual • Shortness of breath with cough with or without sputum • Shortness of breath that keeps you from carrying out everyday activities	• Sudden shortness of breath with chest pain • Sudden shortness of breath and inability to speak or lie down, or both • Shortness of breath with fever of more than 38°C for one hour or fever of more than 38.3°C
Anxiety	• Anxiety that affects your mood • Inability to think clearly or relax	• Anxiety accompanied by trembling, tightness in throat, difficulty breathing • Panic attack

SYMPTOM	REPORT IF…[1]	GO TO THE EMERGENCY ROOM IF…
	• Anxiety that prevents you from conducting everyday (family and social) activities • Difficulty sleeping, difficulty concentrating, frequent crying, loss of interest, loss of appetite	
Drowsiness (tendency to fall asleep easily)	• Drowsiness that keeps you from carrying out everyday activities • Difficulty staying awake	• Unusual difficulty waking the person
Insomnia (difficulty sleeping)	• Insomnia for three days • Insomnia that does not respond to prescribed medication or other interventions • Insomnia that keeps you from carrying out everyday activities	

SYMPTOM	REPORT IF…[1]	GO TO THE EMERGENCY ROOM IF…
Numbness	• Tingling or numbness in the hands or feet; insensitivity to hot or cold • Numbness that does not respond to prescribed medication • Difficulty walking • Difficulty holding objects	• Sudden difficulty walking
Bleeding	• Nose bleeds • Bloody urine • Bloody stool • Blood in sputum • Presence of multiple contusions (bruises) on skin	• Constant nosebleeds despite applying pressure for 10 minutes • Bloody vomit • For women: use of one or more sanitary pads per hour

SYMPTOM	REPORT IF…[1]	GO TO THE EMERGENCY ROOM IF…
Nausea (sick to your stomach)	• *Persistent* nausea despite prescribed medication • Vomiting • Nausea that prevents you from taking prescribed medication	
Vomiting	• Vomiting more than 3 times in 24 hours • Vomiting that does not respond to prescribed medication or other interventions	• Repeated vomiting that prevents you from drinking and eating • Inability to keep down food and liquids • Vomiting that prevents you from taking prescribed medication • Vomiting blood or black liquid • Vomiting with *intolerable* stomach pain • Vomiting with intolerable headache

SYMPTOM	REPORT IF…[1]	GO TO THE EMERGENCY ROOM IF…
Diarrhea	• More than three watery stools a day • Diarrhea that does not respond to prescribed medication • Blood in stools or (tarry) dark stools	• More than ten episodes of diarrhea (watery stools) a day • Diarrhea with *intolerable* stomach or rectal pain • Diarrhea with fever of more than 38°C for one hour or fever of more than 38.3°C
Constipation	• No bowel movements for three days • Constipation that does not respond to prescribed medication • Stools that are very hard, difficult to evacuate • Stomachache or cramping • Swollen or bloated stomach • No passing of gas	• No bowel movements for three days with intolerable stomachache, nausea (sick to your stomach) and vomiting, bloated stomach, no passing of gas

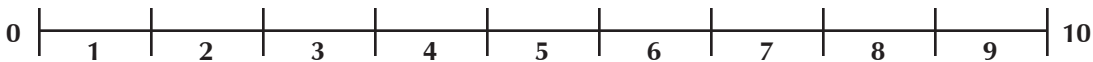
SYMPTOM	REPORT IF…[1]	GO TO THE EMERGENCY ROOM IF…
Loss of appetite	• Loss of appetite lasting more than three days • Rapid weight loss	
Stomatitis (red spots, mouth ulcers)	• Red spots, ulcers in mouth with pain and difficulty swallowing or eating • Mouth pain that does not respond to prescribed medication or other interventions	• Ulcers, red spots in mouth that prevent the swallowing of liquids, including drugs, for more than 24 hours • Lesions in the mouth with fever of more than 38°C for one hour or fever of more than 38.3°C
Esophagitis, gastritis (pain in digestive tract, stomach)	• Pain, burning sensation in throat, neck, chest, or stomach • Difficulty eating • *Reflux* of liquid in throat or mouth • Esophagitis, gastritis that does not respond to prescribed medication	• Vomiting blood

8 MONITORING SYMPTOMS AT HOME

If you monitor your symptoms at home, this scale from 0 to 10 can help you to determine and record the levels of severity and keep track of the methods you use to relieve them.

You should have this information on hand when going to your clinic or telephoning for assistance, since attending medical staff could find it of help in identifying the best steps for relieving your symptoms.

The following example uses pain as an example. The scale can be applied to any symptom you experience.



0 = No symptom **10 = Unbearable symptom**

Example for table below: Enter the date on the indicated line. If you have no pain, enter 0 in the "pain" column. If you have any level of pain, enter the relevant number based on the scale above. Follow the same procedure for all other symptoms.

Date	Pain	Fatigue	Shortness of breath	Anxiety	Insomnia	Numbness	Nausea	Vomiting	Diarrhea	Constipation	Loss of appetite	Red spots in mouth	Other	What did you do to relieve the symptom?

Date	Pain	Fatigue	Shortness of breath	Anxiety	Insomnia	Numbness	Nausea	Vomiting	Diarrhea	Constipation	Loss of appetite	Red spots in mouth	Other	What did you do to relieve the symptom?

Date	Pain	Fatigue	Shortness of breath	Anxiety	Insomnia	Numbness	Nausea	Vomiting	Diarrhea	Constipation	Loss of appetite	Red spots in mouth	Other	What did you do to relieve the symptom?

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Date	Pain	Fatigue	Shortness of breath	Anxiety	Insomnia	Numbness	Nausea	Vomiting	Diarrhea	Constipation	Loss of appetite	Red spots in mouth	Other	What did you do to relieve the symptom?

Date	Pain	Fatigue	Shortness of breath	Anxiety	Insomnia	Numbness	Nausea	Vomiting	Diarrhea	Constipation	Loss of appetite	Red spots in mouth	Other	What did you do to relieve the symptom?

Date	Pain	Fatigue	Shortness of breath	Anxiety	Insomnia	Numbness	Nausea	Vomiting	Diarrhea	Constipation	Loss of appetite	Red spots in mouth	Other	What did you do to relieve the symptom?

9 LIST OF MEDICATIONS

Your local or hospital pharmacy may be able to print out a list of drugs you have been prescribed. **ASK FOR A PRINTOUT AND KEEP IT IN THE FLAP OF YOUR PASSPORT.**

Otherwise, you can enter them in the table below.

Allergy: 1. _____ **Type of reaction:** 1. _____

2. _____ 2. _____

Name of drug	Dosage	Frequency - When?	Reason - Why?	Start date/ end date	Date of Prescription

Name of drug	Dosage	Frequency - When?	Reason - Why?	Start date/ end date	Date of Prescription

Before your chemotherapy treatment, you should tell your hematologist/oncologist and oncology pharmacist about any nonfood substance (**NATURAL PRODUCTS, VITAMINS, AND OTHERS**) you consume, even occasionally. Certain substances can interact with your chemotherapy drugs either by reducing the effectiveness of the treatment or increasing treatment side effects.

Indicate below any nonfood substance you consumed in the past six months or still consume.

Date	Substance	Reason

10 HEALTH SNAPSHOT

Provide the information requested below to the best of your knowledge. If some information is missing, you can ask your doctor or nurse navigator for assistance.

Type of cancer: _____

Name of surgery: _____

Date of surgery: _____

OTHER HEALTH PROBLEMS:

- ☐ Heart condition _____
- ☐ High blood pressure _____
- ☐ Diabetes _____
- ☐ Respiratory problem _____
- ☐ Kidney disorders _____
- ☐ Arthritis _____
- ☐ Epilepsy _____
- ☐ Anticoagulant treatment _____
- ☐ Other _____

11 RESOURCE INFORMATION

Fondation québécoise du cancer (Québec Cancer Foundation)

People living with cancer and their loved ones can have information, resources, and services from the foundation at no charge and confidentially by calling 1 800 363-0063 or visiting the foundation Web site at www.fqc.qc.ca.

- Documentation center. Provides a current inventory of many print and electronic information sources and resources available throughout Québec. Center staff can verify information for you and send you documentation at no charge.
- Cancer - Info Hotline: Answers your cancer-related questions.
- Telephone Sponsor Service: When you need someone to talk to
- Lodging network in Montréal, Trois-Rivières, Sherbrooke, and Gatineau

Just one number: 1 800 363-0063, Monday to Friday, 9 a.m. to 5 p.m. – Web site: www.fqc.qc.ca

Canadian Cancer Society

The Canadian Cancer Society provides a number of free confidential services to support and inform people living with cancer and their loved ones.

- Cancer Information Service: Well-trained information specialists provide answers to your questions and high-quality information either on the telephone or by e-mail.
- Cancer J'écoute: This personalized service matches someone who is touched by cancer with a trained volunteer who has lived through a similar cancer experience.
- Emotional, mental-imagery, and art-expression support groups are available at the CCS's 14 regional offices.
- Financial support (transportation, parking, adapted bra, elastic sleeve, lymphedema preventive treatment, etc.) and material assistance, including the loan of capillary prostheses and gift of temporary breast prostheses.
- A lodge in Montréal.
- Easy-to-understand information brochures about many cancers and treatments.
- A directory of services available in your community.
- A Web site with electronic versions of brochures and an impressive medical encyclopedia, among other features.

Just one number: 1 888 939-3333 – Web site: www.cancer.ca

Leucan

Information and support for children with cancer and their families.

Just one number: 1 800 361-9643 – Website: www.leucan.qc.ca

Resources available in your area (organizations providing support for people living with cancer, etc.)

12 MEMORY JOGGER

Questions: _____

_____

_____

_____

_____

Notes: _____

_____

_____

_____

_____

_____

_____

Notes:

Notes:

Notes:

Notes:

Notes:

YOUR OPINION

You can help us improve on the Oncology Passport by answering the following questions.

1) Overall, the Oncology Passport is useful.

   Yes ☐ No ☐

2) The passport contains enough information for me to take part in my treatment plan.

   Yes ☐ No ☐

3) The information is presented logically.

   Yes ☐ No ☐

4) The general layout of the Oncology Passport is attractive.

   Yes ☐ No ☐

5) It is easy to enter information in the passport and consult it.

   Yes ☐ No ☐

If you have answered no to one or more of the above questions, your comments and suggestions would be very much appreciated. Please provide them in the space below.

Comments & Suggestions _____

_____

_____

_____

_____

_____

_____

_____

Thank you for mailing the questionnaire to:

Ministère de la Santé et des Services sociaux
Direction de la lutte contre le cancer
1075, chemin Sainte-Foy, 7e étage
Québec (Québec) G1S 2M1

You can also send your completed questionnaire to:
passeportoncologie@msss.gouv.qc.ca

Santé
et Services sociaux
Québec

08-902-01FA