

# Advanced Renal Cell Carcinoma

Patient Guide and Diary

Includes ipilimumab + nivolumab  
treatment diary



[cua.org](http://cua.org)

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**[cua.org](http://cua.org)**

- This info booklet deals with advanced renal cell carcinoma (RCC)
- It includes information on immune checkpoint inhibitor (ICI) combinations
  - These combinations may consist of two ICI (called dual ICI) or ICI + VEGF targeted therapy
- This booklet is to **provide you with information** on the side effects to watch for, **to help you to monitor and track** your symptoms between clinic visits and **to help you inform** your cancer care team about important information

The sections of the booklet are:

- Treatment
  - Monitoring
  - Communication
- Your Cancer Care Team will **also** provide you with separate detailed information sheets on your specific treatment
  - There are other treatments for RCC that are not included in this booklet

VEGF: vascular endothelial growth factor



The background features several overlapping, wavy, organic shapes in various shades of blue and teal. The colors range from a deep, dark blue to a bright, light teal. The shapes are layered, creating a sense of depth and movement. The overall aesthetic is modern and clean.

**Treatment**



### What is immune checkpoint inhibitor\* (ICI) therapy?

- Cancer cells are **abnormal**. Our **immune system** is supposed to kill abnormal cells. Cancer cells can **disguise** themselves as healthy cells. When they do, our immune system is **tricked** and can confuse cancer cells for normal cells.
- Our immune system has “**on**” and “**off**” switches. When cancer cells disguise themselves as normal cells, the immune system is switched “**off**”.
- ICI treatment turns the immune system back “**on**” so the immune system can hopefully identify and kill the cancer cells.

### Why this treatment?

- You and your doctor have reviewed the various treatment options for your type of cancer
- Part of your treatment includes an **infusion into the vein** with an **immune checkpoint inhibitor (ICI)**
- ICI therapy has been shown in studies to reduce tumour size, reduce cancer symptoms and extend life in some patients with advanced renal cell carcinoma
- Examples of ICI include ipilimumab, nivolumab, pembrolizumab

\* You may also see the term immuno-oncology (IO) used when referring to ICI.

### What immune-related side effects can I expect from ICI?

ICI treatment may cause the immune system to attack healthy cells – not just cancer cells. This may result in **immune-related side effects**.

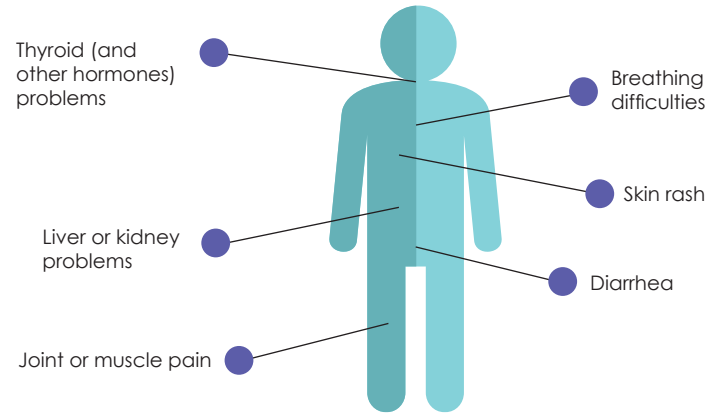
- ICI is given to help limit growth of cancer cells. It may also affect some of the healthy cells in the body. This may result in side effects.
- It is important that you tell your doctor (or cancer care nurse or pharmacist) of any side effects that you experience during your treatment. Your cancer care team has many ways to manage these side effects.
- You can help your doctor to help you by keeping track of the side effects you experience in the diary section of this booklet.

**Immune-related side effects should be reported to your cancer care team without delay.**  
See *Monitoring* for more information on immune-related side effects



### What can I expect from this treatment? ICI – Common Side Effects\*

- Tiredness
- Diarrhea or abdominal pain
- Itching or skin rash
- Shortness of breath or cough
- Joint or muscle pain



Inflammation can occur in any site in the body, not just cancer cells. This may cause **immune-related side effects**. Changes can occur in blood work. Blood work includes blood cell counts, blood tests for your liver, kidney and thyroid gland.

**Immune-related side effects should be reported to your cancer care team without delay.**  
See *Monitoring* for more information on immune-related side effects

\*Please consult the medication monograph sheet provided for complete list of side effects.

## What is VEGF targeted therapy?

- Cancer cells require a blood supply and other nutrients in order to grow. Cancer cells release certain proteins which make **blood vessels** grow. One of those proteins is called VEGF.
- Medications that **block the VEGF pathway** can help stop cancer cells from growing.

## Why this treatment?

- You and your doctor have reviewed the various treatment options for your type of cancer
- VEGF targeted therapy (**as a pill**) is part of your treatment
- VEGF targeted therapy has been shown in studies to reduce tumour size, reduce cancer symptoms and extend life in some patients with advanced renal cell carcinoma
- Examples of VEGF targeted medications include axitinib, sunitinib

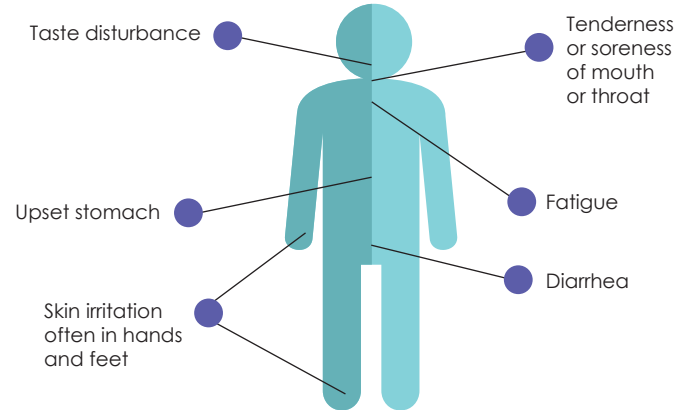
VEGF: vascular endothelial growth factor

## What side effects can I expect from VEGF Targeted Therapy?

- VEGF targeted therapy is given to help to limit the growth of cancer cells. It will also affect some of the healthy cells in the body. This may result in side effects.
- It is important that you tell your cancer care team about any side effects that you experience during your treatment. Your cancer care team has many ways to manage these side effects.
- You can help your doctor to help you by keeping track of the side effects you experience in the diary section in this booklet.

## What can I expect from this treatment? VEGF Targeted Therapy – **Common side effects\***

- Taste disturbance
- Tenderness or soreness of mouth or throat
- Upset stomach (nausea)
- Diarrhea
- Tiredness
- Skin irritation often in hands and feet (hand-foot syndrome)



Your doctor may also notice high blood pressure and changes in your blood work.  
Blood work includes blood cell counts, blood tests for your liver, kidney and thyroid gland.

\*Please consult the medication monograph sheet provided for complete list of side effects.

## Why ICI combinations?

- Sometimes the treatment that is best for you may be an ICI combination
- ICI combinations may give a stronger and more effective anti-cancer effect than single-agent ICI.

### Dual ICI [infusions into the vein]

- Sometimes ICI is combined with another ICI. We call this dual ICI.
- The **immune-related side effects** are often increased (and may be more severe) when dual ICI is given.

### ICI + VEGF Targeted [infusion + oral tablet]

- Sometimes ICI is combined with VEGF targeted therapy.
- Side effects with this combination may be **immune-related** due to the ICI (but less severe than dual ICI), or related to the VEGF targeted therapy, or both.

*See page 17 for more information on ICI combinations.*



# Monitoring

The background features a dark blue base with several large, overlapping, wavy shapes in lighter shades of blue and teal. The shapes are organic and fluid, creating a modern, abstract aesthetic.





## What can I do to help my cancer care team help me?

### Remember the ABC's of Cancer Treatment



#### A Awareness

- **Know** what side effects to look out for.



#### B Be alert and monitor closely for symptoms

- **Keep track** of changes in symptoms.
- Early detection of side effects is important.

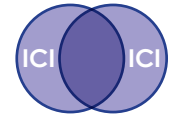


#### C Communication

- **Report** any changes to your cancer care team. Don't wait until your next appointment.
- If you go to the Emergency Department **show wallet card and/or letter from the Cancer Centre to the doctor in the Emergency Department**
- After your visit to the Emergency Department **make sure your cancer care team is aware of your visit to the Emergency Department**

## What do I watch for? Watch for immune-related side effects from ICI.

Immune-related side effects can happen to any part of the body. Report any symptom you think could be a side effect. Some side effects that you should be **particularly aware** of include:



### 1 Skin

- Skin side effects usually happen first and are more common than side effects affecting other parts of the body
- Skin related side effects can include rash, itching and/or sores in the mouth
- Report any new itching or rash anywhere on the body to your cancer care team



### 2 Diarrhea and/or Bowel Changes

- Report any new diarrhea, cramping in the belly, and/or blood in the stool to your cancer care team
- Talk to your cancer care team before taking anti-diarrhea medications (ie. Imodium™)



### 3 Breathing Problems

- Report any new or worsening symptoms related to your breathing to your cancer care team.
- Symptoms that should be reported to the cancer care team include trouble breathing that is worse than normal, dry cough that is new or getting worse or a fever (temperature of 38.3°C or 38°C for over an hour)

Side effects are more frequent and more severe with dual ICI combinations than when only one ICI agent is used.

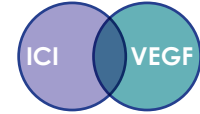
(See page 43 in COMMUNICATIONS section for guidance if after hours)

Adapted from: Horizons Health Network

## How are ICI side effects treated?

- **Immune-related side effects** from dual ICI are always treated based on the individual patient. Report all side effects to your cancer care team.
- **DO NOT** manage side effects at home without speaking with your cancer care team.
- The earlier an **immune-related side effect** is recognized, the better it can be managed.
- Serious **immune-related side effects** (e.g. symptoms that affect daily activities) are usually treated with steroids to suppress the immune system.
  - Steroids act as “water on the fire” and slow down the “activated” immune system.
  - More serious side effects may require a long duration of treatment with steroids or other medications to decrease the immune response. (4-8 weeks)
  - In some cases, the ICI treatment may need to be held while the side effect is being managed.
- Minor symptoms (e.g. symptoms that are noticeable but do not affect daily activities) may be managed more easily with advice from your cancer care team.

## What do I watch for? Immune-related side effects from ICI and side effects from VEGF targeted therapy.



Side effects can happen to any part of the body. Report any symptom you think could be a side effect. Some side effects that you should be **particularly aware of** include:



### 1 Skin

- Skin side effects usually happen first and are more common than side effects affecting other parts of the body
- Skin related side effects can include rash, itching and/or sores in the mouth
- Rash, redness, itching or peeling of the skin on the palms of hands or soles of feet
- Report any new itching or rash anywhere on the body to your cancer care team



### 2 Diarrhea and/or Bowel Changes

- Report any new diarrhea, cramping in the belly, and/or blood in the stool to your cancer care team
- Talk to your cancer care team before taking anti-diarrhea medications (ie. Imodium™)



### 3 Breathing Problems

- Report any new or worsening symptoms related to your breathing to your cancer care team.
- Symptoms that should be reported to the cancer care team include trouble breathing that is worse than normal, dry cough that is new or getting worse or a fever (temperature of 38.3°C or 38°C for over an hour)



### 4 Nausea, Decreased Appetite (Weight Loss), Taste Disturbances

- The VEGF targeted therapy often causes nausea, decreased appetite and taste disturbances

Side effects may be due to the ICI component, the VEGF component or both which means that the list of side effects is longer but there is less overlap than dual ICI.

(See page 43 in COMMUNICATIONS section for guidance if after hours)

## How are side effects treated?

- **Immune-related side effects** and side effects due to VEGF targeted treatment are always treated based on the individual patient. **Report all side effects to your cancer care team.**
- **DO NOT** manage side effects at home without speaking with your cancer care team.
- The earlier an **immune-related side effect** is recognized, the better it can be managed.
- Serious immune-related side effects (e.g. symptoms that affect daily activities) are usually treated with steroids to suppress the immune system.
  - Steroids act as “water on the fire” and slow down the “hyper” immune system.
  - More serious side effects may require a long duration of treatment with steroids. (4-8 weeks)
  - In some cases, one of the medications (either ICI or VEGF targeted) may need to be held
- Minor symptoms (e.g. symptoms that are noticeable but do not affect daily activities) may be managed more easily with advice from your cancer care team.

## What can I do at home to help manage my care?

- It is important for you to monitor certain things at home (see patient diary) and report to your cancer care team any side effects.
- **DO NOT** manage side effects at home without speaking with your cancer care team.
- However, there are some self-management tips you **can** do at home:
  - If you are on VEGF targeted therapy monitor your blood pressure as per your cancer care team guidance (and note it on the diary)
  - Get adequate rest. Short (less than one hour) daytime naps may be needed.
  - Participate in exercise (if your doctor has authorized it)
  - Stay well hydrated
  - Use moisturizing cream on your skin
  - Protect yourself from the sun and use sunscreen
  - Eat a balanced diet
  - Clean your teeth after every meal and at bedtime using a soft-bristle toothbrush and a non-abrasive toothpaste
  - Be sure to inform other health care providers (family doctor, dentist, surgeon, etc) what treatment you have been prescribed
  - Be sure to inform your cancer care team of all medication changes

## Summary



- You are a partner in your care with your cancer care team.
- You can help your cancer care team to care for you by monitoring for specific side effects and reporting to your cancer care team.
- With your help, side effects may be recognized early and managed more easily.



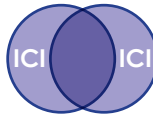
- With **ICI + VEGF targeted therapy**, it may be challenging for your cancer care team to determine if a side effect is caused by ICI or VEGF targeted therapy. Knowing the **onset** and **description** of the side effect may help them to know which medication is causing the side effect. If the side effect requires an interruption in treatment, this information may help your team know which medication should be temporarily held and which can be continued.



- With **dual ICI therapy**, if an **immune-related side effect** requires that treatment be interrupted, both medications are usually held. Recognizing immune-related side effects early may mean that the side effect can be managed without having to stop treatment.

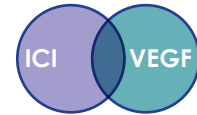
### Dual ICI:

- Side effect profiles overlap
- List of side effects is shorter
- Immune-related side effects may be more severe



### IO + VEGF Targeted:

- Side effect profiles overlap less
- List of side effects is longer
- Immune-related side effects may be less severe







**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

**You are being treated with ipilimumab + nivolumab.**

**Please use this calendar and please bring to your next appointment**

Date of infusion - **Cycle 1 (Day 1):** \_\_\_\_\_

Today's treatment (check appropriate box):

ipilimumab / nivolumab (every 3w)     nivolumab (every 4w)

For the duration of your treatment, please watch for the following side effects and take notes in the "comments" column of the table below:

**Skin:** rash, itching

**Diarrhea or changes in bowel habits:** new diarrhea, pain or cramping in belly, blood in the stool, fever with diarrhea

**Breathing:** Trouble breathing, dry cough that is new or getting worse, fever

**Other:** Change in urine colour, nausea, fatigue, headache, dizziness, vision changes

Also take note of **anything new** you are concerned about.

Day	Date	Comments
Example	Sept 10	3 loose stools today, feeling a bit tired, noticed some itching

Turn over for days 1-21

**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

Cycle 1		
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Date of my next appointment is: \_\_\_\_\_

Date of my next appointment for blood work is: \_\_\_\_\_

Date of next infusion is: \_\_\_\_\_

My next infusion is for:  ipilimumab / nivolumab       nivolumab only

Before my next appointment, I need to do: \_\_\_\_\_

\_\_\_\_\_

My questions for my cancer care team are: \_\_\_\_\_

\_\_\_\_\_

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

**You are being treated with ipilimumab + nivolumab.**

**Please use this calendar and please bring to your next appointment**

Date of infusion - **Cycle 2 (Day 1)**: \_\_\_\_\_

Today's treatment (check appropriate box):

ipilimumab / nivolumab (every 3w)     nivolumab (every 4w)

For the duration of your treatment, please watch for the following side effects and take notes in the “comments” column of the table below:

**Skin:** rash, itching

**Diarrhea or changes in bowel habits:** new diarrhea, pain or cramping in belly, blood in the stool, fever with diarrhea

**Breathing:** Trouble breathing, dry cough that is new or getting worse, fever

**Other:** Change in urine colour, nausea, fatigue, headache, dizziness, vision changes

Also take note of **anything new** you are concerned about.

Day	Date	Comments
Example	Sept 10	3 loose stools today, feeling a bit tired, noticed some itching

Turn over for days 1-21

**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

Cycle 2		
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Date of my next appointment is: \_\_\_\_\_

Date of my next appointment for blood work is: \_\_\_\_\_

Date of next infusion is: \_\_\_\_\_

My next infusion is for:  ipilimumab / nivolumab       nivolumab only

Before my next appointment, I need to do: \_\_\_\_\_

\_\_\_\_\_

My questions for my cancer care team are: \_\_\_\_\_

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

**You are being treated with ipilimumab + nivolumab.**

**Please use this calendar and please bring to your next appointment**

Date of infusion - **Cycle 3 (Day 1):** \_\_\_\_\_

Today's treatment (check appropriate box):

ipilimumab / nivolumab (every 3w)     nivolumab (every 4w)

For the duration of your treatment, please watch for the following side effects and take notes in the “comments” column of the table below:

**Skin:** rash, itching

**Diarrhea or changes in bowel habits:** new diarrhea, pain or cramping in belly, blood in the stool, fever with diarrhea

**Breathing:** Trouble breathing, dry cough that is new or getting worse, fever

**Other:** Change in urine colour, nausea, fatigue, headache, dizziness, vision changes

Also take note of **anything new** you are concerned about.

Day	Date	Comments
Example	Sept 10	3 loose stools today, feeling a bit tired, noticed some itching

Turn over for days 1-21

**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

Cycle 3		
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Date of my next appointment is: \_\_\_\_\_

Date of my next appointment for blood work is: \_\_\_\_\_

Date of next infusion is: \_\_\_\_\_

My next infusion is for:  ipilimumab / nivolumab       nivolumab only

Before my next appointment, I need to do: \_\_\_\_\_

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My questions for my cancer care team are: \_\_\_\_\_

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

**You are being treated with ipilimumab + nivolumab.**

**Please use this calendar and please bring to your next appointment**

Date of infusion - **Cycle 4 (Day 1):** \_\_\_\_\_

Today's treatment (check appropriate box):

ipilimumab / nivolumab (every 3w)     nivolumab (every 4w)

For the duration of your treatment, please watch for the following side effects and take notes in the "comments" column of the table below:

**Skin:** rash, itching

**Diarrhea or changes in bowel habits:** new diarrhea, pain or cramping in belly, blood in the stool, fever with diarrhea

**Breathing:** Trouble breathing, dry cough that is new or getting worse, fever

**Other:** Change in urine colour, nausea, fatigue, headache, dizziness, vision changes

Also take note of **anything new** you are concerned about.

Day	Date	Comments
Example	Sept 10	3 loose stools today, feeling a bit tired, noticed some itching

Turn over for days 1-21

**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

Cycle 4		
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Date of my next appointment is: \_\_\_\_\_

Date of my next appointment for blood work is: \_\_\_\_\_

My next infusion is for nivolumab only. Date of infusion: \_\_\_\_\_

Before my next appointment, I need to do: \_\_\_\_\_

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My questions for my cancer care team are: \_\_\_\_\_

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

**You are being treated with ipilimumab + nivolumab.**

**Please use this calendar and please bring to your next appointment**

Date of infusion - **Cycle 1 (Day 1):** \_\_\_\_\_

Today's treatment: nivolumab (every 4w)

For the duration of your treatment, please watch for the following side effects and take notes in the "comments" column of the table below:

**Skin:** rash, itching

**Diarrhea or changes in bowel habits:** new diarrhea, pain or cramping in belly, blood in the stool, fever with diarrhea

**Breathing:** Trouble breathing, dry cough that is new or getting worse, fever

**Other:** Change in urine colour, nausea, fatigue, headache, dizziness, vision changes

Also take note of **anything new** you are concerned about.

Day	Date	Comments
Example	Sept 10	3 loose stools today, feeling a bit tired, noticed some itching

Turn over for days 1-28

**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

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Date of my next appointment is: \_\_\_\_\_

Date of my next appointment for blood work is: \_\_\_\_\_

My next infusion is for nivolumab only. Date of infusion: \_\_\_\_\_

Before my next appointment, I need to do: \_\_\_\_\_

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My questions for my cancer care team are: \_\_\_\_\_

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

You are being treated with ipilimumab + nivolumab.

Please use this calendar and please bring to your next appointment

Date of infusion - **Cycle** \_\_\_\_ (**Day 1**): \_\_\_\_\_

Today's treatment: nivolumab (every 4w)

For the duration of your treatment, please watch for the following side effects and take notes in the "comments" column of the table below:

**Skin:** rash, itching

**Diarrhea or changes in bowel habits:** new diarrhea, pain or cramping in belly, blood in the stool, fever with diarrhea

**Breathing:** Trouble breathing, dry cough that is new or getting worse, fever

**Other:** Change in urine colour, nausea, fatigue, headache, dizziness, vision changes

Also take note of **anything new** you are concerned about.

Day	Date	Comments
Example	Sept 10	3 loose stools today, feeling a bit tired, noticed some itching

Turn over for days 1-28

**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

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**IMPORTANT:** Please record and report **even minor symptoms**. All side effects must be reported to your cancer care team.

Cycle

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Date of my next appointment is: \_\_\_\_\_

Date of my next appointment for blood work is: \_\_\_\_\_

My next infusion is for nivolumab only. Date of infusion: \_\_\_\_\_

Before my next appointment, I need to do: \_\_\_\_\_

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My questions for my cancer care team are: \_\_\_\_\_

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# Communication

The background features a dark blue base color with several large, overlapping, organic shapes in lighter shades of blue and teal. These shapes are positioned in the top-left, bottom-right, and right-center areas, creating a layered, abstract composition.



## Who do I contact?

### 1. Oncology clinic during regular hours (Monday–Friday)

Medical oncologist is: \_\_\_\_\_

Oncology Nurse is: \_\_\_\_\_

Oncology Pharmacist is: \_\_\_\_\_

Hours: \_\_\_\_\_

Phone no: ( \_\_\_\_\_ ) \_\_\_\_\_

### 2. Go to the Emergency Department (after hours, weekend or holidays), especially if symptoms are new and more severe.

- If you are experiencing an **immune-related side effect** after hours or on a week-end, do not wait until the Cancer Clinic opens.
- If you go to the Emergency Department, be sure to call the Cancer Clinic as soon as they are open.

## Online Resources

- Kidney Cancer Canada  
<https://www.kidneycancercanada.ca/>
- Exercise guide for kidney cancer survivors - Kidney Cancer Canada  
<https://www.kidneycancercanada.ca/resources-for-patients-and-healthcare-professionals/resources-for-patients-and-caregivers/>
- American Society of Clinical Oncologists. **ASCO Answers: Kidney Cancer.**  
Printable version available at: [http://cancer.net/sites/cancer.net/files/asco\\_answers\\_kidney.pdf](http://cancer.net/sites/cancer.net/files/asco_answers_kidney.pdf)
- CancerCare. **Treatment Update: Kidney Cancer.**  
Printable version available at: [https://media.cancercare.org/publications/original/195-ccc\\_renal\\_cell.pdf](https://media.cancercare.org/publications/original/195-ccc_renal_cell.pdf)
- National Cancer Institute. **Renal Cell Cancer Treatment (PDQ®)–Patient Version.**  
<https://www.cancer.gov/types/kidney/patient/kidney-treatment-pdq>









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