

MDS-Specific Organizations

- ▶ Life Beyond Limits
www.mdslifebeyondlimits.org
Brings together an independent group of MDS experts to raise awareness of ageism in access to care for patients with MDS
- ▶ MDS Beacon
www.mdsbeacon.com
Objective and unbiased news and other information related to MDS; mission is to be a key Internet resource and online community for patients with MDS, their families, and others interested in MDS
- ▶ MDS Foundation
www.mds-foundation.org
Multidisciplinary, international, nonprofit organization dedicated to the education of professionals, patients, and caregivers; facilitation and support of clinical trials; and development and support of patient advocacy groups
- ▶ United Kingdom MDS Patient Support Group
www.mdspatientsupport.org.uk
Offers support, information, referral advice, and patient information in the United Kingdom

Organizations That Include MDS Within the Scope of Hematologic Malignancies

- ▶ Aplastic Anemia and MDS Foundation
www.aamds.org
Nonprofit health organization dedicated to supporting patients and families living with aplastic anemia, MDS, paroxysmal nocturnal hemoglobinuria, and related bone marrow failure disease
- ▶ Leukaemia and Lymphoma Research Foundation
www.leukaemialymphomaresearch.org
Programs for support of all of the different blood cancers for patients and their families
- ▶ Leukaemia Care
www.leukaemiacare.org.uk
Resources for people affected by Hodgkin, non-Hodgkin, and other lymphomas; myeloma; MDS; aplastic anemia; and myeloproliferative disorders
- ▶ Leukemia and Lymphoma Society
www.lls.org
Mission is to cure leukemia, lymphoma, Hodgkin disease, and myeloma and improve the quality of life of patients and their families

General Resources

- ▶ American Cancer Society
www.cancer.org
- ▶ American Society of Clinical Oncology
www.asco.org and www.cancer.net
- ▶ American Society of Hematology
www.hematology.org
- ▶ CancerCare
www.cancercare.org
- ▶ Medline Plus®
www.nlm.nih.gov/medlineplus/medlineplus.html
- ▶ Merck Manual Home Edition for Patients and Caregivers
www.merckmanuals.com/home/index.html
- ▶ National Anemia Action Council
www.anemia.org
- ▶ National Heart, Lung and Blood Institute
www.nhlbi.nih.gov
- ▶ National Marrow Donor Registry
www.marrows.org

Clinical Trials and International Drug Approval Information

- ▶ European Medicines Agency
www.ema.europa.eu
Decentralized agency of the European Union, located in London; responsible for the scientific evaluation of medicines developed by pharmaceutical companies for use in the European Union
- ▶ Health Canada
www.hc-sc.gc.ca
Provides a notice of compliance (NOC) for full approval of a new drug or an NOC with conditions in Canada
- ▶ National Cancer Institute, National Institutes of Health
www.clinicaltrials.gov
Registry and results database of federally and privately supported clinical trials conducted in the United States and around the world
- ▶ National Institute of Health and Clinical Excellence
www.nice.org.uk
Guidance for cost effectiveness of treatments for England and Wales
- ▶ Nordic MDS Group
www.nmds.org
Provides Nordic guidelines for MDS management online and patient information in all Nordic languages
- ▶ Pharmaceuticals and Medical Devices Agency
www.pmda.go.jp
Regulation of drug availability in Japan
- ▶ Therapeutic Goods Administration
www.tga.gov.au
Division of the Australian government's Department of Health and Aging; responsible for regulating therapeutic goods including medicines, medical devices, blood, and blood products
- ▶ U.S. Food and Drug Administration
www.fda.gov
Approval required for commercial availability of therapy in the United States

Financial Assistance Programs

- ▶ American Cancer Society
www.cancer.org
- ▶ Anthony Nolan Trust
www.anthonynolan.org
Dedicated to bone marrow transplantation and running a database of donors
- ▶ CancerCare Co-Payment Assistance Foundation
www.cancercarecopay.org
- ▶ Cancer Financial Assistance Coalition
www.cancerfac.org
- ▶ Chronic Disease Fund
www.cdfund.org
- ▶ HealthWell Foundation
www.healthwellfoundation.org
- ▶ Lance Armstrong Foundation
www.livestrong.org
- ▶ Leukemia and Lymphoma Society
www.lls.org/copay
- ▶ MacMillan Cancer Support
www.macmillan.org.uk/Home.aspx
General information, assistance, and financial advice
- ▶ Patient Advocate Foundation Program Co-Pay Relief Program
www.copays.org
- ▶ Patient Handbook: Insurance and Reimbursement Resources for MDS Patients: A Guide to Assistance Programs in the U.S.
www.mds-foundation.org/for-patients-visitors

FIGURE 1. Patient and Caregiver Resource Catalog for Myelodysplastic Syndromes (MDS)

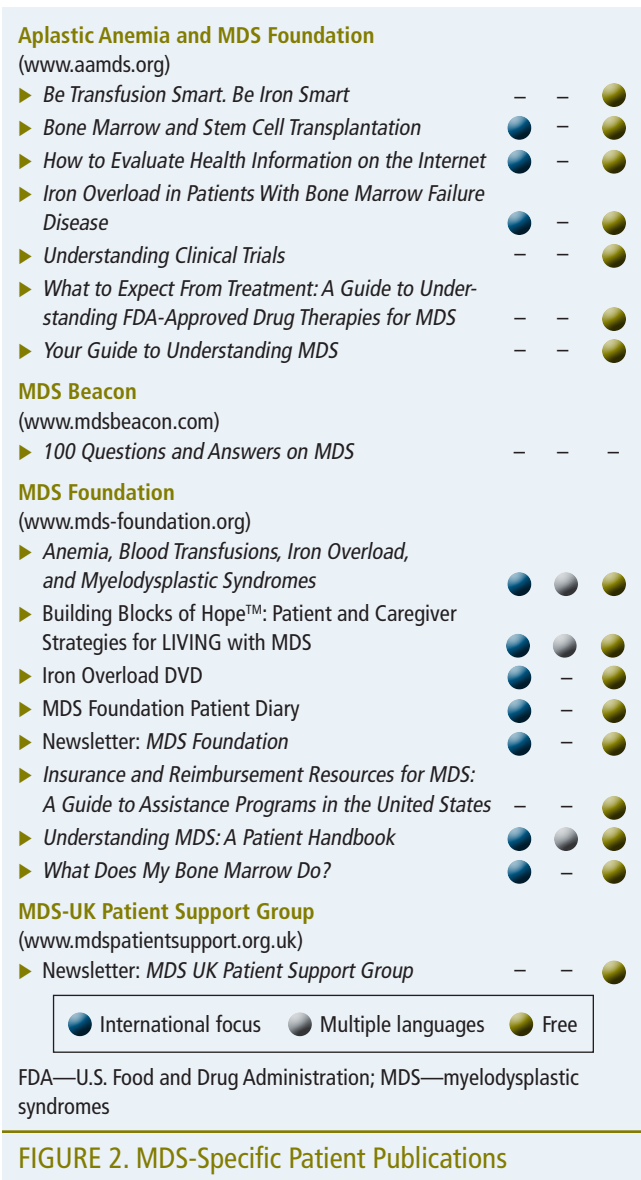


FIGURE 2. MDS-Specific Patient Publications

year, and most locally available support groups for patients with cancer will not include a single patient with MDS.

Together, the heterogeneity of the disease, heterogeneity of older adults, limited provider familiarity with MDS, recent changes in therapeutic and supportive care strategies, and paucity of resources for patient and family support at a local level emphasize the need to identify currently available resources for patients with MDS and their caregivers. Perhaps the most important prerequisite to assist patients and their caregivers in facing the challenge of a cancer diagnosis is to understand the disease itself and what each patient may experience based on an individualized risk analysis and then to have a basic familiarity with appropriate resources for

Patient Outreach and Advocacy Program

The MDS Foundation offers a patient advocacy and outreach program. Patients or caregivers may contact the patient liaison directly by calling (toll-free) 800-637-0839 or via e-mail to ahasan@mds-foundation.org.

patient and caregiver support. Tools and strategies for clinical management of patients with MDS and considerations for quality of life in these patients are reviewed elsewhere in this supplemental publication.

Patient Resources on Myelodysplastic Syndromes

Several surveys of both patients and HCPs have provided some insight into the characteristics of patients with MDS, what patients with MDS understand about their disease, what they perceive as unmet needs, and what they feel are the optimal characteristics of HCPs. The epidemiologic characteristics of the disease in all surveys confirmed the prevalence of MDS in patients older than age 65 years (Demakos & Kurtin, 2011; Ma, Does, Raza, & Mayne, 2007; Sekeres, 2011). That fact is important when considering the best approach to patient education and support given the trend toward online resources.

The MDS Foundation provides a patient advocacy and outreach program, which includes a full-time patient liaison available via telephone and e-mail. Patient phone calls to the MDS Foundation, together with patient surveys conducted as a part of patient and caregiver support programs supported by the MDS Foundation and the United Kingdom MDS Patient Support Group, have provided insight into the educational and supportive care needs of patients with MDS. Members of the International Nursing Leadership Board for the MDS Foundation serve as facilitators for the sessions. The most commonly asked questions in the sessions have been used as a template for the development of patient and caregiver education and support materials (see Appendix A).

Expectations of Patients and Providers

Working with patients facing an incurable disease requires time, compassion, clarity of message, and resilience on the part of HCPs. The shift toward survivorship care planning and personalized medicine places additional responsibilities on the oncology HCP to maintain a current working knowledge of a variety of conditions and treatment standards (Litton et al., 2010). Given the age of most patients with MDS, comorbid conditions are common, often requiring involvement of a number of specialists in addition to a primary care physician (Kurtin & Demakos, 2010). With the limited number of patients with MDS seen in a general oncology practice, the older age of most patients with MDS, and the provision of the majority of care in the outpatient setting where contact with the provider may be limited to 15–20 minutes per visit, clarity and consistency of information provided to patients and caregivers across all HCPs is an imperative and, yet, a daunting task. In addition, patients with cancer identify knowledgeable HCPs and adequate time for questions as desirable attributes of HCPs, emphasizing the need to employ a variety of educational strategies across disciplines.

Most patients facing a cancer diagnosis want to understand their disease, prognosis, available treatment options, potential adverse events, and expected duration of therapy (Protiere,