



INTERNATIONAL
MYELOMA
FOUNDATION

MYELOMA SUPPORT
GROUP

TAKING CONTROL: EMERGENCY PLANNING FOR PEACE OF MIND

2026 IMF SUPPORT GROUP TEAM



**MYELOMA SUPPORT
GROUP**

DISCLAIMER

The **International Myeloma Foundation Support Group Team** presents this information to support learning and conversations with your healthcare team.

This presentation is for informational purposes only and is **not intended to provide medical advice or replace guidance from your medical providers.**



**MYELOMA SUPPORT
GROUP**

MEET OUR TEAM!



Robin Tuohy
Vice President,
Patient Support

- 25+ Year Care Partner
- Advocate
- Support Group Leader



Jenn Wieworka
Director,
Support Groups

- Doctorate-Prepared Nurse
- Clinical Nurse Specialist
- Support Group Leader



Becky Bosley
Director,
Support Groups

- Oncology Nurse
- Breast & Ovarian Cancer Survivor
- Support Group Leader



Yara William
Associate Director,
Support Groups

- Doctor of Public Health
- Community Engager
- Patient Advocate



Katie Atkins
Associate Director,
Support Groups

- Oncology Social Worker
- Resource Navigator
- Support Group Leader



Cecilia Romero
Project & Technology
Manager,
Support Groups

- Public Health Advocate
- Technology Educator
- Project Management Expert

AGENDA

- WHY PREPAREDNESS MATTERS
- WHAT PATIENTS & CARE PARTNERS SHOULD KNOW
- WHEN TREATMENT IS INTERRUPTED
- STAYING WELL DURING EMERGENCIES
- EMERGENCY SUPPLY KIT
- EMOTIONAL WELL-BEING DURING EMERGENCIES

The background features a light gray wavy shape that resembles a stylized wave or a container. Inside this shape, there are numerous gray circles of various sizes, giving the impression of bubbles or particles. A solid blue wavy line runs along the bottom edge of the gray shape.

WHY PREPAREDNESS MATTERS

WHY **PREPAREDNESS MATTERS**

- Emergencies and natural disasters are becoming more frequent and unpredictable. They can happen with little warning
- Having a simple plan in place builds confidence and peace of mind



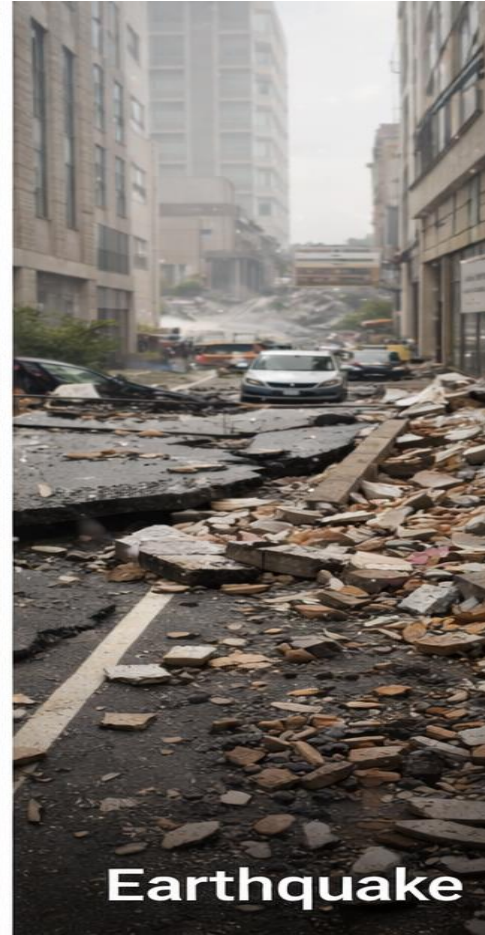
Hurricane



Wildfire



Flooding



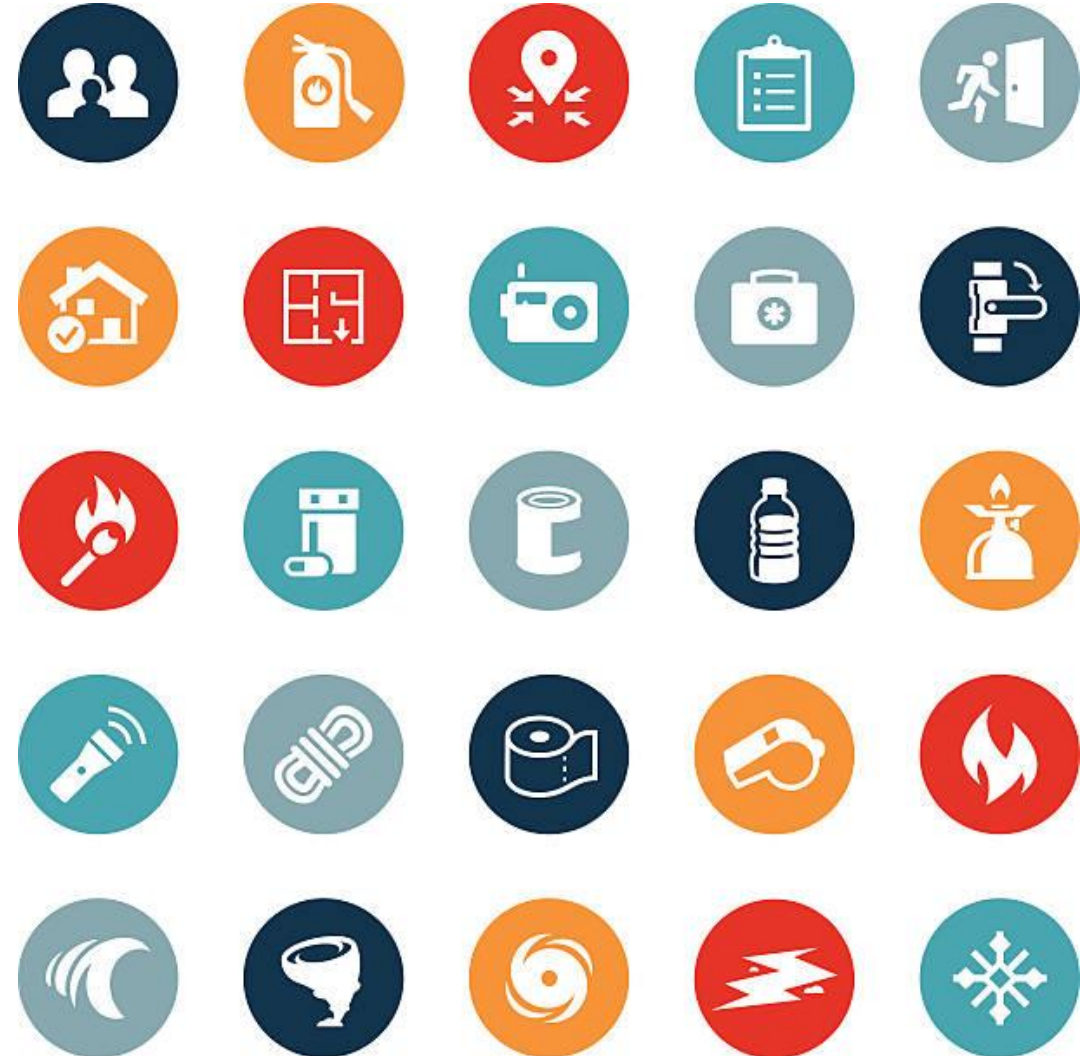
Earthquake



Snowstorm

WHY PREPAREDNESS MATTERS: COMES IN MANY FORMS

- Natural disasters (fires, storms, heat, earthquakes)
- Power or water outages
- Public health emergencies
- Transportation, clinic closures, public safety, etc.



WHAT **PATIENTS AND CARE PARTNERS** SHOULD KNOW

- Health needs can change quickly; having a plan helps you respond with confidence
- Extra attention to infection prevention supports overall well-being
- Planning ahead helps maintain routines like medications and appointments
- Thinking through mobility and transportation needs supports safety
- Preparation brings peace of mind and clarity during unexpected situations and potentially could prevent emergencies from happening
- You don't need to prepare for everything
- Small steps make a big difference
- Planning ahead reduces stress in the moment

HEALTH INFORMATION READINESS

Emergency Folder to Keep Key Info Easy To Access

- Medications & allergies
- Diagnosis and care team contacts
- Emergency contacts
- Insurance information
- Treatment plan
- MOST/POLST/MOLST and other official documents

WHEN TREATMENT IS **INTERRUPTED**

Why Planning Ahead Protects Your Health

- A simple backup plan helps keep treatment on track
- Knowing your options if clinics close provides flexibility
- Clear communication with your care team guides next steps
- Keeping extra medications on hand supports continuity
- Having alternate care locations identified adds peace of mind



PROTECT YOUR KIDNEYS



Stay Hydrated

Drinking water helps your kidneys work better.
Ask your doctor how much is right for you.



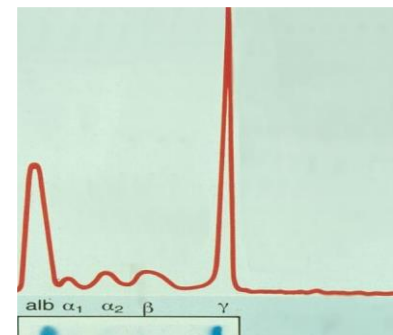
Watch for Warning Signs

Call your doctor if you notice swelling, dark urine,
or less urine than usual.



Avoid Harmful Meds

Some over-the-counter drugs like ibuprofen can
hurt your kidneys. Always check first.



Know Your Numbers

Regular blood and urine tests help monitor kidney
function. Keep track and ask questions.

MEDICATION DELAYS

- Stay calm; solutions are often available
- Contact your pharmacy or care team as soon as possible
- Pharmacists can help identify refill or replacement options
- Emergency refills or temporary alternatives may be available
- Planning ahead makes these situations easier to manage



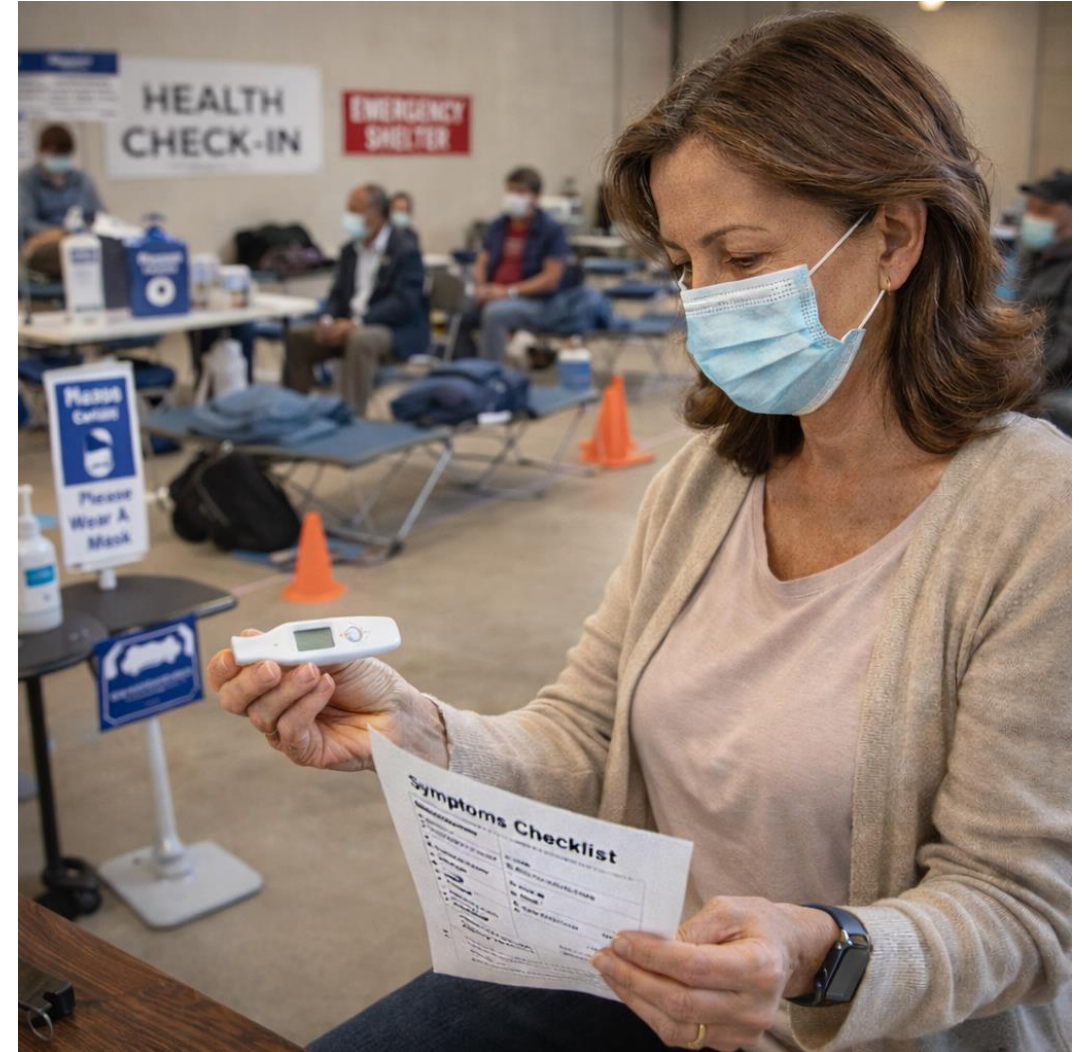
EMERGENCY **PRESCRIPTION REFILLS**

How Some States Support Access During a Crisis

- Many states allow pharmacists to provide emergency refills
 - The Emergency Prescription Assistance Program (EPAP) helps people access prescription refills during declared emergencies
 - Medicare plans may cover out-of-network pharmacy access and drug replacement support
- Rules vary by state and by situation (i.e. type of emergency)
- Pharmacists can explain what is allowed locally
- Planning ahead helps avoid treatment interruptions

STAYING WELL DURING EMERGENCIES

- Early attention to symptoms helps keep small issues manageable
- Everyday illness can have a bigger impact; vaccines offer strong protection
- Some treatments temporarily lower defenses; extra care is helpful
- Masks and spacing in crowded settings add an extra layer of protection
- Knowing when to check in with your care team supports prompt care



PREVENTING FALLS

Steps to Stay Safe and Strong

- Bone Strength Is a Key Risk Area
- Fall-Proof the Home
- Clear Walkways
- Use Assistive Devices
- ***You may be eligible for a free safety assessment of your home through insurance. Check with your provider for more information***



ACCESSIBILITY & MOBILITY



Bones May Be Fragile

Think about comfort and safety. Involve care partners early.



Use Mobility Aids When Needed

Walkers, canes, or wheelchairs can make movement safer. Keep them nearby during emergencies.



Evacuations May Be Risky

Crowds, stairs, or uneven ground can be hard to navigate. This can be dangerous without help or the right gear.



Preventing Falls Is Key

Good lighting, clear walkways, and support from others can lower your risk of falling.

EMERGENCY SUPPLY KIT (KEEP IT SIMPLE)

- Emergency folder (physical and/or electronic)
- Water and snacks
- Masks, sanitizer, portable air purifier
- Phone charger / battery pack
- Extra supply of medications
- Pill organizer



Check contents regularly

Review every few months to replace expired items or update documents

EMOTIONAL WELL-BEING DURING EMERGENCIES

- Stress and worry are normal responses to uncertainty
- Having a plan helps reduce anxiety and decision fatigue
- Simple routines create a sense of stability and control
- Grounding strategies can help calm the body and mind
- Staying connected to others supports emotional resilience



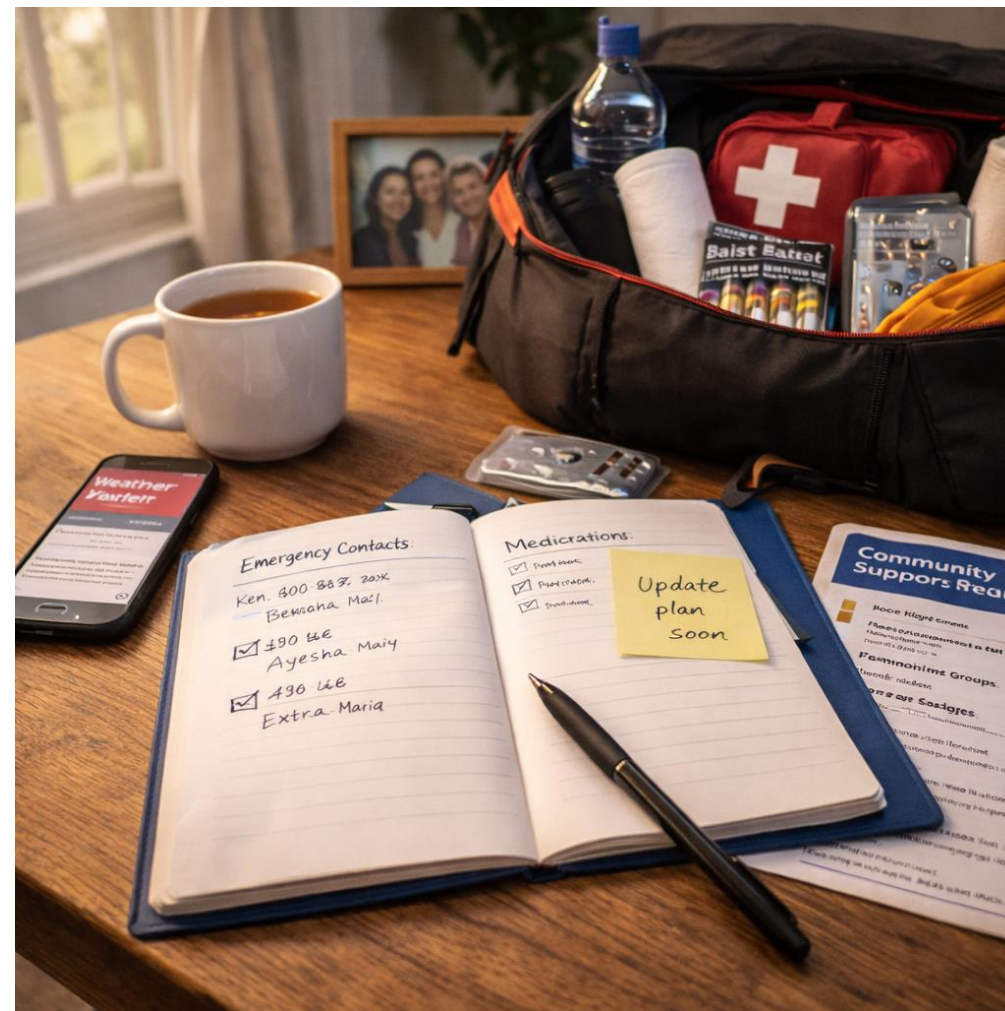
CARE PARTNERS & SUPPORT SYSTEMS

- Share plans with someone you trust
- Identify who can help with specific needs if needed
- Care partners play an important role before, during, and after emergencies
- Support groups provide connection, information, and reassurance
- Community resources and neighbors can be part of your plan
- Preparedness is stronger when it's shared
- Caring Bridge



PREPAREDNESS IS A PROCESS

- Preparedness happens over time, not all at once
- Small, manageable steps make a meaningful difference
- Planning ahead reduces stress and uncertainty
- Flexibility is part of being prepared
- Support systems and coMMunity matter
- You don't have to do this alone



FINDING SHELTER AND SUPPORT DURING EVACUATIONS

- Many communities offer shelters and evacuation assistance.
- Let responders or shelter staff know about health or medication needs.
- If medical transportation is needed during, ambulance services may be covered by Medicare when medically necessary.

Lodging Options for Myeloma Patients

- Hope Lodge Programs: Free housing near cancer centers for patients in treatment.
- Hospital Guest Housing: Discounted or free lodging available at some facilities.

Save contact information for IMF InfoLine, American Cancer Society, American Red Cross, and local services.

FINDING SHELTER AND SUPPORT DURING EVACUATIONS

- Many people worry about what will happen to their pets during an evacuation.
- Planning ahead can help reduce stress for both you and your animals.

Options for Your Pets

- [ASPCA Disaster Preparedness](#): Guidance on creating a pet emergency plan and kit
- [American Red Cross Pet Preparedness](#): Tips for evacuating safely with pets
- [BringFido.com](#): Directory of pet-friendly hotels and lodging.

Save contact information for [IMF InfoLine](#), [American Cancer Society](#), [American Red Cross](#), and local services.

Before



- ☐ Talk to your doctor
- ☐ Identify backup centers
- ☐ Prepare your records
- ☐ Secure extra medications
- ☐ Check telehealth options
- ☐ Prepare an emergency kit
- ☐ Set your family plan

During



- ☐ Follow official instructions
- ☐ Stay in touch with your care team
- ☐ Use backup facilities
- ☐ Use telemedicine
- ☐ Share your records
- ☐ Access additional resources

After



- ☐ Reconnect with your care team
- ☐ Transfer your records back to your primary team
- ☐ Return to your regular care
- ☐ Review and improve your plan
- ☐ Seek emotional support

HELPFUL **RESOURCES** AND SUPPORT

Trusted Places to Turn to in a Crisis

- **International Myeloma Foundation:** Support Group Team, Education, treatment updates, InfoLine support: www.myeloma.org
- **American Cancer Society:** Hope Lodge lodging, 24/7 hotline, and disaster relief: 1-800-227-2345
- **Red Cross Emergency Services:** Shelter, medical help, and evacuation information: www.redcross.org
- **CancerCare:** Free counseling, financial aid, and support: www.cancercare.org
- **National Cancer Institute's Cancer Information Service (CIS):** help with disaster preparedness, updates on situations, and locating healthcare facilities if care is disrupted
- **CaringBridge.org**
- **United Way Resource Hotline - 211**

FOLLOW UP QUESTIONS OR DISCUSSION?

Please feel free to reach out to us!

IMF Support Group
Team: SGTeam@myeloma.org



OUR MISSION:

Improving the quality of life of myeloma patients while working toward prevention and a cure.

OUR VISION:

A world where every myeloma patient can live life to the fullest, unburdened by the disease.

Follow the International Myeloma Foundation on:

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