

Resources for people newly-diagnosed with MDS/ CMML

Website address: www.mdspatientsupport.org.uk

Topic	Resource	MDS UK website link
1. MDS	MDS Handbook –sent to new members	https://mdspatientsupport.org.uk/what-is-mds/information-material/
a. What is MDS?	Handbook and website	https://mdspatientsupport.org.uk/what-is-mds/
b. Different types of MDS	Handbook and website	https://mdspatientsupport.org.uk/what-is-mds/different-types-of-mds/
c. MDS Risk scoring	Handbook and website	https://mdspatientsupport.org.uk/what-is-mds/mds-risk-scoring-system/
d. MDS Symptoms	Handbook and website	https://mdspatientsupport.org.uk/what-is-mds/mds-symptoms/
e. MDS Diagnosis	Handbook and website	https://mdspatientsupport.org.uk/what-is-mds/mds-diagnosis/
f. Treatment of MDS	Handbook and website	https://mdspatientsupport.org.uk/what-is-mds/mds-treatments/
g. Living with MDS	Handbook and website	https://mdspatientsupport.org.uk/what-is-mds/living-with-mds/
h. Glossary of terms	Handbook and website	https://mdspatientsupport.org.uk/what-is-mds/mds-glossary-words-to-know/

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2. What is CMML?	Website	https://mdspatientsupport.org.uk/what-is-mds/what-is-chronic-myelomonocytic-leukaemia/
3. Videos	You Tube	https://www.youtube.com/channel/UCN8S275PPTRYIfodG9CQWkA
a. CMML (Dr Dan Wiseman)	Website	https://mdspatientsupport.org.uk/cmml-diagnosis-treatment-by-consultant-haematologist-dr-wiseman/
b. Low risk MDS (Dr Dominic Culligan)	Website	https://mdspatientsupport.org.uk/low-risk-mds-a-recorded-presentation-by-dr-dominic-culligan-consultant-haematologist-mds-uk-patients/
c. Stem cell transplant (Dr Victoria Potter)	Website	https://mdspatientsupport.org.uk/stem-cell-transplantation-a-recorded-zoom-session-with-mds-uk-patients-and-specialists-from-kings-hospital/
d. REPAIR clinical trial (Trial team)	Website	https://mdspatientsupport.org.uk/zoom-meeting-low-risk-mds-the-repair-mds-clinical-trial/
e. Latest developments in treatments for MDS (July 2023 - Dr Beth Payne)	Website	https://mdspatientsupport.org.uk/mds-diagnostics-treatments-dr-beth-payne/
f. Research on Quality of Life in high risk MDS (Dr Pramila Krishnamurthy and others)	Website	https://mdspatientsupport.org.uk/qol-quality-of-life-in-high-risk-mds-aml/
g. Lifestyle medicine (Dr Shireen Kassam)	Website	https://mdspatientsupport.org.uk/lifestyle-medicine-dr-shireen-kassam/

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4. List of MDS and CMML specialists and Centres of Excellence	Handbook and Website	https://mdspatientsupport.org.uk/what-is-mds/specialists-centres/
5. Prompt list of questions to ask at consultation	Website	https://mdspatientsupport.org.uk/question-prompt-list-to-help-meet-the-information-needs-of-mds-patients/
6. Booklets and fact sheets (Handbook, managing fatigue, nutrition (including neutropenic diet), stem cell transplant, EPO and GCSF, clinical trials, travel advice + insurance	Website	https://mdspatientsupport.org.uk/what-is-mds/information-material/

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7. Meeting others		
a. Meetings	e-newsletter and website	https://mdspatientsupport.org.uk/events/category/patient-meeting/list/?tribe_paged=1&tribe_event_display=list
b. Patient stories	Website	https://mdspatientsupport.org.uk/latest-news/mds-patient-stories-2/
c. Chat Forum	Website	https://mdspatientsupport.org.uk/mds-forum/
d. Facebook	Website link to MDS UK FB pages	https://www.facebook.com/people/MDS-UK-Patient-Support-Group/100064711084871/ (Public group) https://www.facebook.com/groups/196182110586666/?source_id=123295287687778 (Private group)