



Fred Hutch · Seattle Children's · UW Medicine

Thriving and Surviving with Myeloma

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Outline

- Your team
- What to expect
- Remission and relapse in myeloma
- What's available at SCCA

Build your team – who is on your team?

- **Your doctor**
 - Specialist
 - Local/treating oncologist
 - Pain/palliative care
- **Nurses**
 - Clinical nurses
 - Infusion nurses
- **Pharmacist**
- **Social work/navigator**
- **Financial navigator**
- **Family and friends**





Build your team – how to utilize your team?

- **Be your own advocate**
- **Come prepared to your visits**
- **Make sure your team members are communicating**

- **Your doctor**
 - Understand your diagnosis, test results, treatment goals, side effects
- **Nurses**
 - Report side effects early
 - Give time for them to respond
- **Pharmacist**
 - Will discuss new chemo treatments, side effects, other meds you might need to take
 - Report new meds, supplements, anything over-the-counter

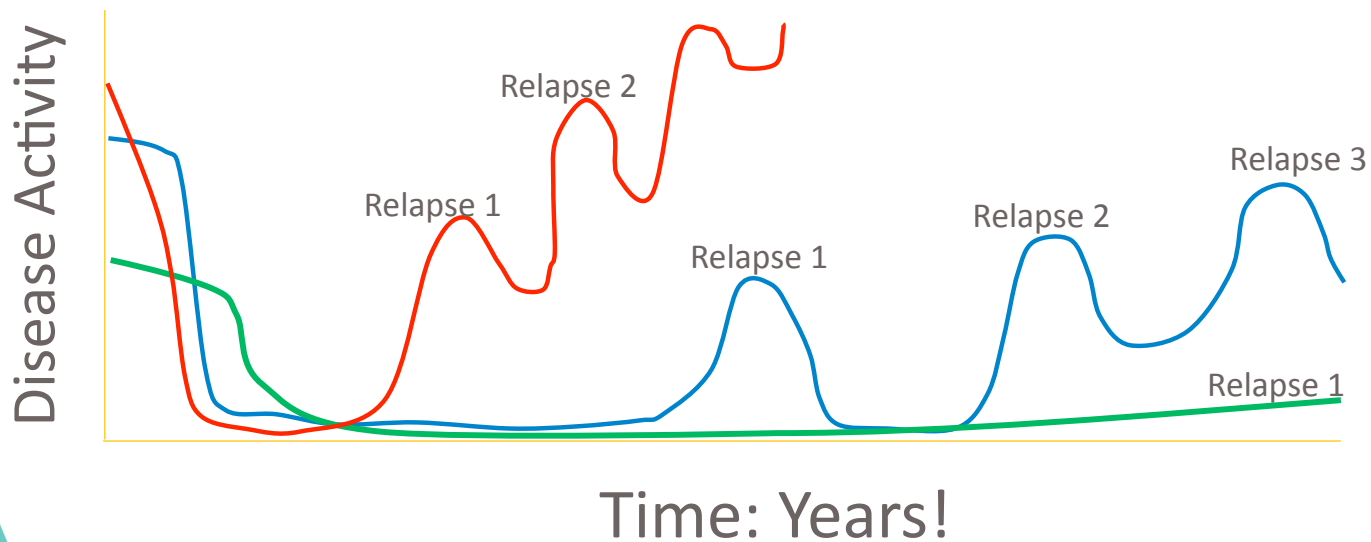


Build your team – how to utilize your team?

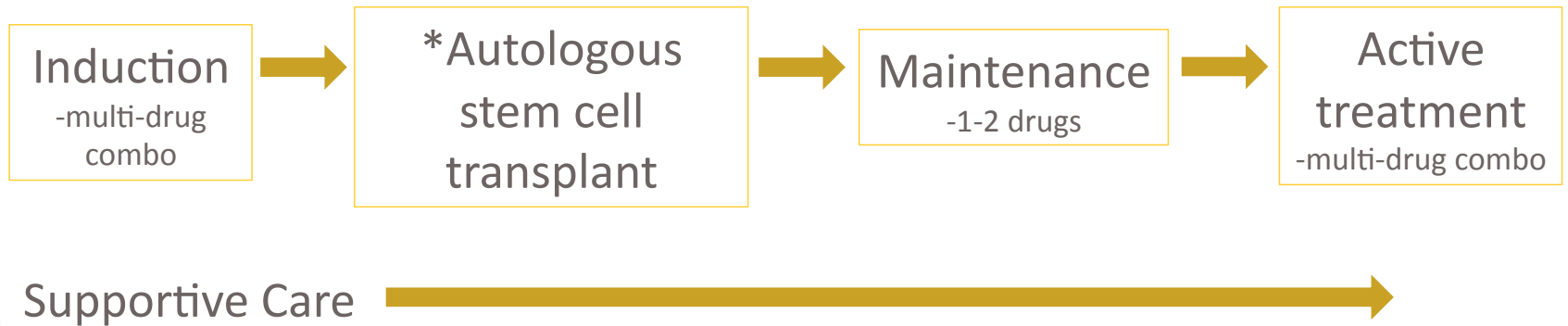
- **Social work/navigator**
 - Counseling
 - Employment/disability forms
 - Handicap parking passes
 - Jury duty excuses
- **Family and friends**
 - Protect your immune system
 - Meals, rides, pet-sitting

What to expect

- **In general (there are always exceptions):**
 - You will always be under the care of an oncologist
 - You will always need to monitor your myeloma
 - You will always be on some form of treatment



What to expect



*Consider a clinical trial at each step

Approved treatments for Multiple Myeloma

- Immunomodulatory Agents
 - Lenalidomide
 - Pomalidomide
 - Thalidomide
- Proteasome Inhibitors
 - Bortezomib
 - Carfilzomib
 - Ixazomib
- Monoclonal Antibodies
 - Daratumumab (CD38)
 - Isatuximab (CD38)
 - Elotuzumab (SLAMF7)
- Alkylating Agents
 - Melphalan
 - Cyclophosphamide
 - Bendamustine
- BCMA antibody-drug conjugate
 - Belantamab mafodotin
- Peptide-drug conjugate
 - Melflufen*
- Selective inhibitors of nuclear export (SINE)
 - Selinexor
- Histone Deacetylase (HDAC) inhibitor
 - Panobinostat
- CAR-T cell
 - Idecabtagene vicleucel (BCMA)



How to navigate remission and relapse in myeloma

- **In remission**
 - Continue active surveillance and monitoring of your disease
 - Blood/urine markers for myeloma, imaging, BM biopsies
 - Ongoing side effect management
 - Stay current with general health management
 - Stay healthy and active
 - Protect your quality of life
- **In relapse**
 - Discuss appropriate timing of when to restart active treatment
 - Discuss clinical trial options
 - Stay healthy and active
 - Protect your quality of life
 - Revisit goals of therapy
 - Be honest with your doctor and your team



How to navigate remission and relapse in myeloma

- **Healthy Lifestyles**

- Achieve and maintain a healthy body weight
- Get adequate amount of sleep
- Avoid inactivity and engage in physical activity
 - Ex) exercise, walk, take the stairs, park in the back, water aerobics, tai chi, restorative yoga
- Maintain a healthy diet high in vegetable, fruits, and whole grains, and low in excess sugars, fried foods, and red and processed meat
- Consume alcohol sparingly



How to navigate remission and relapse in myeloma

- **Healthy Lifestyles**
 - Cigarette/tobacco cessation
 - Practice sun safety
 - Avoid sunburns
 - Use SPF of at least 30 that protects against UVA and UVB rays and is water resistant. Reapply every 2 hours.
 - Consider using physical barriers whenever possible (hats, sleeves)
 - Follow up with your PCP for age-appropriate screening and preventative measures
 - Screening for cardiovascular disease, blood pressure and cholesterol management
 - Screening for other cancers
 - Routine hearing and vision tests



How to navigate remission and relapse in myeloma

- **Immune protection**
 - Immunizations
 - Infection prevention medicines
 - Proper hand washing
 - Travel precautions
 - Safe pet care
 - Ex) Wash hands with soap and water after handling animal feces
 - Gardening precautions
 - Ex) Wear gloves to avoid skin cuts/punctures to avoid possible infections, poor wound healing. Wear a protective mask to avoid spores



How to navigate remission and relapse in myeloma

- **Mental health**
 - Talk to your team!
 - Address factors that might be contributing – pain, fatigue, poor sleep
 - Support networks – in person, online, apps
 - Engage with social work, patient navigation
 - Talk to a therapist, chaplain
 - Regular physical activity and healthy nutrition
 - Practice relaxation techniques
 - Ex) mindfulness, mediation, yoga
 - Get support for yourself, caregiver, couples, family, kids
 - Pharmacologic treatment



Resources at SCCA

Clinical Patient Navigation

Patient navigators are culturally sensitive staff who provide emotional support and help with medical transportation and lodging, financial and insurance concerns, and medication co-pays. Patient navigators identify local and national resources to address these needs and provide information and support.

Phone: (206) 606-1076

Clinical Social Work

The stress of dealing with cancer can affect your feelings, thoughts and behaviors. Our social workers are available weekdays to provide emotional, psychological and practical support to you, your family and caregivers. They can also refer you to our psychologists and psychiatrists, as well as identify other SCCA and community resources.

Phone: (206) 606-1076

Housing

SCCA offers housing options for patients and family members from out of town who need short-term lodging during active treatment: Pete Gross House and SCCA House. We have relationships with several local hotels, apartment and condo owners who offer temporary lodging at or below Seattle's market prices. Please visit seattlecca.org/patients/housing or contact our Housing department for additional information.

Phone: (206) 606-7263

Integrative Medicine

Integrative medicine is a field of cancer care that utilizes mind-body practices, natural products, acupuncture, naturopathic medicine and/or lifestyle changes alongside standard cancer treatments.

Our providers' expertise and discipline in these areas will help support your health and wellness goals.

Phone: (206) 606-5500

Interpreter Services

Interpreter Services helps patients, families and caregivers who have limited or no English proficiency and those who are deaf, hard of hearing or visually impaired communicate with their care team. Interpreters are free of charge and available in person or by video or telephone.

Phone: (206) 606-6419

Living Tobacco-Free Services

Living Tobacco-Free Services are free of charge to patients, caregivers and family members who are thinking about quitting or ready to stop tobacco use. They help you create a plan that includes free nicotine patches, gum and lozenges. Quitting tobacco use at the time of a cancer diagnosis can improve your treatment outcome, as well as reduce side effects.

Phone: (206) 606-7766

Medical Nutrition Therapy

Our registered dietitians provide personalized medical nutrition therapy including: nutrition education, nutrition advice for cancer prevention and survivorship, therapeutic diet counseling, management of treatment-related side effects, tube feeding support, safe food handling and preparation, and use of vitamins, minerals and herbal nutrition supplements.

Phone: (206) 606-1148

Onco-Reproduction

Your fertility may be affected by the treatments used to treat your cancer. Age, gender, type of cancer, type and dose of treatments and any previous chemotherapy or radiation exposure can increase your risk of infertility. Our Onco-Reproduction Clinic helps you understand your fertility treatment and preservation options.

Phone: (206) 606-4100

Pain Clinic

Pain may be caused by your cancer, treatment or an unrelated medical problem. Your care team will help treat your pain with medication or other treatments, such as physical therapy or acupuncture. This may involve a referral to the Pain Clinic, which specializes in managing complex pain related to cancer or treatment.

Patient and Family Assistance

During your treatment at SCCA, funds may be available to help cover basic living expenses if your personal and financial situation meets our financial assistance guidelines. Contact your social worker or patient navigator for an application and guidelines for eligibility.

Patient and Family Resource Center

The Resource Center on the 3rd floor of the clinic offers personalized support and resources, a business center, notary services for health care documents, iPad lending program, and complimentary virtual wig fittings.

Phone: (206) 606-2081

Email: patientresourcectr@seattlecca.org

Physical Therapy

Physical activity during cancer treatment is important to your mobility, health and quality of life. Our physical therapists provide specialized treatment that may include: teaching you how to exercise properly and safely throughout treatment; how to manage fatigue and edema; balance training; and massage. Your provider must refer you to physical therapy.

Phone: (206) 606-6373

Retail Stores: Shine and The Gift Shop

Shine, located at the SCCA House, and The Gift Shop, in our South Lake Union clinic, carry locally sourced and unique gifts. Shine sells oncology-specific products like breast prostheses and bras, compression garments, nutrition products, sexual intimacy aids and specialty skin care products. Free mastectomy fittings are available by appointment. Please call for more information about head shaves, wig trims and haircuts.

Shine phone: (206) 606-7560

The Gift Shop phone: (206) 606-8270

Spiritual Health

Our Spiritual Health team provides respectful spiritual and emotional care for people of all faiths, including those who are not religious or spiritual. Our trained staff work with you and your loved ones as you face unknowns, losses and struggles. They can guide you as you search, grow, cope and heal. Our sanctuary on the 1st floor is open for contemplation or prayer.

Phone: (206) 606-1099

Supportive and Palliative Care

Palliative care focuses on improving the longevity and quality of your life. Palliative care is recommended for people with advanced cancer or major symptoms at the time of their cancer diagnosis, however, it is available at any time; you don't have to stop receiving treatment to be seen by the palliative care team.

Phone: (206) 606-7474

Survivorship Clinic

The Survivorship Clinic helps you thrive after therapy ends. We offer tools to overcome fatigue, memory issues, sexual dysfunction and living with uncertainty. During your visit, we will create a Treatment Summary and Care Plan so you can manage potential late- and long-term health effects of your cancer treatment.

Phone: (206) 606-6100

Volunteer Services

SCCA's dedicated volunteers provide practical, emotional and social support for patients and caregivers. Volunteers offer airport transportation, housing tours and host special events.

Phone: (206) 606-1075

Child Life Services

Using play, expressive activities and age-appropriate conversations, Child Life Services helps children understand and cope with stress when loved ones are sick. Child Life also provides parenting support and helps families improve their own coping skills.

General information:

(206) 606-7621

Appointments:

(206) 606-6593 or (206) 606-7024



Conclusion

- Build a team you trust and can communicate with
- Your experience with myeloma will ebb and flow
 - Time, treatment, side effects, support needed
 - Prioritize your mental and emotional health, but also those around you
- Find out what resources are available to you locally, regionally, nationally

**Thank you patients,
caregivers, and the myeloma
community**



NW MM FIGHTERS

