What is 'Watch & Wait'?

Many people newly diagnosed with follicular lymphoma (FL) do not need immediate anti-cancer treatment. FL often progresses slowly and may not cause any problems for a period of time. Instead, patients will be regularly monitored by their oncologist for months or years until the cancer changes and treatment is considered necessary. This is called 'watch and wait' or 'watchful waiting'.

Once a patient has been treated, the watch and wait phase starts again, as their oncologist will begin to monitor them for a potential return of their cancer.

Clinical trials have compared watch and wait with giving chemotherapy treatment immediately. These have shown that people who are monitored in this way do as well or better than those given treatment immediately.

Watch & Wait for Follicular Lymphoma

A Patient’s Guide to Follicular Lymphoma

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What is Follicular Lymphoma?

Follicular lymphoma (FL) is a cancer that develops when the body makes abnormal B lymphocytes (also called B cells). B lymphocytes are a type of white blood cell that works to fight infection and prevent disease as part of your immune system. It is called ‘follicular’ lymphoma because the cancerous lymphocytes often collect in lymph nodes in clusters that are known as ‘follicles’. FL is the most common type of indolent (slow-growing) non-Hodgkin lymphoma, and typically affects middle-aged or older adults.

What can I do to help myself?

There is no evidence to suggest that you can do anything yourself to keep your FL from progressing. However, as you might need treatment in the future, you should prepare for this by getting yourself as healthy as possible. This might mean making changes to your lifestyle, such as:

- eating a healthy diet and trying to maintain a healthy weight
- not smoking
- limiting your alcohol intake
- doing regular exercise – this will also help with fatigue

You might also want to think about:

- reducing your stress levels
- finding time for the things you enjoy doing, such as your hobbies, travelling or seeing family and friends
- learning more about your follicular lymphoma so that you will be able to make an informed choice when you do need treatment.
Why has my doctor recommended this approach for me?

Watch and wait is the recommended care for those who feel well, have small lymph nodes that are not causing problems or growing rapidly, have acceptable blood tests, and have no significant problems with their liver, kidneys or other organs.

The advantages of watch and wait are:
• Therapy can be as effective if it is only started when symptoms begin or there's evidence of advancing disease.
• You avoid treatment side effects, which can make you feel less well and could limit future treatment options.
• It's feasible that other treatment options may become available when it is eventually time to treat.
• Your quality of life is likely to be better since you don't have to go to the hospital for treatment and will not experience any treatment side effects.

The average time people are on watch and wait varies so it is impossible to say how long each patient will be monitored this way - it may be months or it may be years. Some patients never require treatment as their disease remains stable and they have manageable symptoms or do not experience any symptoms.

How will I know if I need treatment?

During the watch and wait period, you will meet regularly with your oncologist to monitor changes in your disease and overall health. At these appointments, your doctor will examine you, do blood tests and may do other tests like scans. They will also ask how you are feeling and about any symptoms you have.

The results of exams and blood tests over time will help your doctor determine if you need treatment and the type of treatment you should have.

Treatment is usually only started if you show signs of disease progression:
• Weight loss that is more than 10% of body weight in the previous 6 months
• Unexplained fevers higher than 38°C
• Drenching night sweats
• Progression of the tumour(s) in lymph nodes and in the spleen
• Large masses or organ involvement

Why is it important to stay in touch?

If you are on watch and wait it is important that you stay in touch with your oncologist and attend your clinic appointments. Between check-ups, you should contact your oncologist if:
• you have new symptoms such as
  - loss of appetite and weight loss
  - fevers or drenching sweats
  - worsening fatigue
  - widespread itching, without any skin problems
  - abdominal pain or discomfort due to pressure or bloating
  - shortness of breath or chronic cough
• you notice
  - one or more of your lymph nodes starting to grow more quickly
  - new lymph nodes start to swell.

These symptoms might be due to something else, such as an infection, so your oncologist may suggest you wait a week or so to see if things settle down. If the symptoms are not related to lymphoma, they may resolve or require other treatment. If they are lymphoma-related, your oncologist will discuss treatment options with you. In all these cases you are now in the "close monitoring" stage because treatment may be required. It may be helpful to keep a journal of your symptoms to share with your medical team at your appointments.