Making “Music” With Your Healthcare Team

Be the Conductor of Your Health Care Team

Tune Up Your Knowledge

Experience Life’s High Notes
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

Be the Conductor of Your Healthcare Team

Primary Care Provider (PCP)

Subspecialists

General Hem/Onc

Myeloma Specialist

You and Your Caregiver(s)

Family/Support Network

Allied Health Staff
Many Treatment Options

### Medical Data, HCP Experience
- Disease Characteristics
- Efficacy of Regimen
- Health Considerations

### Your Preferences
- Administration, Chair Time
- Finances/Insurance
- Social Status/Support

### Myeloma therapies

<table>
<thead>
<tr>
<th></th>
<th>Common combinations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bortezomib (SQ admin)</td>
<td>VRD, Vd</td>
</tr>
<tr>
<td>Lenalidomide</td>
<td>VRD, Rd</td>
</tr>
<tr>
<td>Carfilzomib</td>
<td>KRd, Kd, K</td>
</tr>
<tr>
<td>Pomalidomide</td>
<td>Pd, DPd, EPd</td>
</tr>
<tr>
<td>Daratumumab</td>
<td>DRd, Dvd, DPd, D-VMP</td>
</tr>
<tr>
<td>Elotuzumab</td>
<td>ERd, EPd</td>
</tr>
<tr>
<td>Ixazomib</td>
<td>IRd</td>
</tr>
<tr>
<td>Panobinostat</td>
<td>Panobinostat + Vd</td>
</tr>
<tr>
<td>Doxorubicin</td>
<td>Liposomal Dox + V</td>
</tr>
<tr>
<td>Cyclophosphamide</td>
<td>PCd, VTD-PACE</td>
</tr>
<tr>
<td>Bendamustine</td>
<td>BRd, BVd</td>
</tr>
</tbody>
</table>

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

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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Tune Up Your Knowledge

Experience Life’s High Notes
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?

Poorly managed symptoms can lead to

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

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)

<table>
<thead>
<tr>
<th>“Mides” Immunomodulatory drugs (IMIDS)</th>
<th>“Mibs” Proteasome Inhibitors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thalomid® (thalidomide)</td>
<td>Velcade® (bortezomib)</td>
</tr>
<tr>
<td>Revlimid® (lenalidomide)</td>
<td>Kyprolis® (carfilzomib)</td>
</tr>
<tr>
<td>Pomalyst® (pomalidomide)</td>
<td>Ninlaro® (ixazomib)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>side effect</th>
<th>Thalomid</th>
<th>Revlimid</th>
<th>Pomalyst</th>
<th>Velcade</th>
<th>Kyprolis</th>
<th>Ninlaro</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neuropathy (PN)</td>
<td>✓</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thrombosis (DVT, PE)</td>
<td>✓ more with dex</td>
<td>✓ more with dex</td>
<td>✓ more with dex</td>
<td>✓ more with dex</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Myelosuppression</td>
<td>✓ neutropenia</td>
<td>✓ anemia, neutropenia, thrombocytopenia</td>
<td>✓ neutropenia</td>
<td>✓ thrombocytopenia</td>
<td>✓ neutropenia, thrombocytopenia</td>
<td>✓ thrombocytopenia</td>
</tr>
<tr>
<td>Cardiopulmonary</td>
<td>✓ slow heart rate</td>
<td>✓ shortness of breath</td>
<td>✓ hypotension</td>
<td>✓ shortness of breath, other</td>
<td>✓</td>
<td>✓ (incl sedation)</td>
</tr>
<tr>
<td>Fatigue, weakness</td>
<td>✓ (incl sedation)</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Renal</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Rash</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>GI disturbance</td>
<td>✓ constipation</td>
<td>✓ diarrhea, constipation</td>
<td>✓ diarrhea, constipation</td>
<td>✓ nausea, vomiting, diarrhea</td>
<td>✓ nausea, vomiting, diarrhea, constipation</td>
<td>✓ diarrhea, constipation, nausea</td>
</tr>
</tbody>
</table>

*Subcutaneous administration reduces rates of PN
dex = dexamethasone; DVT = deep vein thrombosis; GI = gastrointestinal PE = pulmonary embolism; PN = peripheral neuropathy.

Prescribing Information: thalidomide, lenalidomide, pomalidomide, bortezomib, carfilzomib, ixazomib.
### Common Side Effects of Myeloma Drugs (page 2 of 2)

<table>
<thead>
<tr>
<th>“Mabs” Monoclonal Antibodies</th>
<th>HDAC inhibitor</th>
<th>Anthracycline</th>
<th>Alkylating Agents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Darzalex® (daratumumab)</td>
<td>Empliciti® (elotuzumab)</td>
<td>Farydak® (panobinostat)</td>
<td>Doxil® (liposomal doxorubicin)</td>
</tr>
<tr>
<td>Neuropathy (PN)</td>
<td>✓</td>
<td>✓</td>
<td>✓ Acute infusion reactions</td>
</tr>
<tr>
<td>Infusion reaction</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Myelosuppression</td>
<td>✓ neutropenia, thrombocytopenia</td>
<td>✓ neutropenia, thrombocytopenia</td>
<td>✓ neutropenia</td>
</tr>
<tr>
<td>Cardiopulmonary</td>
<td></td>
<td>✓ arrhythmias, ischemia</td>
<td></td>
</tr>
<tr>
<td>Fatigue, weakness</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Rash</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal disturbance</td>
<td>✓ diarrhea</td>
<td>✓ diarrhea, nausea</td>
<td>✓ severe diarrhea, nausea, vomiting</td>
</tr>
</tbody>
</table>

Prescribing Information: daratumumab, elotuzumab, panobinostat, doxorubicin, cyclophosphamide, melphalan.
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

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!

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

► 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.

**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

► 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

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

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

► 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)
“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 InfoLine
1-800-452-CURE
9am to 4pm PST

IMF TV Teleconferences

eNewsletter: Myeloma Minute

Download or order at myeloma.org
You are Not Alone

Questions?