

Managing Side Effects – WMUK Webinar



Q&As

Find answers to some of the key questions people living with WM and LPL have about managing side effects and recovering from treatment.

Need Support?

If you have any more questions, you can always call the Support Line on [0300 373 8500](tel:03003738500) or email support@wmuk.org.uk.

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1. What should I do if the dietary advice for another health condition conflicts with the general eating advice for WM?

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2. I had bendamustine and rituximab and have been told my immune system will always be suppressed. I do get frequent infections. Are preventative antibiotics ever recommended?

Heart Health & Monitoring

1. As someone with a history of atrial fibrillation who is taking zanubrutinib, should I be having regular heart checks?

Managing Treatment Side Effects

1. How long does it take to feel 'normal' again after chemotherapy or immunotherapy?

Everyone's recovery is different and will depend on factors such as your overall health before treatment, the type of treatment you receive and how your body responds.

During treatment, it's common to experience a pattern of good days and more challenging days with each cycle. Once treatment is complete, recovery continues. While many people gradually begin to feel stronger, fatigue is often the side effect that takes the longest to improve.

Although blood counts and parts of the immune system may recover within a few weeks, full immune recovery can take three to six months, or sometimes longer. It's important to remember that there is no set timeline for recovery, and it's perfectly normal for it to take time.

2. Can a rash be linked to WM and LPL or Zanubrutinib?

Skin rashes aren't a common symptom of WM or LPL, although changes to the immune system can sometimes affect the skin. Rashes can also occur as a side effect of BTK inhibitors, such as zanubrutinib, but this tends to be uncommon. In some cases, other medications given alongside treatment (such as allopurinol or co-trimoxazole) may be the cause.

If a rash was present before starting treatment, it may be related to the underlying condition. Some people find that it improves once treatment is started, although this isn't always the case.

If you develop a new rash or an existing rash worsens, it's important to let your healthcare team know so they can assess the cause and recommend the most appropriate treatment.

3. When starting a BTK inhibitor, is it common to have more side effects at first, and do these usually settle over time?

Yes. It often takes the body a little time to adjust when starting a BTK inhibitor, so it's not uncommon to experience more side effects during the first few weeks.

Some people develop nausea, headaches or joint aches when they first begin treatment.

Reassuringly, these side effects usually settle over time as your body gets used to the medication. In many cases, they either resolve on their own or become much easier to manage.

If your side effects are persistent, worsening or affecting your quality of life, it's important to let your healthcare team know. They can help advise on ways to manage them.

4. I recently started zanubrutinib and have developed aching legs, even though I walk every day. Is there anything that can alleviate this?

Keeping active and staying well hydrated can often help when managing aching muscles.

Before assuming the aches are caused by zanubrutinib, it's important to rule out other possible causes, such as circulation problems or existing joint conditions, as treatment can sometimes make these more noticeable. Other medications, including some antibiotics or anti-sickness medicines, can also contribute to muscle aches.

If the aches are related to treatment, they often improve as the body adjusts to the medication.

However, if one leg becomes swollen, hot or red, medical advice should be sought promptly, as this could be a sign of a blood clot rather than a treatment side effect.

5. What happens in a cytokine storm?

A cytokine storm is a very rare reaction, most commonly seen with CAR-T therapy. It happens when the immune system becomes overactive, which can cause symptoms ranging from a mild fever to feeling very unwell with a high temperature, low blood pressure and, in severe cases, the need for intensive care support.

The reassuring news is that it is treatable and reversible. Healthcare teams tend to monitor patients closely, and if it does occur, early treatment with steroids, fluids and supportive care can help to stop it from becoming more serious.

Fatigue, Neuropathy & Recovery

1. How can I tell whether my fatigue is caused by my treatment or is simply part of getting older?

Fatigue can be difficult to pin down because it's often caused by more than one factor. WM itself can cause tiredness, treatments can certainly contribute, and as we get older, it's common to have other health conditions, such as diabetes, that can also affect our energy levels.

It's likely that treatment may contribute to fatigue, but it's unlikely to be the only cause. Even if treatment was stopped, factors such as WM itself, ageing or other health conditions may still affect your energy levels.

If fatigue is persistent or is having a significant impact on your daily life, it's worth discussing it with your healthcare team. They may be able to identify contributing factors and suggest ways to help manage it.

2. Which treatments are most likely to cause or worsen neuropathy?

Neuropathy, or nerve damage that can cause symptoms such as numbness, tingling or pain, is actually more commonly linked to WM and LPL itself rather than the treatments used for WM and LPL.

Some medicines used to treat other types of blood cancer, such as vinca alkaloids, can cause neuropathy. However, treatments commonly used to treat WM and LPL, such as cyclophosphamide or bendamustine, are not usually associated with causing this side effect.

Treatment is often given to help prevent or improve neuropathy caused by the condition itself, so it's important to discuss any new or worsening symptoms with your healthcare team.



Diet & Nutrition

8. What should I do if the dietary advice for another health condition conflicts with the general eating advice for WM?

Generalised healthy eating advice is not always suitable for everyone, especially if you have another medical condition that requires a different diet. In these situations, it's important to seek individualised advice from your healthcare team or a specialist dietitian, so your dietary needs can be managed safely.

If treatment is planned, trying to access this support before treatment begins can be helpful. Taking time to prepare and address any existing health concerns may also help you feel more confident and better supported.

It's important to remember that everyone's situation is different. Your healthcare team will take your individual circumstances into account and tailor your care accordingly.



Immunity & Infections

1. After completing DRC treatment, will my immune system and immunoglobulins (including IgM) return to normal?

Immune system recovery can vary from person to person. Blood counts often recover within a few months, but immunoglobulin levels, particularly IgG and IgA, can take much longer to improve, and for some people they may remain lower than before treatment.

IgM is different, as it is produced by the WM cells. If treatment has been successful, IgM levels usually fall, but they may not return to the normal range.

Your healthcare team will monitor your blood tests and immune function closely during follow-up. If low immunoglobulin levels are leading to frequent infections, they may discuss whether additional support, such as vaccinations or preventative antibiotics may be needed.

2. I had Bendamustine and Rituximab and have been told my immune system will always be suppressed. I do get frequent infections. Are preventable

antibiotics ever recommended?

Yes, they can be. If you're experiencing frequent or severe infections, your healthcare team may consider preventative (prophylactic) antibiotics to help reduce the risk of infections. The decision will be based on your individual needs, including how often you're experiencing infections and how they're affecting you.

They may also review your immunoglobulin levels, as some people with persistently low antibody levels may benefit from immunoglobulin replacement therapy. If infections are becoming a regular issue, it's worth discussing the options with your haematology team.

Heart Health & Monitoring

1. As someone with a history of atrial fibrillation who is taking zanubrutinib, should I be having regular heart checks?

If you have a history of atrial fibrillation or another heart condition, it's important that your healthcare team is aware before you start treatment with zanubrutinib. Whether you need regular heart checks will depend on your individual medical history.

If you are unsure whether any monitoring is needed, or you develop symptoms such as palpitations, dizziness, shortness of breath or chest pain, it's best to speak to your healthcare team. They can advise whether any further assessment or monitoring is appropriate.

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