

# My treatment with REVLIMID®

(lenalidomide)

A guide for people with newly diagnosed multiple myeloma requiring maintenance therapy post autologous stem cell transplantation (ASCT)

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**Note:** Terms in **blue** are explained in the glossary on page 42.

# Dosing calendar Ongoing therapy

In the calendar below, your doctor or nurse will mark up the days on which you will need to take your medication.

R = REVLIMID® (lenalidomide) [dose: \_\_\_\_\_]

Day 1	Day 2	Day 3	Day 4
R	R	R	R
Day 5	Day 6	Day 7	Day 8
R	R	R	R
Day 9	Day 10	Day 11	Day 12
R	R	R	R
Day 13	Day 14	Day 15	Day 16
R	R	R	R
Day 17	Day 18	Day 19	Day 20
R	R	R	R
Day 21	Day 22	Day 23	Day 24
R	R	R	R
Day 25	Day 26	Day 27	Day 28
R	R	R	R

# **Notes**

My doctor's name is:	
Contact details:	
My nurse's name is:	
Contact details:	
Important information about my REVLIMID® treatment:	

# What is multiple myeloma?

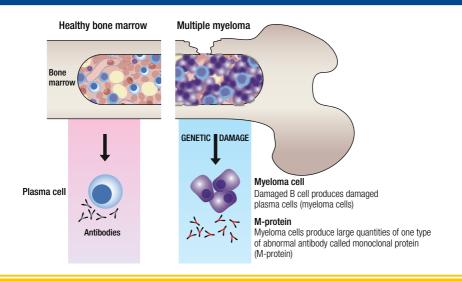
Multiple myeloma is a **cancer** of the **plasma cells** in the blood. Plasma cells are **white blood cells** that originate and collect in the **bone marrow** – the soft, spongy, inner core of the bones. Plasma cells produce **antibodies**, which help the **immune system** recognise and fight infections.

Multiple myeloma occurs when genetically damaged plasma cells – called **myeloma cells** – are produced. The myeloma cells collect in the bone marrow, where they continue to divide and multiply in an uncontrolled way.

The condition is called 'multiple' myeloma because it typically affects multiple sites in the body.

While there is no cure for multiple myeloma, symptoms can be decreased, and in some cases, symptoms can be controlled for a period of time, if they are well managed with continuing treatment and/or monitoring.

Multiple myeloma is a cancer of the cells that make antibodies, the proteins that help your body recognise and fight infections

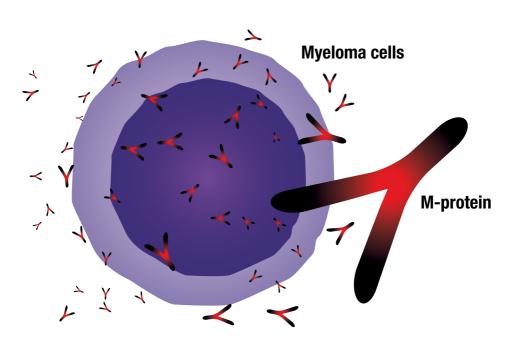


# What is M-protein?

Myeloma cells produce an abnormal type of antibody called **M-protein** (also known as paraprotein).

Unlike normal antibodies, M-proteins cannot fight infection. As myeloma cells continue to divide and multiply, the damaged cells 'crowd out' normal healthy plasma cells and reduce the body's ability to fight infections. As a result, people who have multiple myeloma are at an increased risk of infections, some of which can be serious (e.g. pneumonia).

Myeloma cells can also cause damage to the bones (leading to development of bone pain and/or fractures) and the kidneys.



Myeloma cell producing abnormal antibody, also known as M-protein

# Who is affected by multiple myeloma?

Multiple myeloma becomes more common as people age. It is most often diagnosed in people aged 65–70 years. However, recent studies indicate that the number of people with multiple myeloma is increasing, and that it is occurring more often in younger people. Multiple myeloma occurs slightly more often in men than in women. To date, no cause for multiple myeloma has been identified. However, there are certain factors that may put some people at a higher risk of developing the disease. These include exposure to chemicals, pollutants, radiation or other environmental risk factors.

# What are the symptoms of multiple myeloma?

One of the difficulties in diagnosing multiple myeloma is that its symptoms are varied and may be confused with those of other diseases. Some people may have no symptoms at all and the disease may be discovered only through routine physical examination. Early symptoms associated with multiple myeloma include:



Bone pain



Unexplained weight loss



**Tiredness** 



Unexplained bone fractures



Frequent infections



Abnormal kidney function

# How is multiple myeloma diagnosed?

In order to diagnose multiple myeloma, several tests and investigations are needed. The initial evaluation to confirm a diagnosis of multiple myeloma includes blood and urine tests as well as tests on bone and bone marrow.

Other tests may include X-rays, magnetic resonance imaging (MRI), computed tomography (CT) and positron emission tomography (PET) scans. Having all of the appropriate multiple myeloma tests done is very important, because the results will help your doctor to assess the extent of the disease and to plan and monitor treatment.

# Treatment for multiple myeloma

Treatments for multiple myeloma can be very effective at slowing its progress, controlling the symptoms, and improving quality of life, but they are not able to cure it. Multiple myeloma tends to follow a relapsing disease course. With the help of therapy, most people achieve **remission** (a decrease in or low level of symptoms). However, at some point, symptoms can return and the disease is likely to eventually **relapse**.

# Why have I had a transplant?

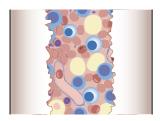
Chemotherapy effectively kills myeloma cells as well as good, healthy cells. An autologous stem cell transplant is when healthy cells are taken from your blood and transplanted back following chemotherapy, replacing what was lost. This allows the safer use of high-dose chemotherapy to destroy more myeloma cells.

#### What is residual disease?

Residual disease is the name given to small numbers of myeloma cells that remain in the bone marrow even when a person is in remission. Residual disease is a major cause of relapse in multiple myeloma.

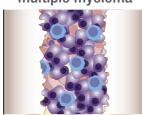
Some studies have shown that continuing to take multiple myeloma medication even when in remission can delay relapse by controlling the residual disease.

#### Healthy bone marrow



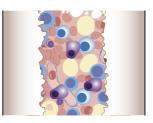
- Plasma cells function normally
- No M-protein

Bone marrow in multiple myeloma



- Myeloma cells crowd out healthy plasma cells
- Significant M-protein produced

#### Residual disease



- Some myeloma cells remain
- Contributes to relapse

# What is REVLIMID®?

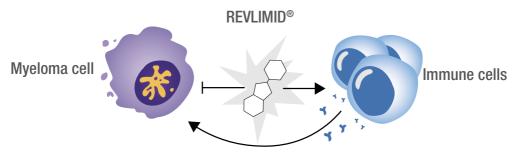
REVLIMID® is the brand name of a medication called **lenalidomide**.

This booklet provides information for people who have been prescribed REVLIMID® as maintenance therapy following stem cell transplantation.

**Maintenance therapy** helps maintain the suppression of multiple myeloma.

REVLIMID® works in multiple ways within the bone marrow to stop or slow the growth of cancerous myeloma cells. One of the ways it works is by stimulating your own immune system to fight myeloma. It also works directly to kill the myeloma cells.

#### Directly killing multiple myeloma cells



Activating the body's immune cells to target multiple myeloma cells



#### How do I take REVLIMID®?

- REVLIMID® works best when you continue to take it exactly as directed by your doctor
- REVLIMID® comes in the form of gelatin capsules, which are taken orally (swallowed whole) with water once a day. Do not break, chew or open the capsules
- REVLIMID® should be taken on an empty stomach at least 1 hour before, or 2 hours after food
- It does not matter what time of day you take REVLIMID®, but it is recommended
  that you take it at the same time each day



#### How should I store and handle REVLIMID®?

- Store REVLIMID® in its original packaging, in a cool, dry place (below 25°C)
- As with all medicines, REVLIMID<sup>®</sup> should be kept out of the reach of children
- Never share your REVLIMID® with anyone else

# What dose will I be taking?







Capsules are not to scale

- REVLIMID® comes in three capsule strengths for people on maintenance therapy:
   5 mg, 10 mg, 15 mg
- For people requiring post-transplant maintenance therapy, the most common starting dose is REVLIMID® 10 mg once a day
- Your doctor will determine the REVLIMID® dose you require, and may increase or decrease your dose depending on your health



#### How often do I need to take REVLIMID®?

- REVLIMID® is taken continuously (every day) when given as maintenance therapy
- Keep taking REVLIMID® until your doctor tells you to stop

#### What if I miss a dose or take too much REVLIMID®?

- You should never skip doses or change your prescribed dose of REVLIMID® without first talking to your doctor
- If you miss your dose of REVLIMID® and less than 12 hours have passed, take it as soon as you remember, then resume your regular dosing schedule
- If you miss your dose and more than 12 hours have passed, skip the dose that you missed. Do not try to 'catch up' by taking two doses the next day; simply continue your regular dosing schedule
- If you take too much REVLIMID® (or overdose), call your healthcare provider or the Poisons Information Centre on 13 11 26 right away

Always take REVLIMID® as prescribed by your doctor and never skip doses. If you are ever unsure on what to do, ask your doctor or pharmacist.

# What tests will I need?

Regular monitoring and follow-up will be an important part of your REVLIMID® treatment. This allows your doctor to assess how well your treatment is working and also to check for evidence of potential side effects. Two of the most common tests are the **full blood count (FBC)** and M-protein tests.

#### **Full blood count**

An FBC is used to measure how many different types of cells are in your bloodstream. There are three main types of blood cells:

- Red blood cells give your blood its red colour and make up almost half of your blood. Red blood cells are filled with haemoglobin (Hb), a molecule that carries oxygen to the rest of the body
- White blood cells are part of your body's defence system against infection.
   There are several types of white blood cell. Neutrophils are the most numerous, and are the first line of defence against infection. Neutrophil numbers can decline temporarily with certain treatments
- Platelets are involved in the blood clotting process. They help stop bleeding, and repair damage to blood vessels

Your doctor can use FBCs to help diagnose multiple myeloma; however, the diagnosis cannot be made from an FBC alone.

Decisions to interrupt and/or reduce your dose of REVLIMID® will be based on the results of these blood tests, as well as the severity of any other symptoms or side effects you may be experiencing.

# M-protein tests

Doctors generally classify multiple myeloma according to symptoms and the extent to which the disease has progressed. In multiple myeloma, one of the ways of determining the activity of the disease is through M-protein tests.

M-protein is the abnormal type of antibody produced by myeloma cells. The levels of M-protein in the blood or urine are a measure of how active the disease is in the body. An abnormal increase in M-protein level is commonly known as an M-spike.

In rare cases of multiple myeloma, known as non-secretory myeloma, the myeloma cells produce little or no M-protein. Although this can make it more difficult to diagnose and monitor multiple myeloma, there are highly sensitive tests available, such as serum free light chain (SFLC) testing, that can help diagnose and monitor the condition.

# What are the possible side effects of REVLIMID® treatment?

Like all medical therapies, treatment with REVLIMID® is sometimes associated with side effects. Not everyone will have side effects, and different people can be affected by the same side effect in different ways.

You will be monitored closely throughout your treatment, which will help to ensure early detection and management of side effects. Managing the side effects should help you to continue with REVLIMID® treatment. If a side effect proves particularly troublesome, your doctor may decide to reduce your dose or, in some cases, temporarily stop your treatment.

This booklet provides information on managing some of the more common side effects of REVLIMID® therapy, but does not replace the advice of your healthcare team. If you have any concerns about the possible side effects of your treatment, speak to your doctor or pharmacist; they will be able to explain the risks, as well as offer advice about how to prevent or minimise possible side effects.

Your treatment will work best if you discuss with your doctor ways to prevent and manage any possible side effects that may arise.

Tell your doctor or pharmacist as soon as possible if you do not feel well while taking REVLIMID®.

**Note:** The following pages discuss some, but not all, of the possible side effects of taking REVLIMID®. For more information, please refer to the REVLIMID® Consumer Medicine Information available at: www.quildlink.com.au/qc/ws/celgene/cmi.cfm?product=cjcrevli

# Potentially serious side effects

#### Possible birth defects or death of an unborn baby

- You must NOT become pregnant while taking REVLIMID®; female patients who are already pregnant or who plan to become pregnant MUST NOT take REVLIMID®
- If you become pregnant while taking REVLIMID®, stop taking it right away and contact your doctor immediately
- Female partners of men who take REVLIMID® must call their doctor right away if they become pregnant

Do not donate semen during treatment or during treatment interruption, or for 1 week after stopping treatment.

# Potentially serious side effects (cont.)

#### **Blood clots**

Blood clots can sometimes occur with REVLIMID® therapy. A blood clot that forms in the large, deep veins of the leg is called **deep vein thrombosis**, or DVT. If a piece of a blood clot breaks off, it may travel to the lungs and block the blood flow there, which is called a **pulmonary embolism**.

#### What you can do:

Stop taking REVLIMID® and see a doctor immediately or go to Emergency at your nearest hospital if you experience any of the following:

- Sudden pain in your chest
- Pain, swelling or tenderness in the lower legs, arms or chest
- Shortness of breath
- Rapid heartbeat/breathing
- Coughing up blood

#### What your healthcare team may do:

- Monitor you closely and suggest actions to minimise your risk
- Recommend some ways to reduce the risk of blood clots
- Prescribe devices or medications (clot-preventing medicines or 'blood thinners') to help treat or prevent blood clots

# Potentially serious side effects (cont.)

#### Serious allergies and skin reactions

Rashes can occur with REVLIMID® therapy, but they are usually mild to moderate, and disappear within a few weeks. However, some rare forms of rash require immediate medical attention.

# What you can do:

Monitor your skin for signs of rash (e.g. redness, itchiness)

Stop taking REVLIMID® and see a doctor immediately or go to Emergency at your nearest hospital if you experience any of the following:

- Itching, rash or hives, especially if it covers large areas or spreads quickly
- Skin that becomes flaky, peels or forms fluid-filled blisters
- Swelling, blistering or bleeding of the skin or mucosa of the face, lips, eyes or mouth
- Shortness of breath, wheezing or difficulty breathing

# What your healthcare team may do:

- Treat you with tablets and/or creams
- If necessary, change the dose or stop REVLIMID®

Certain rare skin reactions may require treatment in hospital

# Potentially serious side effects (cont.)

#### Neutropenia and serious infections

**Neutropenia** is a reduction in white blood cells called neutrophils, which protect against infection. It is quite common with REVLIMID® therapy, especially in the first few months of treatment.

# What you can do:

- Reduce your risk of infections by:
  - Washing your hands with soap, carefully and often, and wearing a mask where necessary
  - Maintaining good personal hygiene
  - Keeping your skin moisturised to prevent it from cracking

Stop taking REVLIMID® and see a doctor immediately or go to Emergency at your nearest hospital if you experience symptoms of infection, including:

- Fever (temperature of more than 38°C) or shaking chills
- Flu-like symptoms
- Confusion, dizziness or fainting
- · Redness at a wound site
- Rapid pulse or breathing
- Cough, phlegm or sinus congestion
- Mouth ulcers, sore mouth or throat
- Pain or burning when urinating
- Passing less urine than normal
- Nausea, vomiting, diarrhoea

# What your healthcare team may do:

- Perform regular blood tests to check your blood counts
- Treat you with medication to prevent infection and stimulate white blood cell growth
- If necessary, change the dose or stop REVLIMID®

# Thrombocytopenia

**Thrombocytopenia** is a reduction in platelets (thrombocytes), which are involved in the blood clotting process.

#### What you can do:

Tell your doctor or healthcare team immediately if you experience any of the following:

- Multiple or large bruises
- Blood in urine or stools
- Spontaneous nosebleeds
- Small red or purple spots on the body
- Bleeding that does not stop with pressure

# What your healthcare team may do:

- Check your platelet count regularly
- Treat you with platelet transfusions
- If necessary, change the dose of REVLIMID®

# Other potentially serious side effects

Some other possible potentially serious side effects are listed below:

- Numbness, tingling, pins and needles, or other unusual feelings in your arms, legs, fingers or toes
- Yellowing of your skin or eyes
- Loss or disturbance of vision

Stop taking REVLIMID® and see a doctor immediately or go to Emergency at your nearest hospital if you experience any of the following:

Potential Side Effect	Symptoms may include:
Stroke	Blurred vision, severe headache, weakness or numbness in the face, arm or leg, trouble speaking or understanding, loss of balance
Heart Attack	Sudden pain in your chest or difficulty in breathing
Heart Failure	Chest pain, severe weakness, rapid or irregular heartbeat, and/or sudden, severe shortness of breath and coughing up pink, foamy mucus
Kidney Disease	Passing little or no urine, drowsiness, nausea, vomiting, or breathlessness
Liver failiure or Hepatits B virus	Abdominal pain, dark urine, fever, joint pain, loss of appetite, nausea and vomiting, yellowing of the skin and/or eyes

# Talk to your doctor immediately if you experience any of the following:

Potential Side Effect	Symptoms may include:
Fast heart beat or atrial fibrillation (irregular heart beat)	Heart palpitations or fast heart beat, chest pains, dizziness or fainting, shortness of breath, weakness, or reduced ability to exercise
Anaemia	Tiredness, headaches, shortness of breath, dizziness and looking pale
Nerve damage	Numbness, tingling, or weakness of the arms and legs
Diabetes (high blood sugar)	Passing large amounts of urine, excessive thirst, and having a dry mouth and skin
Cataracts	Blurred vision or difficulty seeing
Low levels of minerals such as potassium, calcium, magnesium or sodium	Abnormal eye movements, convulsions, mood changes or irregular heart rhythm

#### Other common side effects

**Gastrointestinal** side effects (e.g. constipation, diarrhoea or nausea), fatigue and muscle cramps can be common in people taking REVLIMID® therapy. These side effects can generally be managed, so speak to your doctor if they trouble you.

#### Constipation

# What you can do:

- Increase your fluid intake (e.g. drink a warm/hot beverage about half an hour before your normal timing for bowel movement)
- Eat foods high in fibre (e.g. fresh fruits and vegetables, whole grains);
   consider a fibre supplement if you don't have enough fibre in your regular diet
- Walk and participate in gentle exercise

#### Diarrhoea

# What you can do:

 Keep up your fluid intake (avoid caffeinated, carbonated or heavily sugared drinks)

# Other common side effects (cont.)

#### Nausea

# What you can do:

- Try to prevent nausea, not just control it
- Avoid foods or unpleasant smells that trigger nausea
- Eat small, frequent meals rather than three big meals
- Reduce the amount of fluid you have with your meals
- Try peppermint or ginger tea, a sports beverage, an ice block or ice chips
- Rest after eating but don't lie flat for at least 2 hours after eating

#### Muscle cramps

# What you can do:

- Remain active
- Try massage and stretching exercises
- Try isotonic sports drinks or tonic water

#### **Fatigue**

# What you can do:

- Maintain a healthy diet with plenty of fluid
- Try to include some gentle physical activity every day
- Avoid naps during the day

# Other common side effects (cont.)

#### Other common side effects

Some other common side effects are listed below. Many of these are manageable, so speak to your doctor if they worry you:

- Muscle weakness
- Loss of energy
- Trouble sleeping
- Taste disturbance or loss of taste
- Depression
- Headache
- Dizziness
- Indigestion
- Dry skin
- Sweating
- Aching bones or muscles

# What should I do to help achieve my treatment goals?

There are many things you can do to help achieve your treatment goals and continue getting the most out of life.

- It is very important to try your best to continue taking REVLIMID® until your doctor tells you to stop.
- It is also very important to remain on the lookout for new symptoms or the return of previous ones, as well as signs of any side vany changes to your condition or how you feel.
- Ensure you always have a supply of your medication and remember to take it every day — if you sometimes forget, try setting a reminder or putting a note somewhere that you will see it.
- Look after your overall health by eating a nutritious diet, doing regular gentle exercise, getting enough rest, and reducing stress in your everyday life.
- Ask questions and learn as much as you can about multiple myeloma and its treatment, as well as additional ways to improve your overall health and wellbeing.
- Communicate regularly with your doctor and healthcare team and never be afraid to ask questions about your illness or its treatment.
- Seek support from relevant associations and patient groups (some suggested sources are listed on page 34–35 of this booklet).

One of the best things you can do to manage your myeloma is to stay on your treatment plan prescribed by your doctor. You should never skip doses, change or stop your treatment without first talking to your doctor.

# Are there things I should not do during treatment?

- ➤ Do NOT take this medicine if you are pregnant, or think that you are pregnant. REVLIMID® may cause birth defects (deformed babies), and may affect your developing baby if you take it during pregnancy
- Do NOT take REVLIMID® if you are allergic to lenalidomide or any of the other ingredients listed on the box
- ➤ Do NOT become pregnant while taking REVLIMID® (during the 4-week period before starting treatment, during treatment and also during the 4-week period after stopping treatment)
- **Do NOT breastfeed**, as it is not known whether REVLIMID® can pass into breast milk and potentially harm a breastfeeding baby
- Do NOT donate blood during treatment or during the 1-week period after stopping treatment
- Do NOT donate sperm during treatment or during the 1-week period after stopping treatment, as REVLIMID® passes into semen
- Do NOT share REVLIMID® with other people, even if they have similar symptoms

#### What if I or my partner becomes pregnant?

- If you become pregnant while taking REVLIMID®, stop taking it right away and contact your doctor immediately
- If you are a man and your partner becomes pregnant while you are taking REVLIMID<sup>®</sup>, you must call your doctor right away

# Safety and support - i-access® program

**REVLIMID®** belongs to a group of drugs known as immunomodulatory drugs, or IMiDs. The following information is important for anyone receiving an IMiD. If an IMiD is taken during pregnancy, it may cause birth defects or death to an unborn baby. To avoid exposure to unborn babies, IMiDs are available only under the *i-access*® program.

The *i-access*® program ensures that use and distribution of REVLIMID® is closely monitored and well controlled, and ensures that patients are fully informed about their treatment and — most importantly — that they take all necessary steps to avoid foetal exposure to REVLIMID®.

Patients receiving REVLIMID® have the ability to nominate a local pharmacy to replenish their stock through the i-access® program.

Only patients who are formally enrolled in the *i-access*<sup>®</sup> program and agree to comply with all of the requirements of this program can receive REVLIMID<sup>®</sup>. For a full list of requirements and further information, please refer to the *i-access*<sup>®</sup> resource kit and Product Information.



# What are the requirements for patients enrolled in the *i-access*® program?

Special *i-access*® program requirements for women who are able to become pregnant\*

#### **Important: Do NOT become pregnant:**

- During the 4 weeks before starting IMiD treatment
- While taking an IMiD
- During any interruption in IMiD treatment
- During the 4-week period following the conclusion of your IMiD treatment

#### **Before starting treatment:**

- You must sign an *i-access*<sup>®</sup> patient consent, agreeing not to become pregnant while taking an IMiD
- You must use at least one highly effective and, preferably, one additional effective form of birth control (contraception)<sup>†</sup> during the 4-week period before starting an IMiD
- You must have one negative medically supervised pregnancy test\*\* confirmed by your doctor either at the time of consultation, or in the 3 days prior to the visit to the doctor
- The pregnancy test must be medically supervised and not a pregnancy test from a pharmacy

\*Includes: women who are menstruating, amenorrhoeic due to previous medical treatment, < 50 years of age and/or peri-menopausal; women who have not been in natural menopause for ≥12 consecutive months. 'Highly effective forms of birth control include intra-uterine device (IUD) (copper IUDs are not recommended), hormonal methods' (intra-notrol pills, injections, implants, ring), tubal sterilisation or partners's vasectomy (confirmed by 2 negative semen analyses). Additional effective forms of birth control include diaphragm, cervical cap or latex/polyurethane condom by her male partner. For some IMIDs, progesterone only pills are recommended. Combined oral contraceptives are not recommended. Please ask your doctor which birth control method you should use. "Medically supervised means a test that has been conducted or overseen by a Healthcare Professional (HcDP). Your HCP should refer to the relevant Product Information (Australia) or Data Sheet (New Zealand) for details of what type of pregnancy tests you should have. A test which is done at home without medical supervision is NOT acceptable.

#### **During treatment:**

- You must continue to use at least one highly effective and, preferably, one additional effective form of birth control (contraception)
- You must also undergo regular medically supervised pregnancy tests, regardless of whether continuous abstinence is practised:
  - Every 4 weeks during treatment

#### And

- The pregnancy tests should be performed on the day of the visit to the doctor or in the 3 days prior to the visit
- You must not breastfeed or donate blood^
- Never share, break, chew or open your IMiD capsules

**Note:** If you miss a period, experience any abnormality in menstrual bleeding, become pregnant or have sexual intercourse without using an effective means of birth control (contraception):

 Stop taking your IMiD immediately, tell your doctor straight away and have a pregnancy test

<sup>^</sup>In Australia, patients with myeloma are permanently excluded from donating blood.

#### For 4 weeks after treatment:

- You must continue to use at least one highly effective and, preferably, one additional effective form of birth control (contraception)
- You must continue the medically supervised pregnancy tests every 4 weeks, ensuring that a pregnancy test is conducted 4 weeks after stopping treatment
- You must not breastfeed or donate blood^

**Note:** If you miss a period, experience any abnormality in menstrual bleeding, become pregnant or have sexual intercourse without using an effective means of birth control (contraception):

- Tell your doctor immediately and have a pregnancy test
- If you experience any side effects, you should tell your doctor or pharmacist
- You should always return any unused capsules to the pharmacist for safe disposal as soon as possible

In Australia, patients with myeloma are permanently excluded from donating blood.

# *i-access*® program requirements for women who are NOT able to become pregnant

#### **Before starting treatment:**

- You must sign an i-access® patient consent, indicating that you do not have the ability to have children
- This means that you are at least 50 years old and have been naturally postmenopausal for at least 12 months
- OR have premature ovarian failure confirmed by a specialist gynaecologist
- OR have had your uterus removed (hysterectomy)
- OR have had both ovaries removed
- OR have XY genotype
- OR have Turner Syndrome
- OR have uterine agenesis

#### **During treatment and during treatment interruptions:**

- You must not donate blood^
- Never share your IMiD capsules

#### For 4 weeks after treatment:

- You must not donate blood<sup>^</sup>
- You should always return any unused capsules to the pharmacist for safe disposal as soon as possible

**Note:** If you experience any side effects you should tell your doctor or pharmacist.

<sup>&#</sup>x27;In Australia, patients with myeloma are permanently excluded from donating blood.

# i-access® program requirements for men

#### **Before starting treatment:**

IMiDs are present in semen. You must therefore sign an *i-access*® patient consent agreeing to use a latex/polyurethane\* condom **EVERY TIME** you have sexual intercourse with a woman who either is or can become pregnant (even if you have had a successful vasectomy)

#### **During treatment and during treatment interruptions:**

- You must use a latex/polyurethane condom EVERY TIME you have sexual intercourse with a woman who either is or can become pregnant (even if you have had a successful vasectomy)
- You must tell your doctor immediately if you have sexual intercourse with a woman without using a latex/polyurethane condom, or if you think for any reason that your partner may be pregnant
- You must not donate blood<sup>^</sup> or sperm
- Never share, break, chew or open your IMiD capsules

<sup>\*</sup>If allergic to latex and polyurethane, any female sexual partner must use at least one highly effective and, preferably, one additional effective method of contraception. Please discuss with your doctor.

In Australia, patients with myeloma are permanently excluded from donating blood.

#### For 4 weeks after treatment:

- You must continue to use a latex/polyurethane condom EVERY TIME
  you have sexual intercourse with a woman who either is or can become
  pregnant (even if you have had a successful vasectomy)
- You must tell your doctor if you have sexual intercourse with a woman without using a latex/polyurethane condom, or if you think for any reason that your partner may be pregnant
- You must not donate blood<sup>^</sup> or sperm
- You should always return any unused capsules to the pharmacist for safe disposal as soon as possible

**Note:** If you experience any side affects you should tell your doctor or pharmacist.

<sup>^</sup>In Australia, patients with myeloma are permanently excluded from donating blood.

# Where can I find more information?

Never be afraid to ask your doctor if you have any questions or concerns regarding your illness and/or its treatment, or if you simply want to know where you can go for more information; they will always be your most reliable source of information and advice.

For tips or advice about how to prevent or minimise treatment-related side effects, speak to your doctor or other members of your healthcare team who are involved in your treatment (e.g. nurse or pharmacist).

Further information about REVLIMID® and/or the *i-access*® program can be obtained by calling Bristol Myers Squibb Customer Service on 1800 235 4363 and pressing "3" at the auto-prompt.

#### **Useful contacts**

#### Myeloma Australia

Supports and provides information to those affected by myeloma, while advocating for availability of best treatment and supporting research.

The support line is manned by specialist myeloma nurses supporting patients diagnosed with myeloma.

**Support line:** 1800 MYELOMA (1800 693 566)

Web: www.myeloma.org.au

#### **Leukaemia Foundation**

Can provide support from qualified health professionals, transport to most metropolitan treatment centres, accommodation for regional patients receiving treatment in metropolitan centres, as well as practical support.

**Tel:** 1800 620 420 | **Web:** www.leukaemia.org.au

# **Useful contacts (cont.)**

#### **Cancer Council of Australia**

Provides a wide range of information and support programs for people affected by cancer, including myeloma

Helpline: 13 11 20

Web: www.cancer.org.au

#### **Cancer Institute NSW**

Provides a wide range of information and support programs for people affected by cancer

**Tel:** (02) 8374 5600

Web: www.cancerinstitute.org.au

#### **National Prescribing Service (NPS)**

Provides a wide range of information and support programs for people affected by cancer

**Tel:** 1300 MEDICINE (1300 633 424)

Web: www.nps.org.au

#### **Lab Tests Online**

A public resource on clinical lab testing from the laboratory professionals who do the testing

Web: www.labtestsonline.org.au

# Information for friends, family members and carers

This section of the booklet is designed to be read by family members, friends and carers of people being treated with REVLIMID<sup>®</sup>.

This section contains some general information about ways in which you can help support your family member, friend or person you are caring for, during their treatment with REVLIMID®. Learning about the disease and treatment will help you understand what they may be experiencing.

There are many ways for you to be supportive, such as helping out with the housework, giving medication reminders, or providing a shoulder to lean on. Remember, it's also important to look after yourself during this challenging time — staying healthy and making time for yourself will help you to be better able to provide support.

# What are some practical ways I can help?



#### **Understand their condition**

Reading about multiple myeloma and its treatment will help you to better understand what your family member/friend is experiencing. Attending medical appointments with them is also a great support, as well as an opportunity to ask questions.

Visit the following websites to learn more:

- www.myeloma.org.au
- www.leukaemia.org.au



#### Learn about their medications

Become familiar with what each medication does, when it must be taken, and when prescriptions need renewing (using a diary can help). If they don't always remember to take their medication, you can discuss strategies to remind them, for example setting an alarm or leaving a note somewhere they'll see it every day.



#### Be aware of side effects

A very important way for you to help is by keeping an eye out for any side effects they may experience. If the patient experiences side effects, ensure they contact their doctor or medical team immediately.



#### Help with everyday jobs

Helping with tasks like cooking, shopping, gardening, housework, managing paperwork such as paying bills, babysitting or driving them to appointments can make a big difference. You don't have to do it alone — you could coordinate a schedule or roster with other family members and friends who are eager to help.



#### Just be there for them

Don't underestimate the importance of simple things to show you care, like listening to what's on their mind and staying in touch. If they're feeling well enough, a great way to be supportive and help take their mind off their condition is to organise some 'normal' activities to do together, like seeing a movie, going out for dinner, or getting outside for some fresh air and exercise.

# What are some tips for looking after my own wellbeing?

Caring for someone with multiple myeloma is challenging, and it can be easy to neglect your own wellbeing. But if you're not at your best, it will be difficult to provide the best care for someone else. So it's very important to make time for your needs — including your physical health, emotional wellbeing and social life. Below are some tips that may help.



#### Tips for physical health

- Try to eat three healthy, well-balanced meals per day
- Keep hydrated by drinking plenty of fluids
- Cut down on fatty foods, sugar, caffeine and alcohol
- Ensure you are getting adequate sleep
- Get regular, gentle exercise
- Take time to relax daily
- Don't forget to look after your own health.
   See your healthcare professional when needed



#### Tips for emotional wellbeing

- Be aware of signs of emotional distress (e.g. anxiety, depression, anger and stress), and seek professional help if required
- Do some exercise, deep breathing or relaxation techniques to relieve tension and clear your mind
- Find a regular hobby or take a class you're interested in
- Don't feel guilty about wanting or needing time away from your duties as a caregiver
- Take short breaks and arrange for alternate care, so you can feel secure and comfortable during your time away
- Talk to close friends or family about your feelings, or any changes in your mood they may have noticed
- Join a support group or online chat room with other caregivers who are in a similar situation (see page 34–35) for organisations that can help)
- Seek professional help if you're finding it difficult to cope



#### Tips for maintaining social relationships

- Reassure your family and friends that although you may not see them as often as you'd like, you do need and appreciate their support
- Share your experiences as a caregiver with them so they can try to understand what it's like for you, but also ask them about what's happening in their lives
- Accept invitations to social events, or invite people over to visit you at home
- Call or make plans to see people with whom you have lost touch
- Join a club or group activity

# **Glossary**

**Anaemia:** A condition in which the number of red blood cells is below normal, resulting in fatigue or weakness

**Antibodies:** Proteins that fight infection

**Antiemetic:** A medication that prevents nausea and vomiting

**ASCT (autologous stem cell transplant):** A treatment that is used to replace bone marrow lost after high-dose chemotherapy with healthy stem cells taken from your own blood or bone marrow

**Bone marrow:** The soft, sponge-like tissue in the centre of large bones that produces white blood cells, red blood cells and platelets

**Cancer:** A term for any disease in which damaged or abnormal cells divide and multiply uncontrollably

**CT (computed tomography):** An imaging technique that uses a computer to generate three-dimensional x-ray pictures

**Deep vein thrombosis:** A blood clot in the large veins of the legs

**Full blood count (FBC):** A test that measures the number and types of cells circulating in the blood

**Gastrointestinal:** Related to the digestive system

**Hysterectomy:** A surgical procedure in which the uterus is removed

**Immune system:** The complex group of organs and cells that defends the body against infection and disease

**Immunomodulating agent:** A substance that stimulates the immune system to help the body fight cancer.

**Lenalidomide:** The active ingredient in REVLIMID®; it works in multiple ways within the bone marrow to stop or slow the growth of cancerous myeloma cells

**Maintenance therapy:** An additional therapy that is given to improve the success of a primary cancer treatment, such as stem-cell transplantation

**M-protein:** A type of antibody made by myeloma cells; your doctor may test the level of M-protein in your blood and/or urine to monitor your disease and assess how well you are responding to treatment

M-spike: An abnormal increase in M-protein level

**MRI (magnetic resonance imaging):** An imaging technique that uses magnetic energy to provide detailed images of bone and soft tissue

**Mucosa**: A lubricating membrane that lines the internal surface of an organ

**Myeloma cells:** Damaged plasma cells that are made in the bone marrow

**Neutropenia:** A deficiency of neutrophils in the blood; neutrophils are the most common type of white blood cell

**PET (positron emission tomography):** An imaging technique in which radioactive glucose (sugar) is used to highlight cancer cells

**Plasma cells:** Special white blood cells that make antibodies

**Platelets:** The smallest cells in the blood, essential for blood clotting; also called thrombocytes

**Pulmonary embolism:** A blood clot in an artery in the lungs that prevents normal blood flow

**Red blood cells:** Cells that carry oxygen to the body's tissues

Relapse: The return of the disease or disease progression

**Remission:** Reduction or low level of symptoms

**Residual disease:** The term used for small numbers of cancer cells that remain in the bone marrow during treatment or after treatment when a patient is in remission

**Stem cell:** A cell which can develop into a wide variety of different cell types. Stem cells can be found in bone marrow, where they develop into different types of blood cells

**Thrombocytopenia:** A condition in which the number of platelets — or thrombocytes — is below normal, resulting in the tendency to bruise and bleed more easily

White blood cells: Cells that help the body to fight infection and disease



**WARNING:** REVLIMID® (lenalidomide) is structurally related to 'thalidomide', which is known to cause severe life-threatening human birth defects (deformed babies) and death to an unborn baby if taken during pregnancy. If REVLIMID® is taken during pregnancy, it may cause birth defects or death to an unborn baby. Do not take REVLIMID® if you are pregnant or think that you are pregnant.

**Note:** This booklet does not contain everything there is to know about multiple myeloma or its treatment, and is not intended to take the place of professional medical advice. Your primary source of information should always be your doctor and other healthcare providers who are involved in your care. You should follow your doctor's instructions at all times and contact your doctor if you have any questions about your condition or its treatment.

For more information about REVLIMID®, please refer to the REVLIMID® Consumer Medicine Information (CMI) leaflet, which is available at: http://www.guildlink.com.au/gc/ws/celgene/cmi.cfm?product=cjcrevli

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