

The UK charity for Waldenstrom macroglobulinemia

Confidentiality Policy for the WMUK Support Line.

Background and purpose:

The WMUK support line (SL) is a confidential service which allows patients, family members, friends and health care professionals to gain clinical advice relating to issues related to Waldenstrom's Macroglobulinaemia (WM). The SL is open for 32 hours per week: Monday to Thursday 9am – 5pm.

The support line can be contacted via phone and email.

The purpose of this document is to demonstrate a clear procedure and the expectation of the SL in the relation to confidentiality for internal WMUK staff.

This policy will be available to all to access on the WMUK website.

Role of the Support Line:

We understand that WM is a rare form of blood cancer which currently affects approximately, 4000 people in the UK with around 400 people being diagnosed every year – numbers which we expect to increase over time, once we have been able to increase the exposure of WM and the support which is available.

Many patients and family members have expressed how difficult it is to find support and advice that is specifically related to WM, and the issues which the cancer brings.

The aim of the support line is to ensure that all callers can be provided with WM specific support, information and be signposted to relevant charities or organisations that meet their needs.

The WMUK team aim to ensure that all queries are answered with up to date, reliable information and will liaise with WM specialists to ensure that this is met.

Confidentiality Statement:

The telephone and email services are confidential between the individual who makes contact and WMUK. The individual may choose to provide personal information which will only be used for the purposes of dealing with their enquiry.

Any personal information provided by the individual, will not be passed onto anyone else without the individuals verbal or written permission – except in circumstances where it is needed to comply with the nurses' code of professional conduct or the law.

Examples of this may include anyone reporting potential serious self-harm, if it was felt a child may be at risk or anyone expressing the intention of harming someone else.

The Nursing and Midwifery (NMC) code of professional conduct can be found here: https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf

Any individual contacting the SL has the right to ask for none of their details to be recorded on the Razers Edge (RE) system.

If in the event of a call that raises concerns of a risk to life, and the caller is not willing to provide any identifiable information that will allow further help or support to be contacted, the support line worker will explain the limitations of the support line and it's intended use, encourage the caller to contact emergency services and will then terminate the call.

Email Storage:

Emails that are sent to the SL will be kept within the support inbox - once it has been dealt with, and recorded on RE, it will be deleted.

All emails in the deleted and sent folders will be permanently deleted at the end of each working week – this is the responsibility of the Support Manager.

Voicemail Recordings:

At present, the voicemail option is not activated on the Support Line so no voicemails will be able to be left.

If in the future, this feature is enabled then any voicemails that have been received to the SL will be deleted once listened to, and the information has been gained for the SL nurse to deal with the enquiry.

This is the responsibility of the SL nurse dealing with the call.

Written Notes:

Any written notes that are collected by the SL nurse will be shredded as soon as the information has been recorded on RE and is the responsibility of the SL member who has taken the notes.

Complaints:

Any complaints will be dealt with in accordance with the WMUK Support Line Feedback and Complaints Policy.

Policy Written: October 2022 Review Frequency: 2 yearly or as required

Reviewed and amended: 30/05/2024