

Making “Music” With Your Health Care Team

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Making “Music” With Your Healthcare Team



Be the Conductor of Your Health Care Team

Tune Up Your Knowledge

Experience Life’s High Notes





Be the Conductor of Your Healthcare Team

Keep a contact list of your providers

Understand the different roles

Orchestrate your care

- ▶ Be empowered:
 - Ask questions
 - Participate in decisions
 - Communicate effectively with your entire team



Primary Care
Provider (PCP)



Subspecialists



General Hem/Onc



You and Your Caregiver(s)



Myeloma Specialist



Family/Support Network



Allied Health Staff





Be the
Conductor

Many Treatment Options

Medical Data, HCP Experience

- Disease Characteristics
- Efficacy of Regimen
- Safety & Health Considerations

Your Preferences

- Administration, Chair Time
- Finances/ Insurance
- Social Status/ Support



FDA-approved myeloma therapies	Combinations
Bortezomib (SQ admin)	VRD, Vd
Lenalidomide	VRD, Rd
Carfilzomib	KRd, Kd, K
Pomalidomide	Pd, DPd, EPd
Daratumumab	DRd, DVd, DPd, D-VMP
Elotuzumab	ERd, EPd
Ixazomib	IRd
Panobinostat	Panobinostat + Vd
Doxil	Doxil + V

D = daratumumab; d = dexamethasone; E = elotuzumab; I = ixazomib; K = carfilzomib; P = pomalidomide; R = lenalidomide; SQ = subcutaneous; V = bortezomib

Faiman B, et al. *J Adv Pract Oncol*. 2016;2016:7(suppl 1):17-29.





Shared Decision Making: Creating Harmony Among All the Options



- ▶ **Ask for time to consider options (if needed/appropriate)**
- ▶ **Understand options; consider priorities**
 - Use reliable sources of information
 - Use caution considering stories of personal experiences
 - Consider your goals/values/preferences
- ▶ **Express your goals/values/preferences; create a dialogue**
 - My top priority is [goal/value]; additional [preferences] are also important.
 - I think [treatment] may be a good choice given my priorities... What do you think?
- ▶ **Arrive at a treatment decision together**



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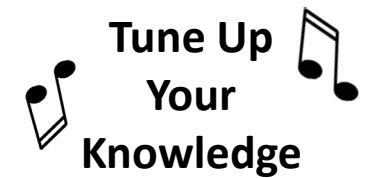
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Myeloma and Treatments Both Contribute to How You Feel



Myeloma cells in excess numbers cause symptoms

- Calcium elevation
- Renal dysfunction
- Anemia
- Bone pain
- Fatigue
- Infection
- Other symptoms

Treatments for myeloma kill myeloma cells but can cause symptoms

- Myelosuppression
- Peripheral neuropathy
- Diarrhea
- Fatigue
- Deep vein thrombosis
- Infection (eg, shingles)
- Other symptoms

How You Feel





What happens if Symptoms Are Not Managed Effectively?

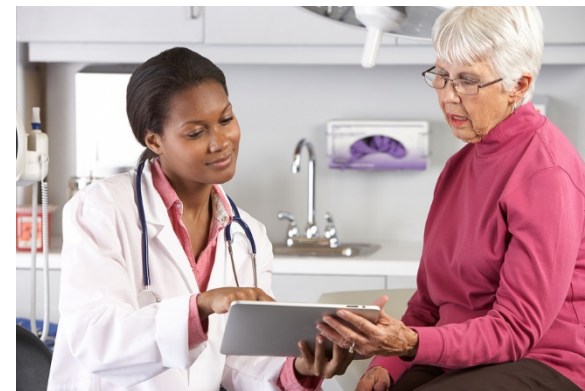
Tune Up
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Poorly managed symptoms can lead to

- ▶ Anxiety
- ▶ Missed doses
- ▶ Depression
- ▶ Reduced treatment efficacy
- ▶ Social isolation
- ▶ Reduced quality of life



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Discuss how you feel with your team

- ▶ Keep a symptom diary; discuss with team
- ▶ Many options but your team cannot help if they don't know
- ▶ Express your priorities
 - Fatigue is common concern but making the right treatment decision is higher priority for most





Common Side Effects of Myeloma Drugs (page 1 of 2)

	“Mides” Immunomodulatory drugs (IMiDS)			“Mibs” Proteasome Inhibitors		
	Thalomid® (thalidomide)	Revlimid® (lenalidomide)	Pomalyst® pomalidomide	Velcade® (bortezomib)	Kyprolis® (carfilzomib)	Ninlaro® (ixazomib)
Neuropathy (PN)	✓			✓*		
Thrombosis (DVT, PE)	✓ more with dex	✓ more with dex	✓ more with dex		✓	
Myelosuppression	✓ neutropenia	✓ anemia, neutropenia, thrombocytopenia	✓ neutropenia	✓ thrombocytopenia	✓ neutropenia, thrombocytopenia	✓ thrombocytopenia
Cardiopulmonary	✓ slow heart rate		✓ shortness of breath	✓ hypotension	✓ shortness of breath, other	
Fatigue, weakness	✓ (incl sedation)	✓	✓	✓	✓	✓ (incl sedation)
Renal	✓	✓	✓			
Rash	✓	✓	✓			
GI disturbance	✓ constipation	✓ diarrhea, constipation	✓ diarrhea, constipation	✓ nausea, vomiting, diarrhea	✓ nausea, vomiting, diarrhea, constipation	✓ diarrhea, constipation, nausea

PN = peripheral neuropathy; DVT = deep vein thrombosis; PE = pulmonary embolism; dex = dexamethasone; Neutropenia (low white blood cell) count; thrombocytopenia (low platelets); GI = gastrointestinal





Common Side Effects of Myeloma Drugs (page 2 of 2)

	“Mabs” Monoclonal Antibodies		HDAC inhibitor	Anthracycline
	Empliciti® elotuzumab	Darzalex® daratumumab	Farydak® Panobinostat	Doxil® doxorubicin
Neuropathy (PN)				
Infusion reaction	✓	✓		✓ Acute infusion reactions
Myelosuppression		✓ neutropenia, thrombocytopenia	✓ neutropenia, thrombocytopenia	✓ neutropenia
Cardiopulmonary			✓ arrhythmias, ischemia	✓
Fatigue, weakness	✓	✓	✓	✓
Rash				✓
GI disturbance	✓ diarrhea, nausea	✓ diarrhea	✓ severe diarrhea, nausea, vomiting	✓ diarrhea, nausea, vomiting, constipation


Neutropenia (low white blood cell count); PN = peripheral neuropathy; Thrombocytopenia (low platelets); GI = gastrointestinal





Steroids Side Effects and Management

Steroid Side Effects

- ▶ Irritability, mood swings, depression
 - ▶ Difficulty sleeping (insomnia), fatigue
 - ▶ Increased risk of infections, heart disease
 - ▶ Muscle weakness, cramping
 - ▶ Increase in blood pressure, water retention
- 
- ▶ Blurred vision, cataracts
 - ▶ Flushing/sweating
 - ▶ Stomach bloating, hiccups, heartburn, ulcers, or gas
 - ▶ Weight gain, hair thinning/loss, skin rashes
 - ▶ Increase in blood sugar levels, diabetes

Managing Steroid Side Effects

- ▶ Consistent schedule (AM vs. PM)
- ▶ Take with food
- ▶ Stomach discomfort: Over-the-counter or prescription medications
- ▶ Medications to prevent shingles, thrush, or other infections

**Steroids help kill myeloma cells.
Do not stop or adjust steroid doses
without discussing it with your health
care provider**





Fatigue, Depression, and Anxiety

- ▶ All can effect quality of life and relationships
- ▶ Sources include anemia, pain, reduced activity, insomnia, treatment toxicity, bone marrow suppression



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▶ Management

- Exercise (walking, yoga, etc)
- Proper rest
- Support (social network, support group, professional counseling, etc)
- Prayer, meditation, spiritual support
- Mindfulness-based stress reduction
- Medications
- Massage, aroma therapy
- Supplements: ginseng
- Transfusion, if indicated
- Effective management of other symptoms

At least 70% of patients experience fatigue, but only 20% tell their provider. Let your provider know about symptoms that are not well controlled or thoughts of self harm.





Infection Prevention & Treatment

- ▶ Compromised immune function comes from multiple myeloma and from treatment
- ▶ Good personal hygiene (skin, oral)
- ▶ Environmental control (wash hands, avoid crowds and sick people, etc)
- ▶ Growth factor (Neupogen [filgrastim])
- ▶ Immunizations (NO live vaccines)
- ▶ Medications (antibacterial, antiviral)
 - New research: for patients receiving active myeloma therapy, levofloxacin 500 mg once daily for 12 weeks reduced infection (fevers, death) (ASH 2017 #903)

Report fever of more than 100.4°F, shaking chills even without fever, dizziness, shortness of breath, low blood pressure to HCP as directed.

Infection is serious for myeloma patients!

**Did you
wash them?**



Hand washing prevents disease.



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Deep Vein Thrombosis (DVT) and Pulmonary Embolism (PE)



► Risk Factors

- Personal or family history
- Lifestyle (obesity, smoking, inactivity)
- Medical (medications, surgery)

► Symptoms

- Swelling, tightness, ache/pain, change in color or temperature
- Chest or shoulder pain
- Shortness of breath, difficult/labored breathing
- Anxiety
- Rapid heart rate

► Provider Management

- Adjusting medications and schedules (weekly steroids, types of chemo)
- Prescribing blood-thinning medications according to assessed risk (aspirin, warfarin, heparin or newer agents)
- Anti-embolism stockings (elastic stockings)

► Self Management

- Lifestyle changes (stop smoking, weight mgmt)
- Activity; Moving frequently when sitting long periods; Travel precautions



Report DVT and PE symptoms immediately!
These are considered a medical emergency & require immediate care



GI Symptoms Diarrhea and Constipation: Prevention & Management



▶ Diarrhea may be caused by

- Laxatives, antacids with magnesium
- Antibiotics, antidepressants, others
- Milk thistle, aloe, cayenne, saw palmetto, ginseng
- Sugar substitutes in sugar free gum

▶ Increase fluid intake but avoid caffeinated, carbonated, or heavily sugared beverages

▶ Take anti-diarrheal medication

- Imodium® or Lomotil® if recommended
- Fiber binding agents – Metamucil®, Citrucel®, Benefiber®
- Welchol® if recommended

▶ Constipation may be caused by

- Opioid pain relievers, antidepressants, heart or blood pressure medications, others
- Supplements: Calcium, Iron, vitamin D (rarely), vitamin B-12 deficiency

▶ Increase fiber

- Fruits, vegetables, high fiber whole grain foods
- Fiber binding agents – Metamucil®, Citrucel®, Benefiber®

▶ Increase fluid intake to work with fiber, also good for kidneys

Discuss GI issues with health care providers to identify causes of and make adjustments to medications and supplements





Understanding Changes to Kidney/Renal Function

Tune Up
Your
Knowledge

► Risk Factors

- Active multiple myeloma (light chains, high calcium)
- Other medical issues (ex: Diabetes, dehydration, infection)
- Medications (MM treatment, antibiotics, contrast dye)

► Prevention

- Drink, Drink, Drink
- Avoid certain medications, when possible

► Treatment

- Treatment for myeloma
- Hydration
- Dialysis

Many myeloma patients will experience kidney function problems at some point; it is important to protect your kidney function early and over time.



Figure 1: Cross Section of a Human Kidney

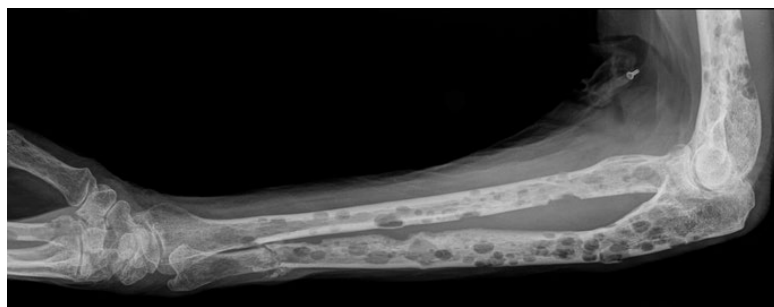




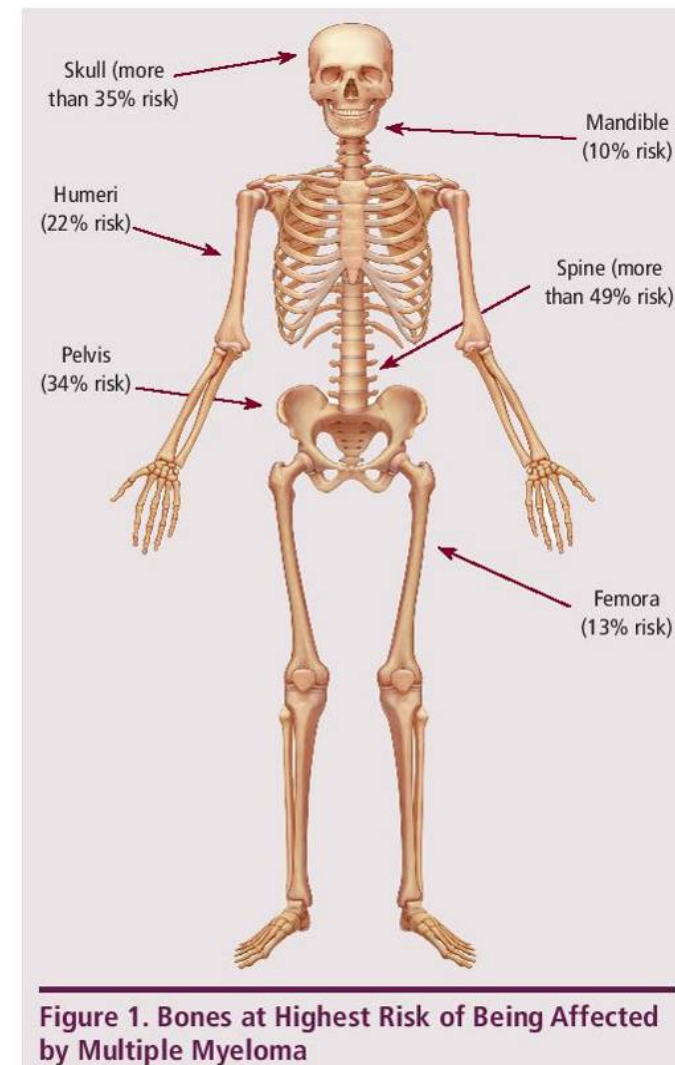
Myeloma Cells Can Cause Damage To Bones

Most myeloma patients will experience bone involvement at some point; it is important to protect your bone health

- ▶ Approximately 85% of myeloma patients develop bone disease
- ▶ Protecting bone health
 - Nutrition
 - Weight-bearing activity
 - Medications
 - Vitamin D
 - Calcium (if approved by doctor)
 - Bone strengthening agents: Zometa® zoledronic acid, Aredia (pamidronate), or Xgeva® denosumab
- ▶ Report new pain to your health care provider



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Peripheral Neuropathy (PN) Management

▶ Peripheral neuropathy: damage to nerves in extremities (hands, feet, or limbs)

- Numbness
- Tingling
- Prickling sensations
- Sensitivity to touch
- Muscle weakness
- Burning pain or cold sensation

Report symptoms of peripheral neuropathy early to your health care provider; nerve damage from PN can be permanent if unaddressed

▶ Prevention / management:

- Bortezomib once-weekly or subcutaneous administration
- Massage area with cocoa butter regularly
- Supplements:
 - B-complex vitamins (B1, B6, B12)
 - Folic acid, and/or amino acids but do not take on day of Velcade® (bortezomib) infusion
- Safe environment: rugs, furnishings, shoes

▶ If PN worsens, your HCP may:

- Change your treatment
- Prescribe oral or topical pain medication
- Suggest physical therapy





Pain Prevention and Management

- ▶ **Pain can significantly compromise quality of life**
- ▶ **Sources of pain include bone disease, neuropathy and medical procedures**
- ▶ **Management**
 - Prevent pain when possible
 - Bone strengtheners to decrease fracture risk; antiviral to prevent shingles; sedation before procedures
 - Interventions depends on source of pain
 - May include medications, activity, surgical intervention, radiation therapy, etc
 - Complementary and alternative medicine (supplements, acupuncture, etc)

Tell your health care provider about any new bone pain or chronic pain that is not adequately controlled





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Experience Life's High Notes by Living Well: Preventative Health Screening & Vaccination

Experience
Life's High
Notes

► Usual screening (see your PCP)

- Blood pressure
- Cholesterol
- Diabetes
- Colonoscopy
- Cardiovascular disease
- Mammography, pap smear
- Prostate (PSA)



► Myeloma specific

- Having multiple myeloma & certain therapies increase your risk of some conditions
- Examples
 - Pneumococcal & annual flu vaccine
 - Higher skin cancer risk
 - Steroids increase cataract risk
 - Revaccination after stem cell transplant with your HCP

People living with multiple myeloma need to adopt long-term healthy behaviors, as do their caregivers!





Living Well: Adopt a Healthy Lifestyle for Patients & Caregivers

- ▶ Managing stress
- ▶ Rest, relaxation, sleep hygiene
- ▶ Maintain a healthy weight, eat nutritiously
- ▶ Activity / exercise / prevent falls, injury
- ▶ Stop smoking
- ▶ Mental health / social engagement
- ▶ Sexual health / intimacy
- ▶ Complementary or alternative therapy
- ▶ Have a PCP for general check ups, preventative care, health screenings, vaccinations
- New research: 2 doses of flu vaccine produce longer lasting immunity in patients with plasma cell disorders (ASH 2017 #438)





Living Well: Enjoy the Music

“Music gives a soul to the universe,
wings to the mind, flight to the imagination
and life to everything.”

— Plato



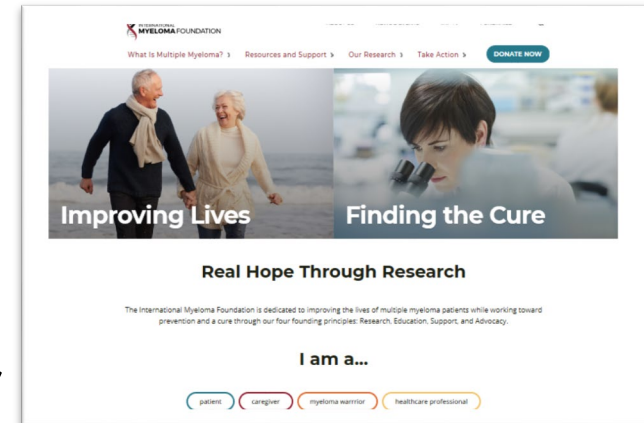


IMF Has Many Resources to Help You



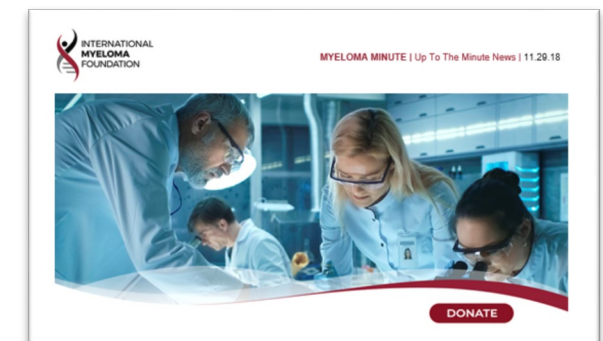
Website: <http://myeloma.org>

IMF TV
Teleconferences



eNewsletter:
Myeloma Minute

IMF InfoLine
1-800-452-CURE
9am to 4pm PST



Download or order at myeloma.org



You are Not Alone



INTERNATIONAL
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Questions?

