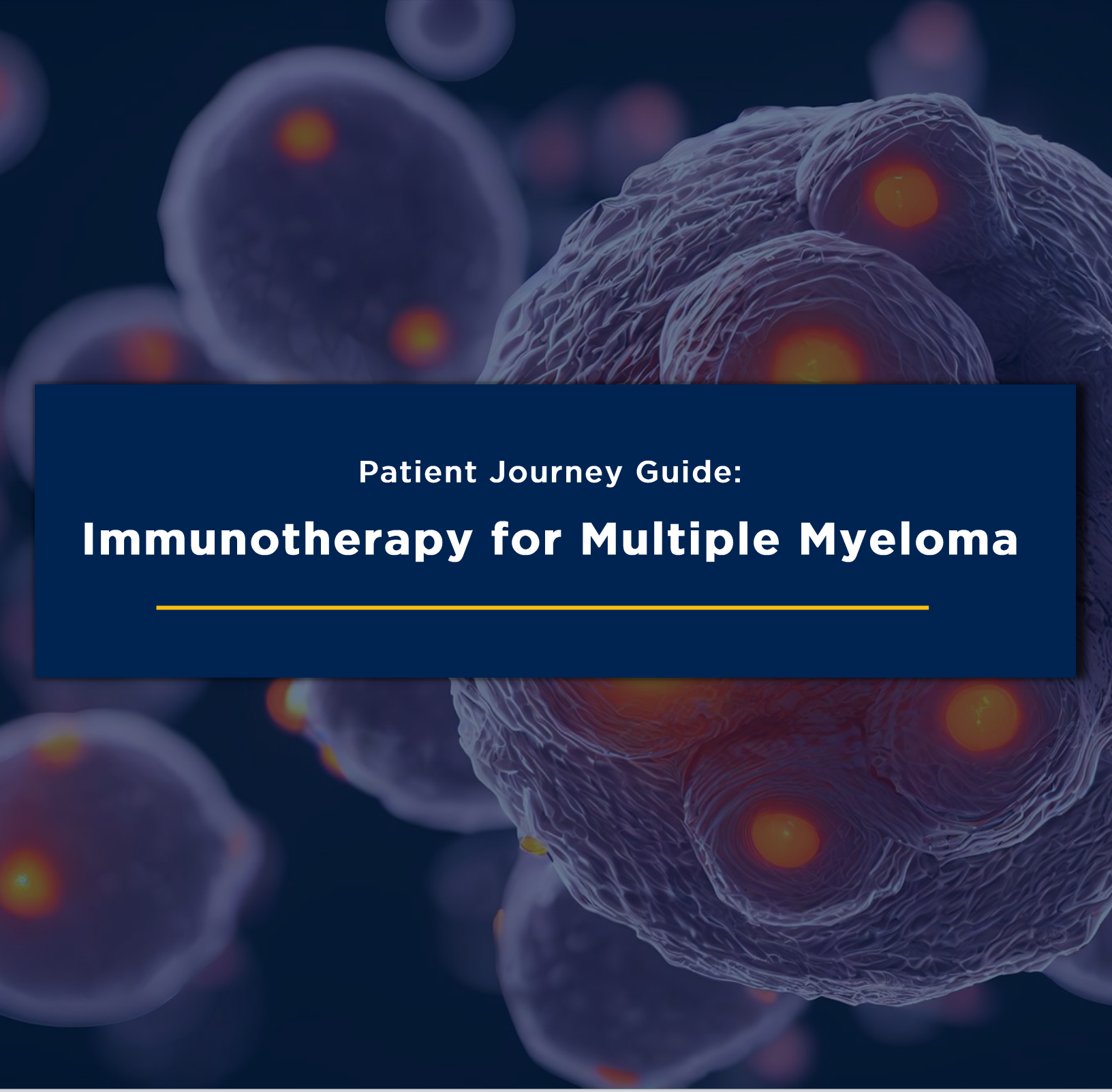

Patient Journey Guide:

Immunotherapy for Multiple Myeloma

Queen's University
HEALTH SCIENCES
Professional Development
and Educational Scholarship

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INTRODUCTION TO MULTIPLE MYELOMA

Multiple myeloma is a type of blood cancer affecting plasma cells in the bone marrow. These cells can become abnormal, multiply uncontrollably, and release proteins that can cause harm to the body, including damaging the bones and kidneys. Symptoms may include:

- Bone pain
- Fatigue
- Infections
- Bleeding problems

Understanding this disease is the first step in facing the journey ahead.

THE PATH TO DIAGNOSIS

Diagnosing multiple myeloma involves:

- **Blood and urine tests:** Detect abnormal proteins produced by myeloma cells or the body's immune response to the myeloma cells.
- **Bone marrow biopsy:** Assesses the extent of cancer in the bone marrow.
- **Imaging tests (X-rays, CT scans, and MRIs):** Reveal bone damage.

Interpreting these results with your healthcare team will guide your treatment plan.

PREPARING FOR APPOINTMENTS WITH YOUR HEALTHCARE TEAM

Maximize your medical appointments with these tips:

- Prepare a list of **questions** before the appointment.
- If helpful to you, take **notes** during the appointment.
- Be your own advocate and bring a **support person** if needed. Your voice in this journey is important.
- Let your healthcare team know where you are struggling and what is important for you. Ask questions about how treatment options will affect your lifestyle.

Your healthcare team can assist you with managing your side effects and navigating treatment options.

MANAGING A NEW DIAGNOSIS

Upon receiving a diagnosis:

- **Address emotional challenges:** Both patients and caregivers should discuss the emotional challenges it presents, actively sharing feelings and experiences to foster understanding and support among friends, family, and caregivers.
- **Seek resources:** Beyond familial support, resources like social workers are available to assist and you should seek out the ones that best fit your lifestyle, goals, and home context. Additionally, local support group information and online communities such as Myeloma

Canada Patient & Caregiver Support Group and Myeloma Canada Support Group for Younger Patients & Caregivers on Facebook can provide valuable support and information.

- **Understand treatment plans:** A clearly outlined treatment plan, understanding and managing medication schedules, and knowing whom to contact within the healthcare team for urgent inquiries are fundamental steps that you should ask and receive answers about.

STANDARD TREATMENTS FOR MULTIPLE MYELOMA

The standard of care for multiple myeloma emphasizes the utilization of highly specialized medical drugs that include:

- **Immunomodulatory imide drugs (IMiDs)**
- **Proteasome inhibitors (PIs)**
- **Steroids**

These treatments are fundamental, with every patient with multiple myeloma typically receiving a combination that includes either an IMiD or a PI, alongside a steroid and a monoclonal antibody (mAb, a modified version of immune cells), tailoring the regimen to the individual's specific needs and disease characteristics.

For patients who have undergone three or more prior lines of therapy, advanced options such as **immunotherapies** become available. These innovative treatments offer hope and potential for improved outcomes, highlighting the personalized and evolving nature of myeloma care.

WHAT IS IMMUNOTHERAPY?

Immunotherapy is a groundbreaking approach to treating multiple myeloma that trains and equips the body's immune system to recognize, target, and eliminate multiple myeloma cells. Unlike chemotherapy, which attacks fast-growing cells indiscriminately, immunotherapy focuses on boosting your immune system's ability to fight cancer more effectively. Compared to chemotherapy and radiation, immunotherapy often has fewer side effects, targeting cancer cells more precisely and sparing healthy cells.

Many of these immunotherapy treatments target the protein **B-cell maturation antigen (BCMA)**. Found on the surface of many myeloma cells, BCMA acts as a "flag" that therapies can recognize. By focusing on this 'flag', treatments like **mAbs**, **chimeric antigen receptor (CAR) T-cell therapy**, and **bispecific T-cell engager (BiTE) therapy** can more accurately identify and attack the myeloma cells, leading to better outcomes for patients. Other targets include a protein called **CD38** that other drugs can use to target myeloma cells.

MONOCLONAL ANTIBODIES (MABS)

Imagine your body's immune system as a security team that's good at its job but sometimes fails to recognize disguised intruders. mAbs are like high-tech goggles given to this security team, helping them see and flag the harmful myeloma cells that were previously invisible to them. Once flagged, the immune system can attack and destroy these cells.

What to Expect: These treatments are usually given intravenously or through an injection into the skin. Side effects can vary but may include flu-like symptoms, fatigue, or allergic reactions. Your healthcare team will monitor you closely and can provide medications to help manage these side effects.

CAR T-CELL THERAPY

CAR T-cell therapy is an innovative treatment that transforms your body's T cells—a type of immune cell—into "super soldiers" designed to fight multiple myeloma. In this sophisticated process, T cells are collected and sent to a lab, where they're genetically modified to produce special structures called chimeric antigen receptors (CARs) on their surface. CARs are engineered structures that allow T cells to recognize and bind to BCMA, directing the patient's immune system to attack and kill the BCMA-expressing myeloma cells. These work by bringing the T cells and the myeloma cells physically close together with the CARs acting like a grappling hook and locking them in close.

What to Expect: The CAR T-cell therapy process involves several steps:

1. **T Cell Collection**: T cells are collected through a process similar to blood donation.
2. **Lab Modification:** T cells are genetically modified to produce CARs, a process that typically takes a few weeks.
3. **Preparation with Chemotherapy:** Before reintroducing the modified T cells, you'll receive chemotherapy to prepare your body.
4. **Infusion of CAR T Cells:** The supercharged T cells are infused back into your body, where they seek out and destroy myeloma cells.

This treatment has shown promising results but can cause significant side effects, including cytokine release syndrome (CRS), which can be managed with prompt medical care.

BISPECIFIC T-CELL ENGAGER (BITE) THERAPY

BiTEs work by bringing T cells and myeloma cells together. Think of BiTEs as a bridge that connects T cells directly to myeloma cells, facilitating a targeted attack.

What to Expect: While specific BiTEs targeting BCMA are still under clinical investigation, their development represents a promising area of research that could offer new hope to patients, especially those who have exhausted other treatment options. The potential side effects of BiTE therapy resemble those of other immunotherapies, including fever, fatigue, and some serious conditions like CRS and Immune Effector Cell Associated Neurotoxicity Syndrome (ICANS). The mode of administration (injection or intravenously) and frequency will depend on the specific BiTE and the protocols established by these clinical trials.

Which immunotherapy is for me? Your healthcare team will help determine which immunotherapy will be part of your treatment plan.

PREPARING FOR IMMUNOTHERAPY

Preparation for immunotherapy involves understanding what to expect.

Preparation: Depending on the treatment, you might need some preparation, like having cells collected or receiving other medications.

Treatment: These therapies are usually given intravenously or through an injection, and the process can vary in length and frequency. Treatments may vary in duration and frequency, and some may require hospital stays.

Side Effects: While these treatments can be easier on your body than traditional chemotherapy, they can still have side effects, including:

- Fatigue
- Fever
- Immunosuppression
- Risk of infections
- Reactions at the injection site

Rare side effects of some of the treatments include eye toxicity or immune reactions that can require medical attention. Your care team will work with you to manage any side effects and respond accordingly. Staying in communication and keeping them informed of your experience is key.

DURING TREATMENT

- Your healthcare team will closely monitor your response to treatment, adjusting as necessary. Regular blood tests, physical exams, and imaging will assess the therapy's effectiveness and side effects. Emotional support is also crucial during this time.
- Many hospitals, clinics, and patient societies offer counselling and support groups for patients and their families.
- During treatment, patients often face concerns about their ability to continue working and must navigate complex processes to apply for financial assistance. These options may include Long-Term Disability (LTD) benefits, the Canada Pension Plan (CPP) Disability program, and the Disability Tax Credit (DTC).
- Knowing who to contact when experiencing side effects is crucial, as managing these effectively is essential for successful outcomes and maintaining quality of life.
- Maintaining a positive attitude during and after hospital stays, taking each day as it comes, and accepting that there will be both good and bad days are important for mental well-being.
- Keep in mind that it is vital to recognize that treatment and care are personalized, reflecting individual differences such as age and health history.
- Patients are encouraged to engage with their healthcare team with any treatment questions and to stay as active as their condition allows.

POST-TREATMENT CARE

Follow-up care is essential to monitor for any signs of relapse. This may include regular visits to your hematologist or oncologist, blood tests, and imaging. Adjusting to life after treatment can be challenging, but support is available to help manage long-term side effects and maintain a healthy lifestyle.

SUPPORT AND CARE

Navigating treatment for multiple myeloma with immunotherapy means you have a team dedicated to using the latest science to help your body fight cancer. It's a partnership between you and your healthcare providers, with the goal of targeting the cancer more precisely and hopefully leading to better outcomes. Some patients will need bisphosphonate therapy for bone protection, some patients will require immunoglobulin therapy to help protect them from frequent infections, and some patients will need blood transfusions based on blood work results. Your healthcare team can help you make decisions based on blood work results.

Understanding these treatments in simple terms can help demystify the process and make the journey through multiple myeloma treatment feel a bit more manageable. Always feel free to ask your care team questions and express any concerns you have—they're there to help guide you through this process.

FREQUENTLY ASKED QUESTIONS

Where can I get information about Multiple Myeloma?

You can get more information from your healthcare team, hospital libraries (Myeloma handbook for patients and caregivers, etc.), and the Myeloma Canada website (https://myeloma.ca/). You might also benefit from seeking out support groups: https://myeloma.ca/recently-diagnosed/find-support/?section=living-with-myeloma

Where else can I learn about immunotherapies?

https://myeloma.ca/wp-content/uploads/2023/09/web_lr_mc_immunotherapy_en_2022_rev_2023_04_11.pdf

Will I be able to work during treatment?

This depends on how you feel; some patients can work full-time, while others need adjustments.

How will I know if the treatment is working?

Your doctor will use tests and scans to track your cancer's response to treatment.

What can I do to manage side effects?

Your care team will provide specific advice based on the side effects you're experiencing.

How long does immunotherapy treatment last?

The duration of immunotherapy can vary greatly depending on the type of treatment, how well the cancer is responding, and how the patient's body is handling the treatment. Some therapies, like monoclonal antibodies, might be given over several months, while CAR T-cell therapy is a one-time treatment but requires a period for cell collection, modification, and reinfusion, followed by monitoring.

Can I live a normal life during immunotherapy?

Many patients can maintain their daily routines with some adjustments. The side effects of immunotherapy are generally less severe than those of traditional chemotherapy, allowing for a more normal lifestyle. However, energy levels may vary, and some days may be better than others. It's important to listen to your body and communicate with your healthcare team to manage any side effects effectively.

Will immunotherapy cure my multiple myeloma?

Immunotherapy has shown promising results in treating multiple myeloma, especially for those who have relapsed or are not responding to other treatments. While it can lead to significant remission periods, calling it a cure is challenging due to the complex nature of the disease. Ongoing research continues to improve these therapies and outcomes for patients.

What are the chances of my cancer coming back after immunotherapy?

The risk of relapse varies from patient to patient and depends on several factors, including the stage of the disease, the specific type of treatment, and how well the cancer initially responds to the therapy. Your doctor can provide more personalized information based on your situation. Monitoring and follow-up care are crucial parts of managing multiple myeloma over the long term.

How much does immunotherapy cost?

The cost of immunotherapy can be high, but it varies widely depending on the specific treatment, duration, and healthcare system. Many insurance plans cover immunotherapy, but coverage can vary. There are also assistance programs available through pharmaceutical companies and cancer support organizations to help with costs.

Can I receive immunotherapy if I have other health conditions?

Your overall health, including any other conditions you have, will be considered by your healthcare team when deciding if immunotherapy is right for you. Some conditions may affect the suitability or type of immunotherapy you can receive. It's important to discuss your full medical history with your doctor.

What should I eat during my treatment?

There are no specific diets for patients undergoing immunotherapy, but eating a balanced and nutritious diet can help support your body during treatment. Your healthcare team may refer you to a nutritionist who can provide personalized advice based on your health needs, treatment type, and any side effects you might be experiencing.

How can I manage the side effects of immunotherapy?

Side effects vary by the type of immunotherapy and the individual. Common strategies include medication to manage symptoms, lifestyle adjustments, and supportive therapies like nutrition counselling, physical therapy, or mental health support. Always report any new or worsening side effects to your healthcare team promptly.

RESOURCES AND SUPPORT

- Canadian Cancer Society: https://cancer.ca/en/cancer-information/cancer-types/multiple-myeloma/what-is-multiple-myeloma
- Myeloma Canada: https://myeloma.ca/
- Myeloma Clinical Trials: https://myeloma.ca/living-with-myeloma/clinical-trials/
- Experiencing a Relapse: https://myeloma.ca/living-with-myeloma/experiencing-a-relapse/

CREDITS

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