The Military Veteran's Perspective on Living with Multiple Myeloma Teleconference

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Adjunct Clinical Professor of Nursing
The University of Arizona Cancer Center
IMF Veterans Focus Group and Online Survey

Veterans Focus Group
- Focus group held February 13, 2015, Boca Raton, Florida
- 9 Veterans, 3 caregivers

Online Survey
- Survey Monkey online survey December, 2014
- 42 Veterans

Years of Service ranging from 2-37.5 years
I started having fatigue and a bloody nose ~ 2 months before I was finally diagnosed with MM.

This is an interesting disease. No two days are the same, because disease symptoms often manifest differently. But you can *LIVE* with MM.

I am looking at the whole broad spectrum of MM. I need as much information as possible.
Veterans Comments

- Care provided in a variety of settings.
- Often determined by Insurance coverage or accessibility.
- Having access to MM experts can positively impact care.
- More physicians are becoming aware of how to care for patients with MM.

Models of Care

- Veterans (VA) System Only
- Combined Model: VA and community care
  - General care at the VA, stem cell transplant at a specialty center
  - Community setting only
  - Community setting with referral to a MM specialist

66% of those surveyed were either moderately or highly satisfied with their care in the VA system.
Topics of interest include:

- Risk factors for Myeloma in veterans
  - Other diseases that are related to MM
  - How to evaluate exposure during service
- Types of Multiple Myeloma (MM) and characteristics
  - High risk vs low risk
  - Different immunoglobulin subtypes, what do their levels tell us about the disease
  - What is the impact of subclones
- Updated criteria for the diagnosis and monitoring of MM
- What are the current guidelines for treatment?
What we heard from you: Information Needs and Topics of Interest

- What are the current guidelines for treatment?
  - What if I do not live near a MM specialist?
  - Where do clinical trials fit in treatment? How do I find out more about them?

- Symptom management
  - Pain management
  - Side effect management

- Preventive Care
  - How to stay well
Access to benefits and resources for Veterans

- How to best navigate disability benefits when Veterans turn 65 and become eligible for social security
- How to ensure that TRICARE remains active when Medicare insurance takes effect
- The roles and functions of difference service organizations (e.g. VFW, DAV, NSO) and how they can best assist Veterans as they live with MM
# Exposure during Service

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<table>
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<tbody>
<tr>
<td><strong>Agent Orange</strong></td>
<td>23</td>
<td>6</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>5</td>
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<tr>
<td><strong>Radiation</strong></td>
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<td>3</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>5</td>
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<td><strong>Asbestos</strong></td>
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<td>5</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>7</td>
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<td><strong>Contaminated Water</strong></td>
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<td>2</td>
<td>2</td>
<td>5</td>
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<td>5</td>
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<tr>
<td><strong>Burning waste</strong></td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
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<tr>
<td><strong>Chemical Exposure other than water</strong></td>
<td>7</td>
<td>7</td>
<td>7</td>
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<tr>
<td><strong>Unknown or not stated</strong></td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
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<td>7</td>
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</table>

**Dr. Durie's Blog:**

Toxic Chemical Exposures and MGUS/Myeloma
Lessons Learned from the Veterans Surveyed

- MM often occurs later in life and is often not readily considered as a diagnosis
- Veterans utilize care both within and without the VA system, and are generally satisfied with their care
- Not all Veterans have access to MM experts at their treatment centers
- Most participants had not been involved in clinical trials
- The process of obtaining disability can be challenging to navigate. Education is needed for both Veterans, physicians and disability administrators
- Veterans are eager to learn about MM
Tools to understand individual approaches to treatment: The 10 Steps to Better Care

The 10 steps are:
1. Know what you're dealing with. Get the correct diagnosis.
2. Tests you really need.
3. Initial treatment options.
4. Supportive care and how to get it.
5. Transplant: Do you need one?
6. Response Assessment: Is Treatment Working?
7. Consolidation and/or Maintenance.
9. Relapse: Do You Need a Change in Treatment?

©2015 International Myeloma Foundation  www.myeloma.org
Classification of MM

- **Heavy chain:**
  - IgG, IgA, IgD, IgM, IgE
  - 77% of myeloma cases
  - IgG and IgA most common

- **Light chain (Bence-Jones protein):**
  - kappa (κ) or lambda (λ)
  - 20% of myeloma cases

**Nonsecretory:**
- no detectable immunoglobulin
- 1%-2% of myeloma cases

The Multiple Myeloma Disease Trajectory

Abbreviations: MM = Multiple Myeloma; MGUS = Monoclonal gammopathy of uncertain significance; SMM = Asymptomatic MM; NDMM = Newly diagnosed MM; MRD0 = Minimal residual disease zero; RRMM = Relapsed and/or Refractory MM
Myeloma Defining Events (MDE)

Myeloma related end-organ damage (CRAB criteria revised)

C: Calcium elevation
   • Serum calcium >0.25 mmol/L (>1mg/dL) higher than the ULN OR > 2.75 mmol/L (>11mg/dL).

R: Renal dysfunction
   • Creatinine clearance <40mL per min or serum creatinine > 177µ/L (>2mg/dL)

A: Anemia
   • Hgb > 20g/L below the LLN or <100 g/L

B: Bone disease
   • One or more osteolytic lesions on skeletal radiography, CT or PET/CT.

Any one or more Biomarkers of malignancy (SLiMCRAB)
   • BMPC > 60%
   • Involved/Uninvolved serum free light chain ratio > 100
   • > 1 focal lesion >5mm on MRI studies

Rajkumar et al., The Lancet Oncology, 201:15(2);e538-3548
Newly Diagnosed Multiple Myeloma
Tailoring therapy

Not all Myeloma is alike
No two people are identical
Myeloma affects both the patient and their caregivers
Patients wishes are important to discuss

- Comprehensive assessment
  - Disease state
    - high risk vs. low-risk
  - Transplant eligibility
  - Patient attributes
    - comorbidities, fit vs. frail, age
  - Life resources:
    - Caregivers, finances, transportation

- Advance Care Planning
- Supportive and Palliative Care
- Caregiver support

Abbreviations: MM= Multiple Myeloma; NDMM = Newly diagnosed MM;
MRD0 = Minimal residual disease zero; RRMM = Relapsed and or Refractory MM; NCCN=National Comprehensive cancer network

Palumbo et al., JCO, 32, 587-600
General Approach to Treatment of Multiple Myeloma

- Estimate risk based on individual myeloma attributes
  - Disease attributes, Organ function, Co-morbidities
- Risk-adapted treatment selection
  - Initiate best available treatment to induce an early and deep response
  - Determine transplant eligibility
  - Achieve an early and deep response
- Limit end organ damage, prevent/minimize Adverse Events
  - Preserve future treatment options
- Maintain a durable response
  - Optimizing each treatment option
  - Consider maintenance therapy if indicated
- Early Identification of lack of or loss of response
- Maintain or improve QOL
Treatment Options Have Greatly Increased

Dex= Dexamethasone; MGUS = monoclonal gammopathy of undetermined significance; MM = multiple myeloma; SC = subcutaneous; SMM = smoldering multiple myeloma

Drugs@FDA.gov
From International Myeloma Foundation – used with permission
MM Survival is Improving


Can we do better ....... MRD0 and the reach for a cure

## Side Effects of Common Myeloma Drugs

<table>
<thead>
<tr>
<th></th>
<th>thalidomide</th>
<th>lenalidomide</th>
<th>pomalidomide</th>
<th>bortezomib</th>
<th>carfilzomib</th>
<th>panobinostat</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></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Myelosuppression</td>
<td>✓ neutro</td>
<td>✓ anemia, thrombo, neutro</td>
<td>✓ neutro</td>
<td>✓ thrombo</td>
<td>✓ neutro, thrombo</td>
<td>✓ neutro, thrombo</td>
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<tr>
<td>Cardiopulmonary</td>
<td>✓ slow heart rate</td>
<td>✓ shortness of breath</td>
<td>✓ hypotension</td>
<td>✓ shortness of breath, other</td>
<td>✓ arrhythmias, ischemia</td>
<td></td>
</tr>
<tr>
<td>Fatigue, weakness</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Sedation</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, nausea, vomiting,</td>
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</tbody>
</table>

* Subcutaneous administration of bortezomib reduces risk of PN

DVT = deep vein thrombosis; dex = dexamethasone; GI = gastrointestinal; PE = pulmonary embolism; Neutro = neutropenia (low white blood cell) count; PN = peripheral neuropathy; Thrombo = thrombocytopenia (low platelets)
NCCN Recommendations for Adjunctive Treatment

**Bone disease**
- Bisphosphonates
- Radiation therapy
- Orthopedic consultation
- Vertebroplasty or kyphoplasty

**Hypercalcemia**
- Hydration, steroids, furosemide
- Zoledronic acid preferred

**Hyperviscosity**
- Plasmapheresis

**Anemia**
- Consider erythropoietin
- Transfusion

**Infection**
- IVIG for recurrent infections
- Pneumovax and influenza vaccine
- PCP, herpes and antifungal prophylaxis for high-dose or long-term steroids
- Herpes zoster prophylaxis with bortezomib

**Renal dysfunction**
- Avoid aggravating factors: contrast, NSAIDs, dehydration
- Not a contraindication to HCT
- Monitor bisphosphonates closely

**Coagulation/thrombosis**
- Prophylactic anticoagulation with IMiDs

NCCN Clinical Practice Guidelines in Oncology: Multiple Myeloma—v.4.2015.
What Can you Do

Continue to seek information
  Web-resources
  Health professionals
  Support Groups
Be a partner in your care = shared decision making
Track your treatment and symptoms
Get immunized (no live vaccines)
Take part in wellness activities
  Diet
  Nutrition
  Exercise
International Myeloma Foundation Hotline:

800.452.CURE (2873)

- US & Canada
- 9:00 am to 4:00 pm Pacific

- Nurses, patients, caregivers, others welcome to call
- Trained staff available to answer questions about finding clinical trials, etc.

www.myeloma.org
Patient Education Tools From IMF

AE Management Sheets
- Preventing Blood Clots and Thromboembolic Events
- Managing Myelosuppression
- Managing Steroid Side Effects
- Managing Peripheral Neuropathy
- Managing Gastrointestinal Side Effects

Understanding Brochures
- Velcade® (bortezomib) for Injection
- Revlimid® (lenalidomide)
- Kyprolis® (carfilzomib) for Injection
- Pomalyst® (pomalidomide) Capsules
- Thalidomide Therapy
- Dexamethosone & Other Steroids
- Bisphosphonate Therapy
- Understanding High-Dose Therapy with Stem Cell Rescue

Tip Cards
- SQ Velcade®
- Kyprolis® for Injection
- Pomalyst® (pomalidomide capsules)
- Revlimid® and Thalidomide®

Download or order at myeloma.org
IMF Resources for Newly Diagnosed Patients: 10 Steps, Patient Handbook 2015, etc.

Available at: Myeloma.org

IMF = International Myeloma Foundation
IMF Resources for Multiple Myeloma

General Information
www.myeloma.org

Adherence to Oral Cancer Therapy

Bisphosphonate Therapy
http://myeloma.org/pdfs/U-Bis.pdf

Kyprolis

Pomalyst (pomalidomide)

Revlimid (lenalidomide)-update in progress

Thalidomide Therapy
http://myeloma.org/pdfs/U-Thalidomide.pdf

Velcade (bortezomib) for injection
http://myeloma.org/pdfs/U-Velcade.pdf
Pharmaceutical assistance programs for currently approved novel agents

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<tr>
<th>Company</th>
<th>Drug</th>
<th>Phone Number</th>
<th>Website</th>
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<tbody>
<tr>
<td>Celgene</td>
<td>Lenalidomide, Pomalidomide, Thalidomide</td>
<td>1-800-931-8691</td>
<td><a href="http://www.celegenepatientsupport.com">www.celegenepatientsupport.com</a></td>
</tr>
<tr>
<td>Novartis</td>
<td>Panobinostat</td>
<td>1-800-277-2254</td>
<td><a href="http://www.oncologyaccessnow.com">www.oncologyaccessnow.com</a></td>
</tr>
<tr>
<td>TEVA</td>
<td>Bendamustine</td>
<td>1-888-587-3263</td>
<td><a href="http://www.cephalononcologycore.com">www.cephalononcologycore.com</a></td>
</tr>
</tbody>
</table>
Resources used by Veterans with Myeloma in this survey

- **Myeloma resources:**
  - International Myeloma Foundation - [www.myeloma.org](http://www.myeloma.org)

- **Veterans Resources**
  - American Legion - [http://www.legion.org/](http://www.legion.org/)
  - Veterans of Foreign Wars - [http://www.vfw.org/](http://www.vfw.org/)
  - National Association of County Veterans Service Officers - [www.nacvso.org](http://www.nacvso.org)
  - Marine Corps League - [www.mclnational.org](http://www.mclnational.org)
  - State Veterans Affairs Board – by state
  - US Department of Veterans Affairs- [www.myhealth.va.gov/index.html](http://www.myhealth.va.gov/index.html)
  - Military Order of the Purple Heart - [http://www.purpleheart.org/](http://www.purpleheart.org/)
  - Other VA-accredited Service Orgs – [www.va.gov](http://www.va.gov) enter VSO in search box

- **Local Politicians as advocates**
The Military Veterans Perspective on Living with Multiple Myeloma: Finding Resources

Susan Leigh, BSN, RN
Vietnam Veteran, Army Nurse Corps, Retired
Cancer Survivorship Consultant
Founding Member, National Coalition for Cancer Survivorship
Goals for Today

Enhance quality of life after a diagnosis of multiple myeloma

- Explore dimensions of advocacy and becoming your own best advocate
- Optimize access to and use of appropriate resources
- Introduce the continuing need for follow-up care through survivorship care planning
How Will We Define our Population?

Multiple ways to define a cancer survivor, including those with multiple myeloma
Who is a Survivor?
Luxury of Labeling

Survivors
Patients
Victors
Sufferers
Activists
Warriors
Veterans
Thrivers
Advocates
“The Blessed”
Cancer Fighters
Cancer Conquerors
Cancer “Killers”
Different Pathways to Survival

Living cancer-free for the remainder of life
Living cancer-free for many years but experiencing one or more serious, late complications of treatment
Living cancer-free for many years, but dying after a late recurrence
Living cancer-free after the first cancer is treated, but developing a second cancer
Living with intermittent periods of active disease requiring treatment
Living with cancer continuously without a disease-free period

(ACS Survivorship Facts & Figures 2013)
Defining Survivorship

**Time Frame**: Pediatric oncology first defined survivor as any patient living 5 years free of disease after diagnosis or at end of treatment.

**Process**: National Coalition for Cancer Survivorship (NCCS) created term “survivorship” as process of survival and labeled anyone with cancer as survivor going through stages.

**Stage**: Oncology (medical) community defines survivor as patient who has completed treatment and is NED.
Focus for today.....

Look at survivorship from:

- Advocacy perspective
- VA perspective
- Civilian perspective
  - Academic centers
  - Community clinics
Where Do I Start?

- Oncologist and oncology team
- International Myeloma Foundation
  - myeloma.org/
- Veterans Against Myeloma
  - veterans.myeloma.org/
- National Cancer Institute
  - Cancer.gov/types/myeloma
Dimensions of Advocacy As Consumer Issue

Self-Advocacy (personal)****
Community Advocacy (groups and local organizations)
National and Public Interest (national organizations)
Legislative Advocacy (public policy)
What is Self-Advocacy?

Self-advocacy does not mean that you have to wave a banner, give speeches or take to the ramparts. In the personal context, it means that you arm yourself with the tools and skills necessary to feel comfortable about asserting yourself and communicating clearly about your cancer care needs. It ultimately means that you are taking responsibility and assuming some control of your life circumstances with cancer.

(National Coalition for Cancer Survivorship Website)
Self-Advocacy Skills

How to ask the right questions?
How to find the right information?
How to understand the answers?
How to communicate effectively?
How to make decisions?
How to negotiate?

Cancer Survivor Toolbox: Building Skills That Work for You
www.Canceradvocacy.org
Examples of Self-Advocacy

- Know oncology team: MD, NP, PA, RN
- Ask about resources: social worker, case manager, navigator, dietician
- Get 2\(^{nd}\) opinions (outside VA system)
- Keep track of medical records: Release of Information office.
- Have system to organize records: binder, accordion file
- Sign up for myhealthevet.va.gov
- If eligible, utilize Medicare and Tricare for care outside VA
- Look for support services in community or online
Basic Skills

- Communicating
- Finding Information
- Making Decisions
- Solving Problems
- Negotiating
- Standing up for your Rights (self-advocacy)

Living Beyond Cancer

Living With Multiple Myeloma
Community Advocacy

Finding Resources
- Reading materials
- Internet support and information
- Specialty clinics
- Community resource centers
- Support groups

Giving Back
- Boards, committees, fund raisers
- Local consumer advocacy
National Advocacy

- Advocacy organizations
  - Staff, Board, Committee members
- National Cancer Institute
  - Consumer advocates
- Raise awareness through writing, publishing, public speaking
- Collaborations
- Professional advocacy
- Raise money for research
Legislative (Public Policy) Advocacy

- Lobbying
- Activism
- Raising awareness through writing, publishing and public speaking
- Collaborations
- Develop & pass cancer-related initiatives
- Testify before government bodies
Brian Novis, along with Susie Novis and Dr. Brian Durie, identified an unmet need to support patients with Multiple Myeloma. They founded IMF in 1990 and work both nationally and internationally to

- Educate patients and families
- Meet emotional needs of patients and their families
- Support myeloma research.
Individual Multi-level Advocate

Michael Katz, tireless advocate and past IMF Executive Board member:

- Struggled to find information before internet was viable option (self-advocacy)
- Offered 1 on 1 counseling & moderated ACOR online listservs (community advocacy)
- Helped set-up patient database and website for IMF (community/national advocacy)
- National speaker for IMF seminars (national advocacy)
- Chair of Director’s Consumer Liaison Group at NCI (national and clinical research advocacy)
- Advocate for Eastern Oncology Cooperative Group (national and clinical research advocacy)
- Voiced concerns in public policy arenas (legislative advocacy)
Cancer is often a chronic condition, but is not treated as one.

When treatment ends, most cancer survivors do not have a follow-up care plan or treatment summary.

Surviving cancer is something to celebrate, but it is not the end of the road.

Cancer changes your life forever, and it also changes your healthcare needs forever.
Goals of Survivorship Care Planning

- Summarize and communicate what transpired during cancer treatment
- Record known and potential late effects of cancer treatments with their expected time course
- Promote a healthy lifestyle to prevent recurrence and reduce the risk of other co-morbid conditions
- Prevent fragmentation of care as well as improve the efficiency of care

Components of Care Plans

- **Treatment Plan**
  (1st step)

- **Treatment Summary**
  (Historical - Past)

- **Follow-up Care Plan**
  (Present & Future, Dynamic)
1. Treatment Plan

- Complexity of cancer treatments
- Numerous members of care team
- Coordination of active treatment
- Aggressive management of symptoms and side effects
- Elements of both acute and chronic care
2. Treatment Summary

- Diagnosis, tumor characteristics, staging
- Reports of test results
- Treatments, dosages, toxicities
- Dates of treatments, completion
- Supportive care
- Contact information, care coordinator

Responsibility: Oncology Team
3. Follow-Up Care Plan

- Surveillance
  - Recurrence
  - New cancers
  - Lingering & Late effects of treatment

- Health maintenance/Health promotion
  - Lifestyle/behavioral interventions
  - Coordinated non-cancer care

- Education, resources and support services

Responsibility: Team effort
  - Oncology, Primary Care, Survivor, Ancillary Caregivers
Care Plan Templates

Myeloma Manager ***
http://myeloma.org/store/page15.html
Only available as APP

Journey Forward
www.journeyforward.org
Medical/Nursing model. Treatment specifics. Adopted by Oncology Nursing Society

ASCO (American Society of Clinical Oncology)
www.cancer.net/survivorship
Medical model. Created by American Society of Clinical Oncology.
Care Plan Templates - General

Oncolife (by Oncolink) ****

www.oncolink.org/oncolife


Livestrong care plan

www.livestrongcareplan.org

Nursing model. Symptom management. Patient & Provider plans.
Resources/Books

Cancer Fitness: Exercise Programs for Patients & Survivors  
Anna Schwartz

Healing Yoga: for people living with cancer  
Lisa Holt

Healing Walks for Hard Times  
Carolyn Scott Kortge

Dying to Know  
Tani Bahti, RN
Helpful Resources

- Myeloma Manager “Personal Care Assistant” from IMF (only available as APP)
- Living with Multiple Myeloma Module from NCCS and the Cancer Survival Toolbox
- Guidelines for Myeloma Patients from NCCN (National Comprehensive Cancer Network)
- Leukemia & Lymphoma Society
- Multiple Myeloma Research Foundation
Complementary Therapies

- Nutrition
- Exercise
- Acupuncture
- Massage
- Movement (Qi gong, tai chi)
- Meditation/imagery/relaxation
- Biofeedback
- Energy therapies (shiatsu, reiki, therapeutic touch)
- Music, art, poetry
- Prayer
- Support groups
American Institute for Cancer Research

Diet and Health Guidelines for Cancer Prevention

Choose a diet rich in a variety of plant-based foods.
Eat plenty of vegetables and fruits.
Maintain a healthy weight and be physically active.
Drink alcohol only in moderation, if at all.
Select foods low in fat and salt.
Prepare and store foods safely.

And, always remember...
Do not use tobacco in any form.
Cookbooks & Cancer

- *Eating Well Through Cancer*
  H. Clegg & G. Miletello, MD

- *One Bite at a Time: Nourishing Recipes for People with Cancer, Survivors, and their Caregivers*
  Rebecca Katz

- *The Cancer-Fighting Kitchen: Nourishing, big flavor recipes for cancer treatment and recovery*
  Rebecca Katz
Physical Health

Exercise

Control lipids

Avoid weight gain

Do not smoke
Final Thoughts

- Whether we are treated in a VA, an academic center, or a community oncology practice, we must learn to advocate for ourselves or find someone who can.
- Resources differ in every community. Know how to find what is available locally, nationally, and online.
- If resources do not exist in our area, we can help create programs to fill the voids.
- We can advocate for ourselves and ask for treatment and follow-up plans.
- We can begin the process of care planning ourselves.
Thank You

On behalf of the International Myeloma Foundation, we thank you for your participation in this webinar.

Please Contact IMF for Further Information and Resources:

1-800-452-CURE
(1-800-452-2873)
TheIMF@myeloma.org
http://myeloma.org