

Things That Are Important To Me And MyWm

An Active Monitoring checklist for people with Waldenstrom's macroglobulinaemia

Active monitoring (AM) is when your healthcare team monitor your WM, rather than treating it right away. You may hear it called 'active surveillance' or 'watch and wait'.

This checklist is designed to outline the essential topics which should be discussed with your clinical team throughout your Active Monitoring care, and can be used within your appointments alongside your clinician.

Some of the terms used in the checklist may vary depending on where in the UK you live, if you have any questions or would like any further information on Active Monitoring then please contact us on support@wmuk.org.uk

What will AM consist of?

- ☐ I understand how often I will have monitoring appointments with my healthcare team
- ☐ I understand and am satisfied with the format of my future appointments (e.g., face-to-face, telephone, virtual)
- ☐ I understand what tests will need to be performed to monitor my condition and how often these will be performed
- ☐ I feel that I have been given enough information about what to expect during the active monitoring phase of my treatment

My Waldenstrom's macroglobulinaemia

- ☐ My current symptoms have been discussed during this consultation
- ☐ I understand that if I experience any of the below symptoms between my appointments, I should contact my clinical team:



Dizziness or Headaches



Repeated infections



Fatigue



Poor concentration or confusion



Weakness or Breathlessness



Blurring or loss of vision



Unexplained weight loss



Swollen glands



Fevers and night sweats



Lumps or masses



Bruising or bleeding easily



Numbness or tingling (pins and needles) in fingers or toes

- ☐ I understand that WM can affect my immune system and therefore I should take reasonable precautions to avoid infection, including ensuring my vaccinations are up to date
- ☐ I feel that I have been given enough information about my condition at this time

Additional support during AM

- ☐ I know the contact details of the Clinical Nurse Specialist (CNS), or key worker, and understand what support they can offer me during active monitoring
- ☐ I have discussed the roles of other members of the Multidisciplinary Team (MDT), and the support which they may be able to provide to me if I need it
- ☐ I have been given information about how to contact or access information from patient support groups/charities such as WMUK

Contributing to WM research

- ☐ My doctor has signposted me to WMUK, who are collecting data on the reality of living with WM to help inform and guide future research.
- ☐ Clinical Trials have been discussed with me and I have been signposted to where I can find more information
- ☐ I have been signposted to the myWM app

My lifestyle

- ☐ I understand the impact of my general wellbeing on my condition and the importance of keeping as well as I can
- ☐ I have discussed the importance of regular and appropriate exercise as it relates to my general wellbeing and my condition with my WM care team
- ☐ I have discussed with my clinical team, the importance of ensuring any other medical issues I may have are being addressed and managed well by my GP or other healthcare provider
- ☐ I have discussed any other issues which are affecting me

If you are unable to tick any of the boxes above, please discuss your concerns or questions with your clinical team



For more information

wmuk.org.uk or call the WMUK Support Line: 0300 373 8500