

# A toolkit for GPs and practice nurses

**This toolkit 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.**

Not everyone with blood cancer or a related condition 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 or related conditions – although management decisions should be made on a case-by-case basis. These conditions include, but are not limited to:

- › chronic lymphocytic leukaemia (CLL),
- › low-grade forms of non-Hodgkin lymphoma (NHL),
- › monoclonal gammopathy of undetermined significance (MGUS),
- › 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),
- › myelodysplastic syndromes (MDS),
- › myeloproliferative neoplasms (MPN),
- › hairy cell leukaemia, and
- › chronic large granular lymphocytic leukaemia (LGLL).

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 is important to share this with patients.

Our website has more information about watch and wait for people affected by it. Go to [bloodwise.org.uk/watchandwait](https://bloodwise.org.uk/watchandwait)

## The role of the GP and practice nurse

The management of chronic blood cancers and related conditions 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 is 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 are responsible for monitoring your patient and their blood tests when they are on watch and wait, their haematologist should provide you with guidance about the signs and symptoms to look out for, and when to refer your patient back to secondary care. If you are unsure about what a symptom or 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, and
- › prioritising tasks and not feeling guilty if they feel unable to complete something.

#### 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. Their 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 is 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 available online at [bloodwise.org.uk/watchandwait](https://bloodwise.org.uk/watchandwait)

### 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, and
- › ways to improve the coordination of care across different services.

For further guidance, along with tools and resources to help you manage comorbidities in watch and wait patients, please go to [nice.org.uk/guidance/ng56](https://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 receive 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](http://gov.uk/government/collections/immunisation-against-infectious-disease-the-green-book) for the latest guidance.

### Psychological support

While patients on 'watch and wait' will experience a range of emotions and no two experiences will be the same, Bloodwise'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 is important to reassure your patients that anxiety is a completely normal reaction 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 diagnosis, 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 also affect their ability to travel, so it is important to know where to refer them for more information.

Patients can download or print our fact sheet, **Watch and wait: A quick guide for employers**, at [bloodwise.org.uk/watchandwait](http://bloodwise.org.uk/watchandwait)

It includes information to help their employer understand how to support them at work.

Patients may also find Macmillan's information about work and cancer, travel and holidays, benefits, and financial support helpful. Direct them to [macmillan.org.uk/information-and-support/organising](http://macmillan.org.uk/information-and-support/organising)

### 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 [bloodwise.org.uk/watchandwait](http://bloodwise.org.uk/watchandwait), or by following the links below, 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?

### Further reading and signposting for patients

We offer patient information on many blood cancer types and topics, online and in free printed booklets. They cover everything from symptoms and diagnosis through to treatment and living with a blood cancer or related condition.

 For more information about watch and wait, go to [bloodwise.org.uk/watchandwait](http://bloodwise.org.uk/watchandwait)

 Or, for other patient information, go to [bloodwise.org.uk/info-support](http://bloodwise.org.uk/info-support)

 Patients and their loved ones can also call our Support Line on **0808 2080 888** (Mon–Fri 10am–4pm). This is a freephone number.

 See our website for more details of cancer information specialists and support groups: [bloodwise.org.uk/info-support/living-with](http://bloodwise.org.uk/info-support/living-with)

### About Bloodwise

We're the UK's specialist blood cancer charity. We've been working to beat blood cancer since 1960.

We fund world-class research; provide practical and emotional support to patients and their loved ones; and raise awareness of blood cancer.

We'd like to thank Dr Sajir Mohamedbhai, Dr Kevin Boyd, Dr Fiona Neale, Dr Margaret Keightley and Dr Loretta Chu for their help and support in developing this toolkit and checking it for clinical accuracy. A list of references used in this document is available on request, please email [information@bloodwise.org.uk](mailto:information@bloodwise.org.uk)

#### Disclaimer

We have made every effort to make sure that the information in this toolkit is accurate, but it's important to liaise with your patient's haematologist and seek their advice if you have any concerns about your patient's condition.

The examples included in this toolkit are just some of the ways to manage and support watch and wait patients in primary care. Although the information included in this resource is based on current evidence, healthcare professionals should use this toolkit in accordance with national guidelines – which may change over time.

Bloodwise 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 printed (November 2017).

Date of next review November 2019.

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