

# Guide for CAREGIVERS

A diagnosis of myeloma can cause uncertainty and anxiety for everyone involved – patient, family members, partners and friends.

Caring for a patient can be an overwhelming challenge. The sudden transition might throw you off balance as you make adjustments in your daily routine and take on responsibilities that you were not anticipating.

While the immediate focus is on the patient, it is important that caregivers recognize that they play a critical role and need to maintain good emotional and physical health.

You might feel unprepared and unskilled. Remember, you were not expecting to be in the position you are in. The Myeloma Institute staff appreciates and values your essential role and is here to help you, as well as your loved one who is undergoing treatment.

Many patients and caregivers at the Myeloma Institute are far away from home, family and friends. Being in an unfamiliar city without one's built-in support system poses an extra layer of stress. Figuring out where to stay and how to deal with the essentials of daily living in a new place requires energy, patience and flexibility. And, coping with the financial demands of setting up house for a temporary stay away from home can be taxing.

We can help you select lodging that meets your needs and your budget. We maintain a list of short-term and

long-term lodging options, many of which offer special services, such as shuttle transportation, to Myeloma Institute patients and caregivers. Our social workers and customer service manager can help you choose an option that will work best for you. Our goal is to help you create a home away from home while you are here.

Social workers can also visit with you about resources for financial assistance and support services.

Communication is key! Keep an ongoing list of questions for the doctors and nurses. Be a good advocate for your loved one and for yourself. Make sure your questions are answered and your needs are being met.

The “Myeloma Institute Day Planner” notebook was custom-designed by our patient education staff. It is a useful tool for managing schedules and treatment regimens, tracking progress, and staying organized.

Keep contact phone numbers with you at all times. We encourage you to enter them into your cell phone.

Outpatient Clinic	501-686-8230
Infusion Unit	501-686-8220
Inpatient Unit	501-526-1700
After hours and week-ends	501-686-5000
Social Workers	501-686-8145
Chaplain	501-688-2060
Campus Police	501-686-7777

Be ready for changes, delays, surprises or setbacks. Remember, there are a lot of things you cannot control. Focus your energy on the things you can control and take one step at a time. Always bring extra clothes with you in case you have to stay in Little Rock longer than you had originally anticipated.

### Participating in education classes and support groups can help you feel empowered and confident.

- **New Patient Orientation for Patients and Caregivers** Every Wednesday at 3:00 pm in the Betsy Blass Board Room (10th floor of the Cancer Institute)
- **Infusion Unit Education Class for Caregivers** Every Wednesday at 8:00 am in the Infusion 4 Conference Room (4th floor of the Cancer Institute)
- **Little Rock Blood Cancer Support Group** First Tuesday of every month from 6:00 to 8:00 pm American Cancer Society, 901 North University Avenue. A support group for adult patients and their support persons coping with blood cancers. Co-sponsored by the UAMS Myeloma Institute, the UAMS Cancer Institute, the Leukemia and Lymphoma Society, and the American Cancer Society. For information, call 501-603-1612.

### ■ High-Risk Disease Support

At the Myeloma Institute each patient's disease is identified, through gene expression profiling and other diagnostic tools, as "low-risk" or "high-risk." High-risk disease is characterized by resistance to treatment and frequent relapses. This can be especially stressful for caregivers, since periods of progress can be so quickly followed by setbacks. Our staff are especially sensitive to the emotional toll that accompanies high-risk disease and are equipped to help you navigate the ups and downs.

### Professional staff at the Myeloma Institute are always available to meet with you.

- **Social workers.** Even if you have plenty of support, you may find it helpful to talk with someone other than your family or friends.
- **Psychotherapists.** They can help you examine your methods of coping, handling stress and

managing depression and anxiety. Counseling can be provided on an individual or family basis.

- **Chaplains.** Regardless of your religious preference, the chaplains at UAMS can offer spiritual guidance and comfort.



The **Patient Support Pavilion** on the main floor of the Cancer Institute provides information and educational resources for patients, family members and caregivers in a comfortable, relaxing setting. Hours: Monday through Friday, 8:00 am to 4:30 pm 501-686-5578

### The Patient Support Pavilion offers:

- A quiet family room for resting between appointments and making private phone calls
- Relaxation Room with guided imagery sessions to assist in relaxation and stress reduction
- Cell phone chargers and disposable ear buds
- Classes for patients and caregivers
- Interfaith chapel
- Business Center with Internet access, fax machine and copier
- Assistance in accessing online medical journals
- Books for use by patients, caregivers and families
- "Sit and Knit Sessions" – an informal time to knit and visit with fellow knitters; every Wednesday from 1:30 to 3:00 pm



### Keeping your family and friends updated about your loved one's progress

Caring Bridge is a non-profit organization that offers free web pages to those receiving care and their caregivers. It is a very useful tool that you can use to keep family and friends informed about your loved one's progress and how you are doing and to receive messages. [www.caringbridge.org](http://www.caringbridge.org)

### Taking care of yourself

As a caregiver, you need to take care of yourself. You can help your loved one best if you maintain your own physical and mental health.

Asking for help is not a sign of weakness. It is a sign of taking positive action.

Let your family, friends and co-workers know what they can do to help.

Accept their offers of assistance and assign them specific responsibilities (for example, bringing meals or doing the grocery shopping).

Avoid isolation, which can lead to depression. When in Little Rock, reach out to other caregivers at the Myeloma Institute. They, too, are in need of a supportive ear and companionship.

When at home, keep up with your friends. Invite them to come over and visit if you cannot get out, or take a walk together.

- Enjoy relaxing music.
- Maintain an exercise routine

- Eat nutritious meals.
- Visit with friends, engage in leisure and social activities.
- Practice deep breathing and meditation.
- Keep a sense of humor.
- Write your feelings in a journal.
- Set realistic limits on what you can and cannot do.
- Always remember you are doing the best you can.

Caregiving can be a truly rewarding experience. It can be a time to heal old wounds and improve relationships. It can be a chance to serve a loved one.

But caregiving also can be demanding and time-consuming. It may even raise your risk of stress-related disorders.



### Watch for signs of stress

Mental and physical signs of caregiver stress:

- A lot of anger or fear
- A tendency to overreact
- Feeling depressed, isolated or overburdened
- Thoughts of guilt, shame or inadequacy
- Headaches
- Digestive upsets
- Weight loss or gain
- Trouble sleeping
- Fatigue
- Illness



There will be times when you feel alone, sad, resentful, fearful and worried. That is normal. Try to be patient and give yourself a break. Always remember that the Myeloma Institute staff is here to help you and make your journey easier.

**Do something for yourself every day. It doesn't matter how small it is. Whatever you do, do not neglect yourself!**

### **Other Source of Caregiver Information**

An excellent guide and source of helpful information is "Support for Caregivers: When Someone You Love Is Being Treated for Cancer," a publication from the National Cancer Institute.

<http://www.cancer.gov/publications/patient-education/when-someone-you-love-is-treated.pdf>

### **Seek help when you need it.**

- Call a friend or a support hotline. Just having someone listen may help.
- Speak with a counselor. A professional can help you sort through your feelings.
- Talk with your religious adviser.
- Make an appointment with your primary care provider.