

Resources for Patients and Caregivers With Multiple Myeloma and Their Providers

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Author's disclosures of potential conflicts of interest are found at the end of this article

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Whether approaching multiple myeloma as a health-care provider, patient, or caregiver, informational and educational resources are a critical part of complete patient care. In the clinic setting, informational needs are often acute, and the availability of smartphone or tablet applications (apps) provides instant access to needed resources. For information where an app is lacking, many providers have bookmarked selected websites on their mobile devices or clinic computers for quick and easy access. For patients and caregivers, informational and educational needs are generally much more “chronic,” and they are often directed to reputable websites they can visit as needs arise throughout the course of their disease trajectory (Table 1). Some of these sites have downloadable programs or mobile apps that help patients and caregivers track medical information, manage medications and appointments, or simply stay abreast of new information and clinical trials (Tables 2–4). Health-care providers have a similar need for

updated information and continuing education to keep them current with the latest guidelines related to treatment of multiple myeloma. Readily available apps and educational resources are especially important for advanced practice providers who may not treat large numbers of these patients in their clinics (Table 5).

The “Tools & Technology” sections in previous issues of the *Journal of the Advanced Practitioner in Oncology* have provided excellent reviews of resources available for caregivers of family members with cancer (Hanson, Ferrell, & Grant, 2013), general cancer survivorship (Economou, Grant, & McCabe, 2012), and continuing education for the advanced practice provider (Vogel, 2012). It is not the intent of this short article to duplicate those efforts but rather to focus on resources available to patients living with multiple myeloma, their caregivers, and health-care providers who help manage their treatment. The following tables list resources that are commonly accessed and recommend by advanced practice nurses who specialize in the treatment of patients with multiple

Table 1. Health-Care Provider and Patient Education Resources

Organization	Website	Focus
International Myeloma Foundation (largest and oldest nonprofit)	myeloma.org	Patient and professional resources (international) <ul style="list-style-type: none"> • The most comprehensive myeloma resource site • Convenes International Myeloma Working Group to publish consensus statements and guidelines • In-person patient workshops and seminars
Multiple Myeloma Research Foundation	themmrf.org	Patient and professional resources <ul style="list-style-type: none"> • Sponsors in-person patient educational programs
Myeloma Post App (Thaumaturgix, Inc)	Mobile App only iOS only (free)	Patient resources <ul style="list-style-type: none"> • Gateway to educational, research, support, and advocacy programs and information on the IMF website; updated daily
Leukemia & Lymphoma Society	lls.org	Patient resources <ul style="list-style-type: none"> • Financial support
Multiple Myeloma Opportunities for Research and Education (MMORE)	mmore.org	Patient resources <ul style="list-style-type: none"> • Fundraising, community awareness, education, patient support, with links to reputable sites
The Myeloma Beacon	myelomabeacon.com	Patient resources <ul style="list-style-type: none"> • Physician contributions, patient columns, online discussion, with links to reputable sites
Smart Patients	smartpatients.com	Patient resources <ul style="list-style-type: none"> • Partners with IMF for myeloma-specific community • Online support for patients and caregivers
Blood & Marrow Transplant Information Network	bmtinfont.net	Patient resources <ul style="list-style-type: none"> • Information about marrow, stem cell, and cord transplants
Multiple Myeloma Center for Nurses	mmcenterfornurses.com	Nursing-specific educational resources
International Myeloma Society	myelomasociety.org	Professional society of clinicians and researchers <ul style="list-style-type: none"> • Organizing society of the biannual International Myeloma Workshops

Table 2. Patient Support Apps

App	Notes	Focus
MediSafe Meds and Pill Reminder App (Medsafe Project)	iOS and Android (free) 4.5 stars	<ul style="list-style-type: none"> • Medication and tracking reminder
Dosecast Medication Reminder App (Montuno Software)	iOS and Android (free) 4.3 stars	<ul style="list-style-type: none"> • Medication and tracking reminder
My Medical App (Hyrax, Inc)	iOS and Android (\$4.99) 4.0 stars	<ul style="list-style-type: none"> • Comprehensive record-keeping for medical information • Interacts with mobile device calendars • Allows image storage
PearlPoint Side Effects Helper App (PearlPoint Cancer Support)	iOS and Android (free) 5.0 stars	<ul style="list-style-type: none"> • Track and minimize side effects of cancer and treatment • Nutrition guidance and practical tips • Patient support website: pearlpoint.org
My Fitness Pal App (MyFitnessPal.com)	iOS and Android (free) 4.6 stars	<ul style="list-style-type: none"> • Online nutrition and calorie database • Track calories, activity, and weight loss • Website: myfitnesspal.com
Fitbit App (Fitbit, Inc)	iOS and Android (free, but requires purchase of device)	<ul style="list-style-type: none"> • Activity tracker and website: fitbit.com

Table 3. Clinical Trial and Support Group Resources

Website or App	Focus
<p>http://matrix.myeloma.org</p> <p>myeloma.trialx.com</p> <p>SparkCure</p>	<ul style="list-style-type: none"> • Preclinical through phase III trials • Transplant trials included • Phase I through phase III trials • Observational and treatment trials • Transplant trials included • Most personalized search engine • Search for clinical trials based on diagnosis (MGUS, smoldering, or active disease), status (newly diagnosed, relapsed, etc.), or treatment type (immunotherapy, targeted therapy, etc.) • Search for expanded-access trials • Clinical trials 101 education for patients
<p>Myeloma Ally App</p> <ul style="list-style-type: none"> • iOS and Android (free) • 4.2 stars • Sponsored by Celgene 	<ul style="list-style-type: none"> • Search for myeloma-specific trials via clinicaltrials.gov • Navigate International Myeloma Working Group Guidelines • Excellent clinical app as well (see Table 5)
<p>myeloma.org/SupportGroup.action?tabId=6&menuId=0&queryPageId=7</p> <p>themmrf.org/living-with-multiple-myeloma/myeloma-patient-support</p>	<ul style="list-style-type: none"> • Search for support groups in the United States and internationally • Search for support groups in the United States

Table 4. Patient Programs/Apps for Tracking Myeloma

Program or App	Website/Notes	Focus
<p>The Myeloma Manager Personal Care Assistant</p> <ul style="list-style-type: none"> • PC-based only (free) • No app available 	<p>myeloma.org/store/page15.html</p> <p>Tutorial available at: youtube.com/watch?v=8lZ9MCL1FF0</p>	<ul style="list-style-type: none"> • Organizes laboratory results, notes, and reports • Data stored online • Daily myeloma news feed
<p>Track My Multiple Myeloma App</p> <ul style="list-style-type: none"> • Sponsored by Celgene 	<p>iOS and Android (free)</p> <p>4.2 stars</p>	<ul style="list-style-type: none"> • Calendar, health-care provider contact list, medication reminders, refill reminders, lab results log, printable reports • Myeloma patient resources

Table 5. Helpful Clinical Apps

App	Notes	Focus
<p>Managing Myeloma App (MediCom Worldwide, Inc)</p>	<p>iOS only (free)</p> <p>4+ stars</p>	<ul style="list-style-type: none"> • Myeloma-specific treatment calculators and patient care tools • Daily news feeds • Extensive CE opportunities at website: managingmyeloma.com
<p>CDC Vaccine Schedules App (Centers for Disease Control and Prevention)</p>	<p>iOS and Android (free)</p> <p>4.4 stars</p>	<ul style="list-style-type: none"> • Access CDC-recommended immunization schedules and footnotes
<p>National Comprehensive Cancer Network Guidelines App (TIP Medical Communications)</p>	<p>iOS and Android (free)</p> <p>4.3 stars</p>	<ul style="list-style-type: none"> • Access NCCN guidelines for supportive care and treatment of cancer by site
<p>Calculate App (QxMD Medical Software, Inc)</p>	<p>iOS and Android (free)</p> <p>4.5 stars</p>	<ul style="list-style-type: none"> • Clinical calculators and decision support tools • Staging and prognosis tools for myeloma

myeloma. Most of these resources are not exclusive to any single group but provide wide-ranging information that is applicable to patients, caregivers, and health-care providers.

The most established organizations devoted to multiple myeloma research and support are the International Myeloma Foundation, the oldest and largest foundation serving myeloma community worldwide, and the Multiple Myeloma Research Foundation. In addition to printed and multimedia materials, these organizations sponsor workshops, seminars, and other live educational programs that bring patients into direct contact with renowned myeloma experts across the country. These programs are held throughout the year at multiple sites in the United States, and a schedule of events can be found at their respective websites. In addition to these live events, there is a network of more than 150 myeloma support groups (in 46 states across the United States) that hold regular meetings for members of the myeloma community. Patients can search for a complete listing of support groups near them on the IMF website (see Table 3).

Finally, the IMF is in the final stages of completing an online Survivorship Care Plan for patients with multiple myeloma that can be completed at the IMF website. Depending on the

information entered, it will provide specific health-care recommendations based on the latest guidelines. As patients with myeloma are surviving longer than ever before, it is critical to focus on health-care maintenance to maintain overall health and quality of life. ●

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