WHAT YOU NEED TO KNOW
You or your loved one has been diagnosed with smouldering multiple myeloma (SMM). It’s an inactive type of multiple myeloma that shows no symptoms. What does it mean and how will it affect you?

This fact sheet will help you:

- Learn about SMM and how it is diagnosed
- Get an overview of risk factors
- Find out how SMM is monitored and managed
- Understand what happens next
What is myeloma?
Myeloma is a cancer of the plasma cells. Myeloma occurs when B lymphocytes (B-cells), a special type of white blood cell found in bone marrow, produce abnormal protein (monoclonal protein, or M-protein). Myeloma cells are usually found in your bone marrow, but they may also accumulate in any part of your body, including your skin, muscles, blood, or lungs. These accumulations are called plasmacytomas. This presence is associated with signs of organ damage (increase of calcium, renal dysfunction, anemia) and bone lesions.

About smouldering multiple myeloma
- It’s a rare, indolent (slow-growing) type of multiple myeloma
- It usually affects people over the age of 60
- It is also called asymptomatic because there are no symptoms
- This is a stage between monoclonal gammopathy of undetermined significance (MGUS) and active multiple myeloma
- It is characterized by the production of abnormal M-protein
- 10 to 60% of myeloma cells are in your bone marrow
- Most people with SMM will eventually develop active (symptomatic) multiple myeloma, but for some people, it may never happen
- People with SMM go for regular tests and monitoring to see if it’s progressing
- You may be considered at low, intermediate, or high risk for developing active multiple myeloma

Signs and symptoms
Most people who have SMM don’t have any symptoms. Some may experience:
- Fatigue
- Peripheral neuropathy (tingling in the hands and feet)

Asymptomatic
SMM does not have symptoms. SMM is an early sign that you may develop multiple myeloma. For some people, it may take years for myeloma to develop. Others may never develop active myeloma.
After your diagnosis

Often, a doctor will determine you have SMM after routine blood tests are done for other reasons. Your test results help your doctor predict how your SMM will likely progress to multiple myeloma.

<table>
<thead>
<tr>
<th>Name of test</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical history and physical exam</td>
<td>The doctor reviews past illnesses, injuries, and symptoms. He/she examines your lungs, heart, and other organs.</td>
</tr>
<tr>
<td>Complete blood count (CBC)</td>
<td>This test measures the number of red blood cells, white blood cells, and platelets in a sample of your blood to find out if the counts are high or low.</td>
</tr>
<tr>
<td>Blood chemistry</td>
<td>This blood test measures substances released into the blood to determine how well your kidneys, liver, and other organs are working.</td>
</tr>
<tr>
<td>Blood and urine tests</td>
<td>Blood and urine tests look for a certain protein, called M-protein (monoclonal protein), to see how present the disease is in your body.</td>
</tr>
<tr>
<td>Fluorescence in situ hybridization (FISH)</td>
<td>This lab test looks at alterations of genes and chromosomes in the SMM cells.</td>
</tr>
<tr>
<td>Bone marrow biopsy</td>
<td>A bone marrow biopsy will confirm the presence and percentage of plasma cells in the bone marrow.</td>
</tr>
<tr>
<td>Imaging tests</td>
<td>An x-ray uses electromagnetic radiation to produce images of internal body structures. It is used to look for bone lesions.</td>
</tr>
<tr>
<td></td>
<td><strong>Positron emission tomography (PET)</strong> uses radioactive material to create a 3D image of your body. It can identify presence of myeloma cells in the bone marrow and other parts of the body.</td>
</tr>
<tr>
<td></td>
<td>Less commonly used:</td>
</tr>
<tr>
<td></td>
<td>A <strong>computed tomography (CT)</strong> scan uses a computer linked to an x-ray machine to make a series of detailed pictures of areas inside your body.</td>
</tr>
<tr>
<td></td>
<td><strong>Magnetic resonance imaging (MRI)</strong> uses magnetic fields and radio waves to create images of the body’s organs and tissues.</td>
</tr>
</tbody>
</table>
Risk groups of SMM

There is a risk that your SMM may progress to active multiple myeloma. The risk can be described as:

- In the first five years after diagnosis 10% of people per year with SMM may develop active multiple myeloma
- In the next five years the risk is 3% per year
- After 10 years the risk is 1% per year

SMM can be divided into three risk groups:

<table>
<thead>
<tr>
<th>Low risk</th>
<th>Intermediate risk</th>
<th>High risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Your plasma cells are less than 10% in your bone marrow</td>
<td>- Your plasma cells are 10% or more in your bone marrow</td>
<td>- Your plasma cells are 10% or more in your bone marrow</td>
</tr>
<tr>
<td>- The M-protein level in your blood is at least 30 grams/litre</td>
<td>- The M-protein level in your blood is less than 30 grams/litre</td>
<td>- The M-protein level in your blood is at least 30 grams/litre</td>
</tr>
</tbody>
</table>

Monitoring and managing your SMM

When you have SMM, it’s important to monitor your illness. Your doctor should do a full medical exam and blood work if any symptoms suggest multiple myeloma. There is no treatment for SMM: the focus is to determine the risk of it progressing.

Most people with SMM have no symptoms (are asymptomatic) when they are diagnosed. Many may not require treatment for years. Active treatment begins when symptoms develop.

Treatment

Your doctor will likely take a “watch and wait” approach and no treatment is required at this stage (unless you are part of a clinical trial). This is also called active surveillance and it delays treatment until the disease progresses to active multiple myeloma. You will have regular tests to monitor signs of organ damage (increase of calcium, renal dysfunction, anemia), M-protein levels and presence of bone lesions.

Your risk factors will determine how often you are monitored. Your doctor may recommend treatment if you become high risk.

Managing SMM

Talk to your healthcare provider about what to expect and what you can do to help manage SMM.

Steps you can take for your overall health include:

- Eat a healthy diet
- Get lots of sleep
- Stop smoking
- Stay active
- Avoid infections
- Focus on your emotional health
Living with SMM can be overwhelming. Seek medical help if you feel “down” or “blue” or don’t want to do anything – and your mood does not improve over time. These could be signs of depression, an illness that should be treated. Treatment for depression has important benefits for people living with cancer. Remember, you are not alone.