



# CANCER SUPPORT COMMUNITY.®

*A Global Network of Education and Hope*

Uniting The Wellness Community and Gilda's Club Worldwide

# Making Educational Materials for Bone Health and Bone Metastases Accessible to Cancer Survivors and Caregivers

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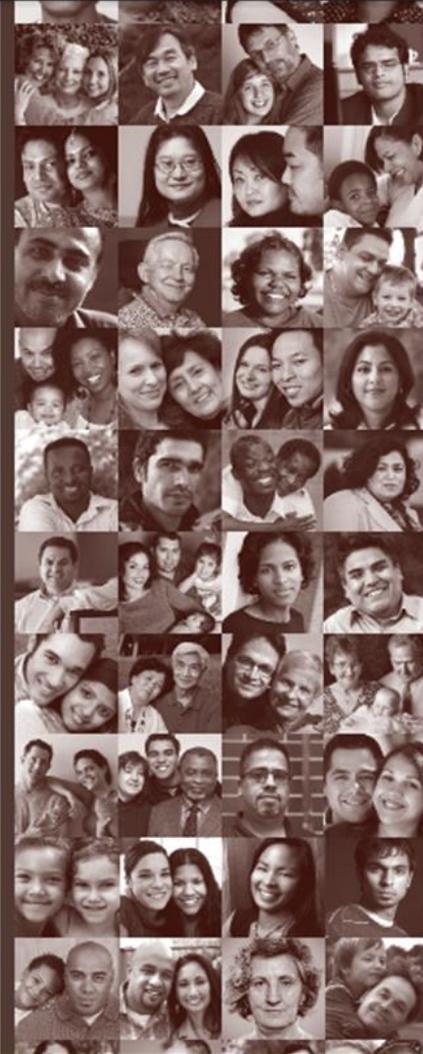
# Conflict of Interest Disclosure

I do not have any potential conflicts of interest to disclose.

# Cancer Support Community

OUR MISSION:

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.



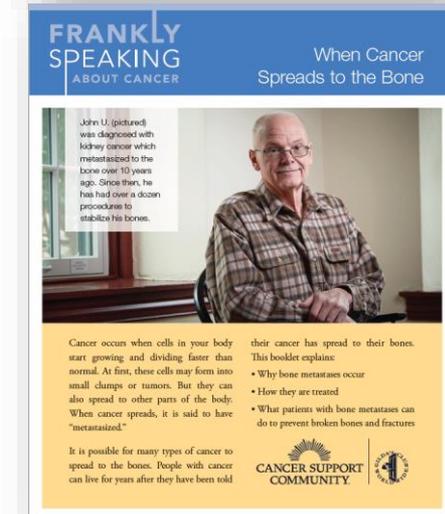
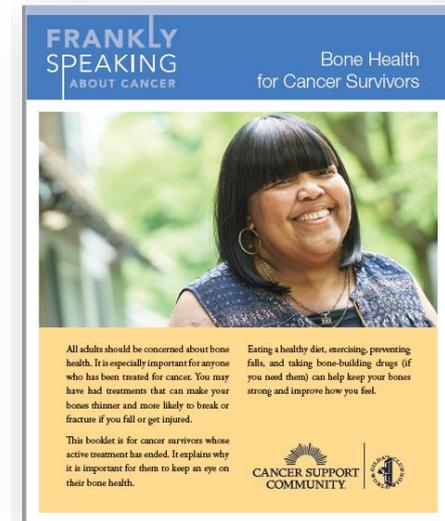
# Frankly Speaking About Cancer®

- High quality, evidence-based educational programming for cancer patients, survivors, caregivers, and health care professionals.
- Frankly Speaking About Cancer (FSAC)
  - Provide easy to understand in-depth coverage of topics relevant to those affected by cancer.
  - To educate and to empower cancer patients, survivors, caregivers, and health care professionals.
  - Topics are tumor type-specific (e.g. melanoma, lung, metastatic breast, liver, colorectal, multiple myeloma) or cross-tumors (e.g. immunotherapy, clinical trials, treatments and side effects).
  - Provide up-to-date content and reflect new advances in knowledge.



# FSAC Bone Health Program

- In 2018, CSC launched its FSAC Bone Health program.
- Feedback from community research assisted in the development of two booklets about bone health:
  - ✓ *FSAC Bone Health for Cancer Survivors*, and
  - ✓ *FSAC When Cancer Spreads to the Bone*



# FSAC Bone Health for Cancer Survivors

This booklet is for cancer survivors whose active treatment has ended.

Topics include:

- Bone health after cancer treatment.
- What to do to keep healthy bones.
- Bone health tests.
- Questions to ask the health care team.

**FRANKLY SPEAKING ABOUT CANCER** Bone Health for Cancer Survivors



All adults should be concerned about bone health. It is especially important for anyone who has been treated for cancer. You may have had treatments that can make your bones thinner and more likely to break or fracture if you fall or get injured.

Eating a healthy diet, exercising, preventing falls, and taking bone-building drugs (if you need them) can help keep your bones strong and improve how you feel.

This booklet is for cancer survivors whose active treatment has ended. It explains why it is important for them to keep an eye on their bone health.

**CANCER SUPPORT COMMUNITY**



- Osteoclasts (*OS-ter-oh-klasts*), which break down the bone
  - Osteoblasts (*OS-ter-oh-blasts*), which form new bone
  - Osteocytes (*OS-ter-oh-sites*), the cells inside the bone (these cells start out as osteoblasts)
- As you get older, the tissue inside your bones changes. These changes make it easier for your bones to break if you fall or get injured. The medical terms for these changes are:
- Osteopenia (*OS-ter-oh-PEE-nyoo-ah*)—bone tissue is thinner than normal
  - Osteoporosis (*OS-ter-oh-POH-roh-sis*)—bone tissue has become very thin and can break more easily
- Osteopenia and osteoporosis are very common.

### What are Osteopenia and Osteoporosis?

As you get older, the tissue inside your bones changes. These changes make it easier for your bones to break if you fall or get injured. The medical terms for these changes are:

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Osteopenia and osteoporosis are very common.

**EATING FOR HEALTHY BONES**  
Try to get your daily recommended levels of calcium and vitamin D from the food you eat.

DAILY RECOMMENDATIONS	CALCIUM	VITAMIN D
Women ages 19 to 50	1,000 mg/day	600 IU/day
Men ages 19 to 70	1,000 mg/day	600 IU/day
Women ages 51 to 70	1,200 mg/day	600 IU/day
Women and Men 70+	1,200 mg/day	800 IU/day

- Broccoli, acorn squash, butternut squash, and okra
  - Beans and peas, especially soybeans and black-eyed peas
  - Figs, dried fruit, and almonds (Good as snacks or in hot cereals)
  - Calcium-fortified foods and drinks (Orange juice, soy milk, almond milk, some cereals, breads, and tofu are often fortified with calcium and vitamin D)
  - Fish, dried fish, and almonds (Good as snacks or in hot cereals)
  - Beans and peas, especially soybeans and black-eyed peas
- Talk to your health care provider about whether calcium and vitamin D supplements are right for you.



*"I only had to make a few changes to be sure I was getting the calcium and vitamin D I need every day. I drink milk every morning and try to eat broccoli or another high-calcium veggie with dinner."*

—Janice R., ovarian cancer survivor



### PROSTATE CANCER & OSTEOPOROSIS

Androgen deprivation therapy (also known as hormone therapy or androgen suppression therapy) is used to treat prostate cancer. It reduces the testosterone that helps the cancer grow. But it also slows bone production. Surgery to remove both testicles (orchiectomy) has the same effect. The most rapid bone loss often occurs during the first 12 months of treatment. If you received these treatments, you should:

- Have bone density (DEXA) scan every two years.
- Take calcium and vitamin D supplements.
- Talk to your doctor about taking a bone-building drug if your DEXA scan score is below -2.5.
- Be treated, when necessary, with denosumab (Prolia), zoledronic acid (Zometa), Zoledronic acid (Zometa), or strontium (Prostate™).

### QUESTIONS TO ASK YOUR HEALTH CARE TEAM

- Should I have a bone density test now? If not now, when?
- Am I at risk for osteopenia or osteoporosis? Why or why not?
- What are some things I can do on my own to take care of my bones to make sure they stay healthy?
- Are you recommending bone-building drugs? Why or why not?
- How long should I stay on my medication?

# Community Research

- CSC facilitated 4 virtual focus groups to test new materials
- 17 breast and 6 prostate cancer patients and their caregivers
  - Highest risk of osteoporosis as survivors of non-metastatic disease
  - These cancer types often spread to the bone
- Non-metastatic breast and prostate cancer patients reviewed the ***FSAC: Bone Health for Cancer Survivors***.
- Metastatic breast and prostate cancer survivors and caregivers reviewed the ***FSAC: When Cancer Spreads to the Bone***.

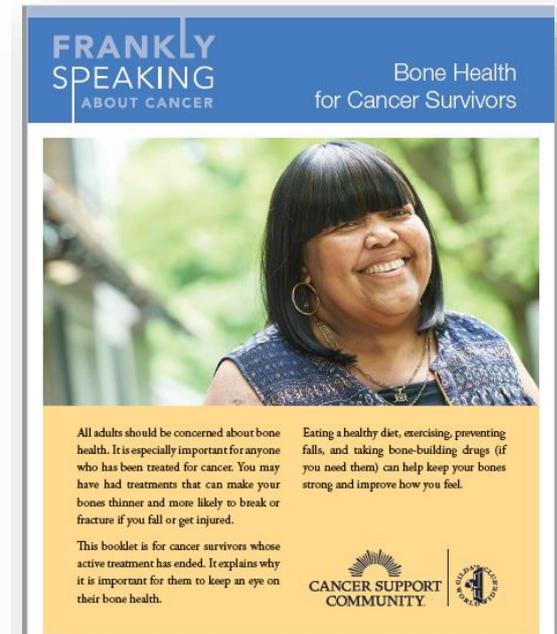
# Methods

Participants in each focus group reviewed each booklet and gave feedback about:

1. Ease of understanding
2. Reactions to specific sections and content in the books
3. Suggestions for improvement

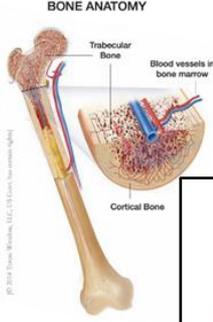
# Main Findings: *FSAC Bone Health for Cancer Survivors*

- Most participants have not previously seen a booklet that is dedicated to bone health and found the content to be new information.
- Highlighted that this booklet raises awareness about bone health for those out of active treatment.
- Influenced some participants to ask about bone health and bone density testing.



# Main Findings cont.

- Participants liked pictures of actual, diverse survivors
- Participants want actionable content
  - Who, specifically, is most at risk based on what treatment?
  - How often to get bone checks?
  - Be as specific as possible on dietary recommendations – foods & how much
- Unaware of risk to male survivors
- Exercise component
- List of preventative steps
- Visuals helped increase awareness and knowledge



**BONE ANATOMY**

Trabecular Bone  
Blood vessels in bone marrow  
Cortical Bone

**What is Bone?**

You probably don't spend much time thinking about your bones. They pretty much do what you expect them to do—until they don't, like when you break a bone. But there is a lot going on inside them. Bone is living, growing tissue, made up of proteins and minerals. Your bones have two layers. The outer layer, called cortical bone, is very thick. The inner layer—the trabecular (*trab-BEH-kyoo-lar*) bone—is very spongy. Inside the spongy bone is your bone marrow. It contains stem cells that can develop into white blood cells.

**RESOURCES ON BONE CANCER**

Cancer can start in the bone or the blood that circulates in the bones. You can learn more on the CSC website at [www.CancerSupportCommunity.org/](http://www.CancerSupportCommunity.org/). Cancer can spread to the bones from "bone metastases" or "bone mets." It's about bone metastases in our booklet, "About Bone Metastases in our booklet," available on the CSC website at [www.CancerSupportCommunity.org/](http://www.CancerSupportCommunity.org/).



**GETTING STARTED**

- **Low Fitness:** Walk for 10 minutes in your neighborhood or a mall. Set a pace where you can talk easily while walking.
- **Medium Fitness:** Walk at a brisk pace, increasing time by 5 minutes every day or two. Use music with a good beat to increase speed and time.
- **High Fitness:** Add resistance workouts, power-walk, jog, bike, or swim. Work on increasing distance, time, and speed.

**EXERCISE FOR BONE HEALTH**

Exercise is a key part of a healthy lifestyle that helps maintain bone density. Exercise improves balance, which makes you less likely to fall. It lowers your risk of heart disease.



**PROSTATE CANCER & OSTEOPOROSIS**

Androgen deprivation therapy (also known as hormone therapy or androgen suppression therapy) is used to treat prostate cancer. It reduces the testosterone that helps the cancer grow. But it also slows bone production. Surgery to remove both testicles (orchiectomy) has the same effect. The most rapid bone loss often occurs during the first 12 months of treatment. If you received these treatments, you should:

- Have bone tests every two years.
- Take calcium and vitamin D supplements.
- Talk to your doctor about taking a bone building drug if your T-score is below -2.5.
- Be treated, when necessary, with denosumab (Prolia), zoledronate (Reclast, Zometa), or alendronate (Fosamax).

Here are some tips that can help you get started:

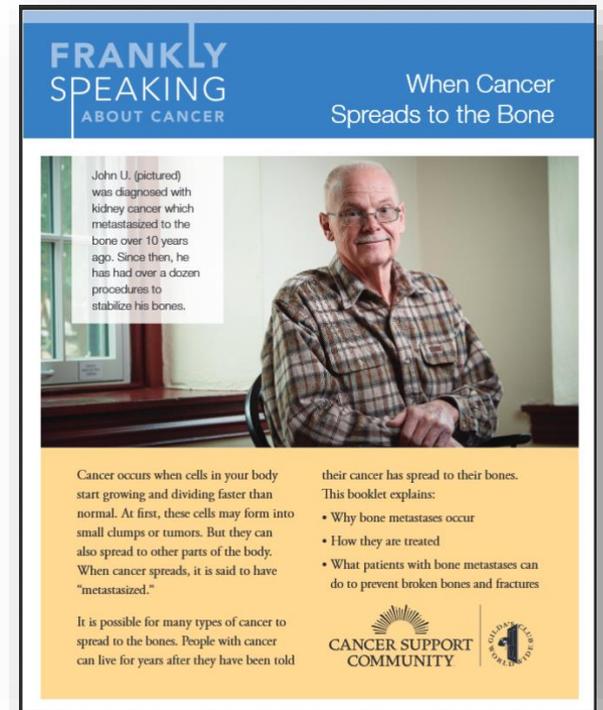
- Try to build up to exercising 30 minutes each day.
- Find things that feel good and safe to you—walking with friends, gardening, swimming, or gentle yoga. It doesn't have to be strenuous to be exercise.
- Try to add in some resistance exercises. These exercises build muscle strength, which helps support your bones. They can also help with balance, which can help prevent falls. Examples include lifting weights and stretching with exercise bands.
- When you feel sick, exercise only as much or as strenuously as you feel comfortable.
- Allow yourself to exercise gently, slowly, and for short amounts of time.

**QUESTIONS TO ASK YOUR HEALTH CARE TEAM**

- Am I at risk for osteopenia or osteoporosis? Why or why not? \_\_\_\_\_
- Should I have a bone density test? \_\_\_\_\_
- What are some things I can do on my own to take care of my bones to make sure they stay healthy? \_\_\_\_\_
- Are you recommending bone-building drugs? Why or why not? \_\_\_\_\_

# Main Findings: *FSAC When Cancer Spreads to the Bone*

- Participants emphasized the need of educational resources aimed at patients with metastatic bone cancer.
- Participants view this tool as a way to empower patients to become active partners in their care.



# Main Findings cont.

- Visuals and lists were informative, helpful, and comprehensive
- Additional testing was requested to be added to section of Bone metastases
- Clinical trials section aligned with patient knowledge
- Managing pain was important and was expanded to include palliative care
- Health tips & prevention sections were helpful, with some additions recommended to the list.
- Stories were relatable and gave hope.

- **Orthopedic fixation.** Using metal plates, screws, and nails to stabilize bones that have become weak or are at risk of breaking.
- **Bone cement to stabilize bones.** The cement is injected into a bone that is broken or has been damaged by the bone metastases. This procedure can also help reduce pain.
- **Repairing broken bone** with metal plates, screws, and nails.
- **Joint replacement** to repair a broken bone or to reduce bone/joint pain.

#### TREATMENT WITHIN A CLINICAL TRIAL:

Clinical trials are research studies with patients. Their goal is to find better ways to treat cancers. Often, the most promising treatments are only available through clinical trials. Many people with bone metastases participate in a clinical trial.

#### KEY THINGS TO KNOW

- People who receive their treatment
- No one receives a placebo or
- People who join clinical trials
- There are laws to protect the
- Some clinical trials may require at major cancer centers.
- Not all costs may be covered by insurance coverage.

Be sure to ask your doctor about for everyone. There are rules about

#### Managing Bone Pain

Bone metastases can be very painful. Your treatment may help to reduce your pain, but it may not get rid of it completely. You may also need other medicine or treatments for the pain itself. If you have bone pain, tell your health care team. You can ask about:

- **Getting a referral to a pain specialist or a palliative (PA-lee-uh-tee) care specialist.** Palliative (or supportive) care is used to treat pain or other symptoms caused by cancer and its treatments. *Palliative care is not the same thing as hospice care, which is end-of-life care. You can ask for a referral to a palliative care specialist at any point during your cancer treatment.*

#### AMANDA B.

Four years after completing treatment for early-stage breast cancer, Amanda learned her cancer had returned and spread to her liver, ovaries, spine and pelvis.

She started on chemotherapy to shrink the tumors in her organs and had radiation therapy to treat the metastasis on her spine. She also started taking Zometa® to strengthen her bones. Slowly the tumors shrink.

Every year, she says something new pops up. But that hasn't kept Amanda from being active. She runs a CSCC affiliate, and appreciates the opportunity to help others.



#### PROSTATE CANCER IS ONE OF THE MOST COMMON CANCERS TO SPREAD TO THE BONE.

- About 12 of every 100 men will be diagnosed with prostate cancer at some point in their lives.
- Out of 100 men diagnosed with prostate cancer, about 5 will be told at diagnosis that it has spread to the bones and about 20 more will be diagnosed with bone mets in the next 5 years.

The most common symptoms felt by men with prostate cancer that has spread to the bone are fatigue and pain or aches.

Your health care team can do a lot to relieve pain. However, men with bone metastases may be unlikely to tell their health care team about their pain. Be sure to regularly tell your care team about your level of pain, especially if it keeps you from doing normal activities, makes it hard to sleep, or causes you anxiety or stress.



# Conclusions

- Following feedback, we revised the booklets to reflect participants' input, which focused on clear and actionable steps patients can take to maintain bone health.
- Cancer survivors and caregivers were very receptive to the use of CSC's FSAC Bone Health booklets for purposes of patient education.
- Our results supported the utility of seeking patient feedback on bone health educational materials. Booklets are available through CSC and Gilda's Club affiliates, program partners, and [CancerSupportCommunity.org](https://CancerSupportCommunity.org).

# THANK YOU!

For More Information, contact Alex Swales at  
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