

# Watch and Wait: Patient Information

## My doctor says I don't need treatment and we are going to 'Watch and Wait'. What does 'Watch and Wait' mean?

Some patients with slow growing blood cancers are advised that no treatment is necessary yet, and the management is 'Watch and Wait'. This approach is used for diseases such as

- the low grade lymphomas (follicular lymphoma, marginal zone lymphoma, Waldenstrom's macroglobulinaemia)
- some types of myeloma (asymptomatic myeloma) and monoclonal gammopathy of undetermined significance (MGUS)
- the low grade leukaemias such as chronic lymphocytic lymphoma.

Watch and Wait is appropriate for some blood cancers that grow so slowly that they may not cause problems for some time. In these situations, your doctor may elect to Watch and Wait rather than give treatment immediately.

"Watch" means active monitoring with visits to your doctor, blood tests and sometimes scans on a regular basis, often every 3-6 months.

In this situation your doctor has determined that it is better to reserve treatment for when it is really needed, such as when your disease becomes more active or causes problems.

It is important to note that Watch and Wait does not mean that:

- your lymphoma is untreatable
- you are too old to be treated

Some lymphomas are unlikely to be cured by treatment, but are not yet causing significant problems for the patient. These patients benefit from active monitoring and treatment when it is needed for symptoms or other problems.

## Which patients are offered 'Watch and Wait'?

Your doctor may suggest Watch and Wait for you if:

- your disease is slow growing or very stable
- you feel well, with no symptoms
- your disease is not causing problems or growing rapidly
- your blood tests or scans are acceptable and stable

## When do I switch to active treatment?

Active treatments may be offered in your situation if:

- you develop symptoms that are troublesome
- the amount of disease in your body increases significantly
- your other organs or bone marrow start to not function properly

Some patients can remain stable without treatment for months to years.

## What is the benefit of Watch and Wait?

There has been a lot of study and data collected in patients treated with Watch and Wait. These studies have shown that with careful monitoring, there are benefits in reserving treatment until it is really needed, and avoids chemotherapy being given earlier than is needed.

Potential benefits from Watch and Wait include:

1. avoiding side effects of treatment until it is really needed
2. avoiding the cancer cells becoming resistant to treatment
3. minimising hospital visits during the monitoring phase
4. good quality of life and response to treatment once it is needed

## What are the risks of Watch and Wait?

Although there has been some concern that Watch and Wait may allow the disease to transform to a higher-grade disease. This has not been borne out in the studies and in fact is no greater a risk in patients receiving early treatment compared to Watch and Wait.

## What do I need to do if I am being managed with Watch and Wait?

You can help by monitoring yourself and reporting anything new including:

- Loss of appetite or weight
- Fevers or sweats
- Severe fatigue or tiredness
- Itching
- New lumps or lymph nodes getting larger
- New or worsening pain or other symptoms



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These symptoms may mean that your disease is becoming more active, and may require treatment. There are other explanations for these symptoms as well (such as infection) so it is important to get these checked out by your doctor.

Make sure you keep yourself as healthy as you can, so that if you do require treatment one day you are in the best shape possible. This includes:

- eating a healthy diet and maintaining a healthy weight
- don't smoke
- limit your alcohol to a healthy intake
- exercise regularly

## What is it like living with Watch and Wait?

Some people find it difficult initially to know that they have a disease but are seeming not to do anything 'active' to treat it. Initially this may make people anxious or uneasy, but remember that this decision was made by your doctor after carefully balancing out the risks and benefits to you, and that this course of action was chosen in your best interest.

Keep talking to your Haematologist, our specialist nurse, your family and your local doctor. Talking with friends or a psychologist may also be helpful. Let us know if you are struggling with 'Watch and Wait' as there may be more we can do to reassure you, to revisit the decision to Watch and Wait, and to increase your sense of control over your disease.