

Watch and wait explained: for family and friends

This fact sheet explains what watch and wait is, suggests ways you can support a loved one on watch and wait, and highlights places you can go for advice and support.



**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

What is watch and wait?

Not everyone who's diagnosed with blood cancer needs treatment straight away.

'Watch and wait' is a way of monitoring these people with regular check-ups until they need treatment.

You may also hear it called 'active surveillance' or 'watchful waiting'. Around 27,000 people – 13% of all blood cancer patients – are currently monitored in this way in the UK.

Our website has more information about watch and wait for anyone affected by it. Go to

bloodcancer.org.uk/watch-and-wait

Why is watch and wait the best way to manage blood cancer for some people?

Although researchers are constantly looking for better ways to treat, and ultimately cure, blood cancer, many of the treatments available today can cause unwanted side effects.

So treatment is usually only recommended when it's known to be most effective – usually this is for people with cancer that's developing quickly or affecting their quality of life.

For people with slow-progressing blood cancers, with few or no worrying symptoms, it's usually better to have regular check-ups and only start treatment when it's needed.

Research shows that people on watch and wait aren't any more at risk of their condition getting worse than people receiving active treatment, like chemotherapy.

What does watch and wait mean for my loved one?

If someone close to you is placed on watch and wait, this means that their blood cancer isn't currently having a worrying impact on their health, and it's better for them to delay treatment.

Watch and wait stops people being exposed to potentially toxic treatments until they're necessary, and also helps to prevent people from possibly developing a resistance to chemotherapy drugs. Some people like to think of watch and wait as a way of saving treatment for later, when it will be most effective.

Lots of people live a good quality of life on watch and wait for several years before needing treatment – and some never need it.

Supporting someone on watch and wait

There is no right or wrong way to support someone on watch and wait, but there are some things you can do to show your loved one that they aren't alone.

If someone close to you is put on watch and wait, they'll have regular check-ups with their specialist doctor (consultant) to monitor their condition. Some people find it helps to have their partner, a family member or close friend with them at these appointments. You may want to ask your loved one whether this is something they would find helpful.

Other people just need someone to share their thoughts with. If your loved one struggles to talk to you, they may feel more comfortable sharing their feelings with others going through the same thing at a local support group or through an online community forum.

Regular sessions with a cancer specialist psychologist may also help. Your loved one's consultant can make a referral if they think this might be helpful.

Your loved one may find our toolkit **Living well with or after blood cancer** helpful. It includes practical tools, helpful tips and real stories from people living with or after blood cancer. Visit **bloodcancer.org.uk/living-well**

Looking after yourself and getting support

Coping with anxiety and stress

It's completely normal to feel anxious between your loved one's appointments. If you find that you feel increasingly anxious or upset, there are a number of things that can help.

Our Support Services Team is there for anyone affected by blood cancer. Call them on **0808 2080 888** or email **support@bloodcancer.org.uk**. Lines are open 10am–4pm on Mondays, Tuesdays, Thursdays and Fridays, and 10am–1pm on Wednesdays.

Joining a support group, whether face-to-face or online, is another good way to get in touch with others who are supporting someone with blood cancer. Visit our online community forum at **forum.bloodcancer.org.uk** and view the thread: 'Caring and supporting a loved one with blood cancer'.

Maggie's is a nationwide network of drop-in centres providing practical, emotional and social support for anyone affected by cancer. To find your nearest centre, go to **maggies.org** or ask your loved one's healthcare team for more information.

Managing day-to-day practicalities, like work and finances

If you're supporting someone who has blood cancer, this may have an impact on your home life, work, education or financial situation.

You may find that you need to take time off work to take your loved one to appointments. Or, if your partner or someone you live with is struggling with extreme tiredness (fatigue) as a result of blood cancer, for example, some of the things you used to share responsibility for may now fall to you.

If your loved one's condition is having a big impact on your day-to-day life, don't be afraid to seek or accept support from family, friends, healthcare professionals, or your local community.

If you're caring for someone who's dependent on you, you're entitled to a reasonable amount of time off work (paid or unpaid) to use in the event of emergencies, under the Employment Rights Act 1996. This would cover taking your loved one to hospital if they develop an infection, for example.

If you've worked for your employer for at least 26 weeks, you can also request flexible working, to help with things like hospital appointments. This might include different working hours or days, or working from home for some or all of that time. By law, your employer has to respond to your request in a 'reasonable manner'. This means:

- assessing the advantages and disadvantages of your application
- setting up a meeting to discuss your application
- providing an appeals process if they reject your request.

It's up to you whether you want to share your loved one's diagnosis with your employer or colleagues, but some people find that talking to their HR department or line manager helps get them the support they need. For example, you may find it easier to request flexible working hours if your employer understands your situation.

For more information about supporting someone with blood cancer, visit **bloodcancer.org.uk/someone-i-know**

Macmillan's **Looking after someone with cancer** booklet also includes helpful, practical guidance.

Planning ahead

You may not want to think about what might happen if your loved one eventually needs treatment, but some people find it's helpful to know what to expect later down the line. There are lots of different types of treatment, ranging from stem cell transplants to daily tablets that can be taken at home, so it's important not to jump to any conclusions until a consultant has explained the available options.

Below are some questions that you or your loved one may want to ask their healthcare team.

- How can I best support my loved one?
- What effect will watch and wait have on their daily life?
- How often will their appointments be?
- If they eventually need treatment, what will this involve?

Notes:

Notes:



**“We just try to enjoy life
and continue doing
the things we love.”**

Trevor, 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 Sally Moore, Dr Kevin Boyd and Clinical Nurse Specialist Barbara Von Barsewisch 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).

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Because we face it together

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Get in touch for:

- free and confidential support by phone or email
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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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