

The Good, The Bad, and The Ugly

Living with Metastatic Cancer

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My Story

Postpartum

Diagnosed with breast cancer — took my doctor's hand at the delivery table

4 Years Later

Subtle signs missed: weight loss, fatigue, stomach bug that wouldn't go away

The Call

Voicemail messages at the border. The Olive Garden. Life changed.

Stage 4

Cancer had spread to my liver. An out-of-body experience. No one had prepared me.

23 Years Later

I am not a doctor. I am not a researcher.

I am a patient, a mother, a wife, a friend, and an advocate.

I have sat in every single chair you may be sitting in right now.

This is a patient-to-patient conversation.

**"I am not here to inspire you.
I am here to be honest with you."**

The Stages of Grief Are Real

Disbelief & Denial

"There must be a
mistake..."

Anger

Sometimes at your
own body — the
deepest betrayal

Bargaining

"If I try this...
maybe I can fix it."

Depression

Not always crying.
Sometimes just going
through the motions.

Acceptance

Finding a way to live
alongside it.

Grief is not linear. You may cycle through more than once. That is not failure — that is human.

The Feelings Nobody Talks About

Fear

3am fear — dying, your kids, being a burden, the next scan

Isolation

A loneliness only cancer patients truly understand

Guilt

For being sick. For doing well when others aren't.

Jealousy

Of people without cancer, of better prognoses — then guilt about that

Anticipatory Grief

Grieving things that haven't happened yet

Rage

You are allowed righteous anger. Every single day.

You do not have to be brave every single day.

Things People Say (They Mean Well. Really.)

"Everything happens for a reason."

"Have you tried turmeric?"

"At least it's a good cancer."

"God doesn't give you more than you can handle."

"My cousin had cancer and she..."

"You look great for someone who's sick!"

Give them grace — and give yourself permission to limit the conversation.

How Relationships Change



Your Partner / Spouse

Caregiver, companion, and grieving person — all at once. Roles and intimacy change. Honest conversation and a good therapist help.



Your Children

Keep things normal. Tell them what they need to know. They are always picking up more than you think.



Friends

Some disappear. Unexpected people become the most important. Cancer sorts people.



Your Support Circle

Mom moved in. Daughters stepped up. Let people show up — and let them see you need them.

You Get to Decide.

● **How much information**

Everything — or just next steps, not statistics. Both are valid.

● **Which treatments to pursue**

A good oncologist presents options and respects your choice.

● **What you share and with whom**

Your diagnosis is yours. Public, private, or selective.

● **How you spend your energy**

Protect it. You don't have to educate everyone.

This disease takes so much. But it cannot take all of you unless you let it.

How to Prepare for Appointments

1

Bring someone with you

Two sets of ears. They take notes while you absorb.

2

Write questions down — ranked

Most important first, in case you run out of time.

3

Record the conversation

Many doctors welcome it. Listen again when you're calmer.

4

Ask for plain-English explanations

"Can you explain that without the medical language?"

5

Ask the question that changes things

"What would you recommend if this were your wife? Your daughter?"

Why I Said Yes to a Clinical Trial

My Story — 2004

Phase 1 vaccine clinical trial — Cancer Vaccine Institute, University of Washington with Dr. Nora Disis, who was and still is doing incredible work.

**20 participants. I was the third to receive the vaccine.
10 of us are still alive — 23 years later.**

In 2018 — 14 years later — I received a booster dose from that same trial.

"I didn't know if it would help me. But I knew it might help someone. And that was enough."

Clinical Trials — The Practical Questions

Why consider a trial?

- ✓ Access to treatments not yet available elsewhere
- ✓ Close monitoring — extra attention
- ✓ Contribute to science that helps those who come after
- ✓ Some trials cover treatment costs
- ✓ Your oncologist remains your primary doctor

Ask before you enroll:

Who pays for travel?

Some trials cover it. Cancer Care & Patient Advocate Foundation have travel funds.

What does insurance cover?

Call your insurer first. Get it in writing. Your social worker can help.

Should I travel for a trial?

Sometimes yes. Discuss benefit vs. disruption with your oncologist and family.

Your Team is Bigger Than Your Oncologist

Mental Health

Role-played conversations with my kids. Not weakness — wisdom.
Ask your care team for a referral.

Social Work

Free for ALL Fred Hutch patients. Emotional support, insurance, community resources. Ask any care team member.

Palliative Care

NOT hospice. NOT end-of-life. Available at any stage alongside treatment — manages symptoms, supports decisions, helps plan.
Ask your oncologist early.

Integrative Medicine

Acupuncture, nutrition, mind-body. Complements — not replaces — oncology care. See resource sheet.

Palliative care is NOT hospice. It is available from day one, alongside your treatment.

How to Let People Help You

People want to help. Give them something specific to do.

"I would love to go for a walk with you. Can we plan that for next week?"

"Could you pick my children up from school on Tuesday and Wednesday? I have chemo those days."

"I'm putting together a meal train — I'll send you the link."

"Could you just come sit with me? Not to talk about cancer. Just to be there."

"I have an appointment Thursday and I'm not supposed to drive. Could you take me?"

Specific. Concrete. Actionable.

Appoint a Gatekeeper.

One trusted person who:

- › Fields calls, texts, and questions on your behalf
- › Gives updates to people who love you
- › Politely keeps well-meaning people at a distance when you need space
- › Knows exactly what you need — so they can tell others

Write once. Reach everyone.

CaringBridge.org • LotsaHelpingHands.com • MealTrain.com

Post when you want to. Go quiet when you need to. Protect your energy.

What's Available at Fred Hutch

MBC Support Group

1st Thursday monthly, 4–5:15pm via Zoom

See resource sheet

Patient Navigators

Remove barriers to care. Free.

See resource sheet

Spiritual Health

All faiths and no faith. Trained to be present.

See resource sheet

Patient & Family Resource Ctr

Sloan Clinic, 3rd floor. Materials, wig fittings, notary.

See resource sheet

750+ Clinical Trials

More than any other Pacific NW center.

See resource sheet

Expressive Arts & Integrative Med

Journaling, acupuncture, nutrition, mind-body.

See resource sheet

MET-X Center

Center for Metastasis Research Excellence

What They Are Researching:

- ✦ How dormant cancer cells 'wake up' and create metastatic tumors
- ✦ Earlier detection and prevention of metastatic progression
- ✦ New treatments — and ultimately cures — for Stage 4 solid tumor cancers

Led by Dr. Cyrus Ghajar | Launched 2023 | Fred Hutch Cancer Center

Only ~2–5% of breast cancer research funding has historically gone to metastatic disease. That is changing.

Additional Resources Worth Knowing

Metastatic Breast Cancer

METAvivor

metavivor.org

Only org focused solely on MBC research & advocacy

Male Breast Cancer Global Alliance

mbcglobalalliance.org

Men with breast cancer — advocacy, research, support

Other Metastatic Cancers

GO2 Foundation

go2.org

Lung cancer support & advocacy

PanCAN

pancan.org

Pancreatic Cancer Action Network

Colorectal Cancer Alliance

ccalliance.org

Colorectal cancer education & support

National Brain Tumor Society

braintumor.org

Brain cancer research & advocacy

For Everyone

Cancer Care

cancercares.org

Free counseling, support groups, financial assistance

Patient Advocate Foundation

patientadvocate.org

Insurance navigation, financial help, trial travel

ClinicalTrials.gov

clinicaltrials.gov

Search all active trials

What Living with This Actually Looks Like

What 23 years has taught me:

- ◆ Scanxiety never fully goes away — but you learn to sit with it
- ◆ Focus on the present. Authentic relationships. What actually matters.
- ◆ You find your people in waiting rooms and infusion centers
- ◆ Joy does not require good health
- ◆ Asking for help is not weakness — even if it's still hard

"Living with metastatic cancer is hard.
It is frightening. It is not fair.

And it is also a life —
a full, real, and meaningful life."

You Are More Than Your Diagnosis.

- ✦ You do not have to be brave every single day
- ✦ You do not have to inspire anyone
- ✦ Keep going — one appointment, one scan, one day at a time
- ✦ Let the people who love you walk alongside you

Q & A

Questions & Discussion

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