

Watch and wait explained: for GPs

This fact sheet for GPs explains ‘watch and wait’ for blood cancer patients, outlines the role of primary care professionals and suggests ways they can support patients being monitored in this way.



**Blood
cancer
UK**

How we can help

We're a community dedicated to beating blood cancer by funding research and supporting those affected. We offer free and confidential support by phone or email, free information about blood cancer, and an online forum where you can talk to others affected by blood cancer.



bloodcancer.org.uk
forum.bloodcancer.org.uk



0808 2080 888
(Mon, Tue, Thu, Fri: 10am–4pm, Wed: 10am–1pm)



support@bloodcancer.org.uk

Why has my patient been asked to 'watch and wait'?

Not everyone with blood cancer needs treatment straight away. 'Watch and wait' (sometimes referred to as 'active surveillance' or 'watchful waiting') is a way of monitoring these patients with regular check-ups and blood tests until they need treatment.

UK clinical guidelines only recommend watch and wait for asymptomatic, low-risk patients with chronic blood cancers – although management decisions should be made on a case-by-case basis. These conditions include, but are not limited to:

- chronic lymphocytic leukaemia (CLL)
- follicular lymphoma

- myelodysplastic syndromes (MDS)
- essential thrombocythemia (ET)
- myelofibrosis (MF)
- asymptomatic or smouldering myeloma, but only in patients with < 60% clonal plasma cells on bone marrow biopsy, a serum free light chain (sFLC) ratio of < 100 (the involved sFLC must be < 100 mg/l) and no more than one unequivocal focal lesion on advanced imaging (low-dose whole-body CT, MRI, fluorodeoxyglucose positron emission tomography).

Our website has more information for people affected by watch and wait. Visit **[bloodcancer.org.uk/watch-and-wait](https://www.bloodcancer.org.uk/watch-and-wait)**

According to data compiled by the Haematological Malignancies Research Network, around 27,000 people – 13% of all blood cancer patients – are currently monitored in this way in the UK.

While there is limited comparative research into the use of monitoring across a range of different chronic blood cancers, studies into its use for specific blood cancers and related conditions show that people on watch and wait do no worse or better than people receiving treatment. It's important to share this with patients.

The role of the GP and practice nurse

The management of chronic blood cancers currently varies across the UK, with some haematology centres advising regular check-ups with a specialist consultant and others recommending an approach led by primary care.

If your patient is diagnosed with a chronic blood cancer or related condition, it's their haematologist's responsibility to let them know how their care will be managed.

Their haematologist will also usually share a personalised holistic care plan with you, which outlines next steps. This should highlight your responsibilities, which could range from helping your patient cope with anxiety, to managing their blood tests and arranging regular appointments to discuss the results. If any of these steps are unclear, you should contact the haematologist.

If you're responsible for monitoring your patient and their blood tests when they are on watch and wait, their haematologist should provide you with guidance about signs and symptoms to look out for, and when to refer your patient back to secondary care. If you're unsure about what a symptom or blood test result means for your patient, you should seek advice from their haematology team.

Supporting patients

Coping with fatigue

A number of patients will experience fatigue while on watch and wait.

The following suggestions can help patients cope with these symptoms, although some patients might find these more beneficial than others:

- getting good-quality rest, ideally at a similar time every day
- if possible, maintaining regular, light exercise
- eating a healthy, balanced diet and drinking plenty of fluids
- maintaining activities that make the patient happy, such as socialising
- making time to do things that the patient finds relaxing, such as listening to music
- accepting help from others
- prioritising tasks and not feeling guilty if they feel unable to complete something.

Patients may find our information about living with blood cancer helpful, which includes tips on coping with fatigue. Go to **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**

Reporting signs and symptoms

Your patient may need to self-monitor for signs and symptoms (such as new painless swellings or growing lumps, worsening fatigue, unexpected weight loss or frequent infections) between their check-ups. The haematologist can advise both you and your patient on what to look out for.

These symptoms may be a sign that your patient needs to start treatment, so it's important that you report any change in symptoms to their haematologist. You should also advise your patient to contact a member of their healthcare team if they notice any changes between their appointments. Further tests, including a full blood count, will help to confirm whether they require treatment.

We have lists of common signs and symptoms that should be reported on our website. Go to **bloodcancer.org.uk/watch-and-wait**

Managing comorbidities

Research by the Royal College of General Practitioners (RCGP) shows that by 2025, the number of people living with one or more one long-term condition (comorbidity) is expected to increase by nearly one million, to 9.1 million.

If your patient has comorbidities, you should consider the following:

- how their health conditions and treatments interact and how this affects their quality of life

- their individual needs, preferences for treatments, health priorities, lifestyle and goals
- the benefits and risks of following recommendations from guidance on single health conditions
- ways to improve their quality of life by reducing treatment burden, adverse events and unplanned care
- ways to improve the coordination of care across different services.

For further guidance on managing comorbidities, go to **[nice.org.uk/guidance/ng56](https://www.nice.org.uk/guidance/ng56)**

You may also find this report by the RCGP useful:
Responding to the needs of patients with multimorbidity: A vision for general practice

Vaccinations for patients with immunodeficiency

Many patients on watch and wait for blood cancer will be immunocompromised. However, vaccination recommendations will depend on the patient's condition and individual circumstances.

Live vaccines can harm patients with compromised immune systems, so should be avoided. Public Health England states that these patients should still be given inactivated vaccines in accordance with national guidelines. Patients with lowered immunity should have the influenza vaccine on a yearly basis.

See Public Health England's **Green Book** at [gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book#the-green-book](https://www.gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book#the-green-book) for the latest guidance on vaccinations.

Psychological support

Blood Cancer UK's **Patient Need** report shows that the uncertainty associated with monitoring and the idea of delaying treatment can be hard for many to digest and understand.

It's important to reassure your patients that anxiety is completely normal in these situations, but that speaking to their healthcare team, attending support groups and receiving counselling can help. If your patient's mental health suffers as a result of their watch and wait treatment plan, discuss this with their haematology team and consider referring them to a counsellor or clinical psychologist.

Work, finances and travel

Living with blood cancer may also have an impact on your patient's home life, work or financial situation, and could affect their ability to travel, so it's important to know where to refer them for more information.

Patients can order or download our fact sheet **Watch and wait explained: for employers** at [bloodcancer.org.uk/information](https://www.bloodcancer.org.uk/information)

Patients' FAQs

Below are some questions commonly asked by patients on watch and wait. You can find general guidance on many of these questions at bloodcancer.org.uk/watch-and-wait, but for tailored information you should speak to your patient's haematologist.

- Why have I been put on watch and wait?
- Why am I not being treated?
- How long could I be on watch and wait for?
- What are the advantages and disadvantages of watch and wait?
- What signs and symptoms should I look out for?
- Who should I contact if I feel unwell or develop new symptoms?
- Where will I go for my appointments and how often will they be?
- What will happen at my appointments?
- How will I know if I need to start treatment and what will this involve?
- Where can I find more help and support?

**“I try to take something
positive from every
single day.”**

Kate, currently on watch and wait



About this fact sheet

We have produced this fact sheet in collaboration with expert medical professionals and people affected by blood cancer. Thank you to Dr Sajir Mohamedbhai, Dr Kevin Boyd, Dr Fiona Neale, Dr Margaret Keightley and Dr Loretta Chu for their support checking the content of this fact sheet.

Our fact sheets contain general information. Always listen to the advice of your specialist about your individual condition because every person is different.

A list of references used in this fact sheet is available on request.
Please email information@bloodcancer.org.uk

Disclaimer

We make every effort to make sure that the information in this fact sheet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health. Blood Cancer UK can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

The information in this fact sheet is correct at the time it was published (November 2017).
Date of next review: November 2020.

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Because we face it together

We're a community dedicated to beating blood cancer by funding research and supporting those affected.

Get in touch for:

- free and confidential support by phone or email
- information about blood cancer and life after diagnosis
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Your feedback on this fact sheet can help us improve – please send any comments to **information@bloodcancer.org.uk**

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