

IMF HOTLINE COORDINATORS ANSWER YOUR QUESTIONS

The IMF Hotline 800-452-CURE (2873) consistently provides callers with the best information about myeloma in a caring and compassionate manner. The Hotline is staffed by Paul Hewitt, Missy Klepetar, Nancy Baxter, and Debbie Birns. The phone lines are open Monday through Friday, 9am to 4pm (Pacific Time).

To submit your question online, please email TheIMF@myeloma.org.

I have recently become somewhat computer literate and am wondering what information you provide via computer other than your website?

That is a great question because the International Myeloma Foundation (IMF) is also becoming more computer savvy and is able to provide more help via computer to patients regarding all aspects of their journey with myeloma.

Website

You mentioned that you are familiar with our website, but we'd like to remind everyone what is readily accessible via our website www.myeloma.org:



Paul Hewitt, Missy Klepetar, Nancy Baxter, and Debbie Birns

1. A full library of PDF versions of all IMF publications, including the Patient Handbook, the Concise Review, and all booklets from the *Understanding* series.

2. Webcasts from medical meetings held by the American Society of Hematology (ASH) and the American Society of Clinical Oncology (ASCO), as well as the

bi-annual International Myeloma Workshop, and the IMF Patient & Family Seminars. Just click on the "Webcasts" tab at the top of the IMF home page and you will get a dropdown menu of all of our webcasts or go directly to <http://webcasts.myeloma.org>.

3. The publications of the International Myeloma Working Group (IMWG) are also on our website. There are over 30 IMWG publications, with subjects ranging from diagnostic criteria to response criteria. These can be found under the "Research" tab and then under "Myeloma Working Group." In addition to the full papers, we have begun to create summary guidelines of each of these papers, which are also listed on that page.

4. The links to clinical trials and clinical trial search tools are constantly being updated on the IMF website, and these are a good way to find relevant clinical trials. Just click on "Clinical Trials" on our website.

5. Our support group directory can help you find a group in your area. Just click on "Find Support" and you will go to <http://support.myeloma.org> page. Myeloma support groups in the US are listed by state, and international groups are listed by region and country. Some of the groups have their own websites that feature specific details on their activities and upcoming meetings, and those links can be found in the group descriptions.

6. The IMF website also features an index of links to other online resources that range from financial help to advice for caregivers. This is available as the last item on the drop-down menu under "Living with Myeloma."

Myeloma Listserv

In addition to face-to-face local support groups, the IMF has created a cyber community of patients and caregivers in conjunction with the Association of Online Cancer

Resources (ACOR). The listserv helps members communicate quickly and easily via e-mail. This incredibly supportive and informative "family" of 1700 participants can be found by clicking on the "Find Support" and then the "Online group" tab. It is easy to sign up for this list by following the directions on the ACOR link provided or you can go directly to <http://listserv.myeloma.org>.

While the listserv is a wonderful source of all sorts of information, we remind everyone, as always, to verify anything you have read with your physician and not to follow any suggestions or advice offered that you might receive without talking to your doctor.

Myeloma Manager™ Personal Care Assistant™

The Myeloma Manager™ Personal Care Assistant™ (MMPCA) is a software program designed specifically for patients and caregivers battling multiple myeloma. It was developed by the IMF to help patients and caregivers deal with the glut of information and constantly increasing complexity of myeloma treatment programs. The program runs on your computer and stores all personal data on your computer. None of your data is transmitted to anyone. Access to the Myeloma Manager is password-protected and the data is encrypted (scrambled) so that it cannot be accessed from outside of the Myeloma Manager.

At its core, the Myeloma Manager provides a tool to capture laboratory results and display and print tables and charts to show how those results change over time. Other features include automatic backup of your data each time you shut down the program, calendars, and graph features such as plotting multiple tests on one graph and time-scaled graphs. The software also includes real-time news feeds from the IMF website and a reference shelf, with links to useful publications and web pages.

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- Adjust medications
- Recommend an exercise program that includes training in gait and balance, and stretching
- Assessment and modification of daily routines
- Safety of home environment

What precautions should be considered?

Patients need to be educated as to when they need to modify or abstain from their exercise regimen. For example, when they have a fever, patients should avoid group participation; if they have low platelets, a greater concern for strenuous activity and maintaining security of balance needs to be emphasized. Patients with balance problems may need to use a chair or wall for balance.

Patients must be cautioned to listen to their own bodies and abstain from activities that cause discomfort. Clinicians should recommend safe activity as part of the plan of care for every patient. On the one hand, a patient who had been active previously may not want to adhere to restrictions such as calling for help or using a walker. On the other, a sedentary individual may not understand the importance of exercise on bone health. Safe mobility and physical activity programs need to be tailored to the needs of each individual patient.

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At this time, the Myeloma Manager is available for Windows computers running XP, Vista, or Windows 7. It is not yet available for Macintosh, although it can be run on a “dual boot” Mac running Windows.

You can find the Myeloma Manager on the IMF website and download the program by either clicking on “Living with Myeloma” and then going to Myeloma Manager or going directly to the link <http://manager.myeloma.org>.



Personal Memory Stick

In an ideal world, every person would create, update, and carry around a small memory drive on which to store their health history, medications, and current year’s laboratory data. Some institutions like the Kaiser system in California, which has fully implemented electronic medical records, make these small memory sticks and all laboratory results available to their patients. Storing and carrying your medical data on a memory stick is a safe and reliable way to share medical information when visiting different doctors who need to know your medical history, what medications and dosages you’re taking, and what your current lab values are. If you already have all this information stored in your computer on your Myeloma Manager, it is a small step to transfer all the information on that program to a memory stick and carry it with you in your pocket, ready to share with your doctor.

Webinars

A “webinar” is a web-based seminar. The IMF’s first webinar was a training session for people interested in learning about the Myeloma Manager. Look for more webinars from the IMF in the future. On a smaller scale,

In any setting, the immediate need for patient safety (e.g. prevention of falling) should be the priority, and the patient’s environment should be assessed and modified to maximize safe mobility (e.g. rug placement, handrails, and grab bars).

What about ongoing assessment and readjustment?

Cancer rehabilitation is seldom linear; myeloma survivors may have varied problems and symptoms over time, such as pain, neuropathies, etc. Ongoing patient assessment of risk of falling, physical activity, medications and their side-effects, laboratory and diagnostic tests, nutrition, and adequate management of other health issues is essential.

Maintaining a weekly exercise log helps patients track the frequency, intensity, and duration of the exercises they perform. Based on patients’ documented exercise performance, programs could be altered to best accommodate their physical functioning (e.g. if the patient is feeling very fatigued the intensity of the exercises can be lowered accordingly).

Any closing comments?

Whatever is recommended or endorsed as exercise or activity needs to be carefully evaluated by the patient’s healthcare providers. Patients and their family members should be instructed to tailor the patient’s activities based on daily health status and communicate with the healthcare team regarding any questions or concerns they might have. **MT**

we have the capacity to hold virtual meetings between two people who are logged on to their computers. This is a tool that has come in handy for our webmaster, Abbie Rich, as she assists support groups in building their own websites.

Miscellaneous resources

There are a lot of other computer-based resources and services that you might find useful. For example, the CaringBridge website at www.CaringBridge.org allows patients or their caregivers to create a free personalized website to connect family and friends. These personalized websites are private and accessible 24 hours a day and can greatly ease the burden of keeping family and friends up-to-date with a patient’s progress. For example, if someone is having a stem cell transplant or is hospitalized for some other reason, the author can provide health updates and even photos to share their story. Visitors to the CaringBridge webpages can leave messages of love and support in the guestbook for the patient and family.

Finally, we want to remind everyone that while computers are great, there is sometimes nothing better than a live human being at the end of the phone. So don’t forget about the IMF Hotline, even if you just need help finding something on our website. **MT**

Need telephone help fast? Go to the web, click to talk.

Check out the new instant Hotline telephone access. Go to the IMF website and click on this icon in the upper right corner...and we’ll give you a call.

