

Screening Misconceptions and Fear of Recurrence

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What This Talk is — and is Not

What it is Not

- Telling clinicians which guideline to follow.
- Providing individualized medical advice.
- Replacing radiology, oncology, genetics, or primary care judgment.

The Center

- How fear changes attention and decisions.
- How uncertainty fuels avoidance.
- How communication can reduce threat and increase follow-through.

The Bridge

- Know enough guidelines to reduce confusion
- Clarify risk lane.
- Help the patient reach the right clinical decision-maker.

Fear is Not Refusal

Many people delay screening because they are trying to manage fear, not because they do not care.



Anxiety says:

“Avoid this and you will feel better.”

Healthcare says:

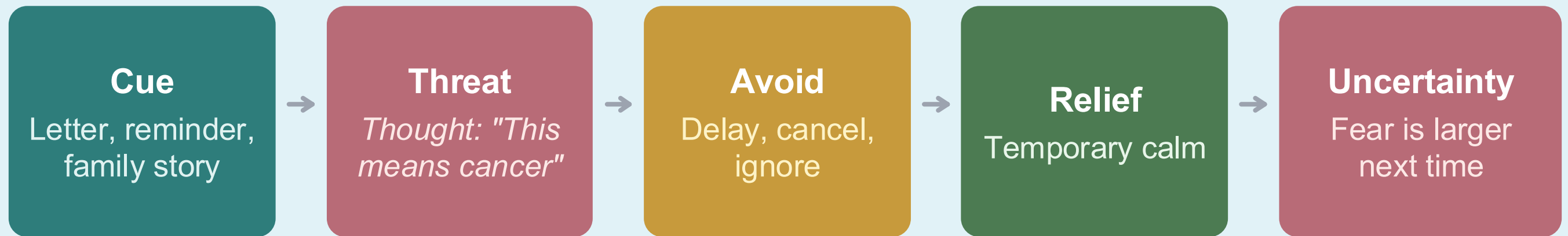
“Come back and face uncertainty again.”

The task:

Help people feel respected, prepared, and supported to return—even when fear is present.

The Screening Anxiety Loop

Avoidance works in the short term but grows fear over time.



Interrupt with clarity

What is the next step?

Interrupt with support

Who helps me do it?

Interrupt with agency

What choice do I still have?

What is The Fear Made of?

Do not assume “fear of breast cancer” means one thing.

Pain or discomfort

“I heard it hurts.”

Bad news

“What if they find cancer?”

Follow-up burden

“I want to. I just can’t get there.”

Guideline confusion

“My doctor said I do not need it.”

Family stories

“I saw my grandmother suffer.”

Recurrence fear

“What if they find cancer again?”

Start with curiosity, not persuasion.

Guideline Changes Created Real Confusion

Sept. 2002 USPSTF

Mammography
every 1–2 years
for women age
40+

Nov. 2009 USPSTF

Individualized
40–49; biennial
screening for
ages 50–74

Oct. 2015 ACS

Optional ages
40–44; annual
45–54; biennial
55+

Jan. 2016 USPSTF

Reaffirmed
individualized
decision 40–49;
biennial 50–74

Apr 2024 USPSTF

Universal
biennial
screening
mammography
ages 40–74

Uncertainty is a threat cue — for patients and providers.

Conflicting advice over two decades of shifting starting age recommendations creates anxiety and confusion.

How Can Non-Medical Professionals Reference Guidelines Safely?

Do not debate the mammogram. Reduce uncertainty and route the patient appropriately.

Common ground

Major U.S. groups now begin screening at 40.

Do not overstep

Avoid individualized advice or debating guidelines.

Do bridge

Encourage clear conversations with their clinical team.



Your role: make the next clinical conversation easier to have.

Different Fears Need Different Pathways

A one-size-fits-all script can increase anxiety.

Average risk

Fear

Pain, bad news, cost, callbacks

Need

Clear screening plan + normalizing
what happens next

Team

PCP, screening site, navigator



Different Fears Need Different Pathways

A one-size-fits-all script can increase anxiety.

Elevated risk

Fear

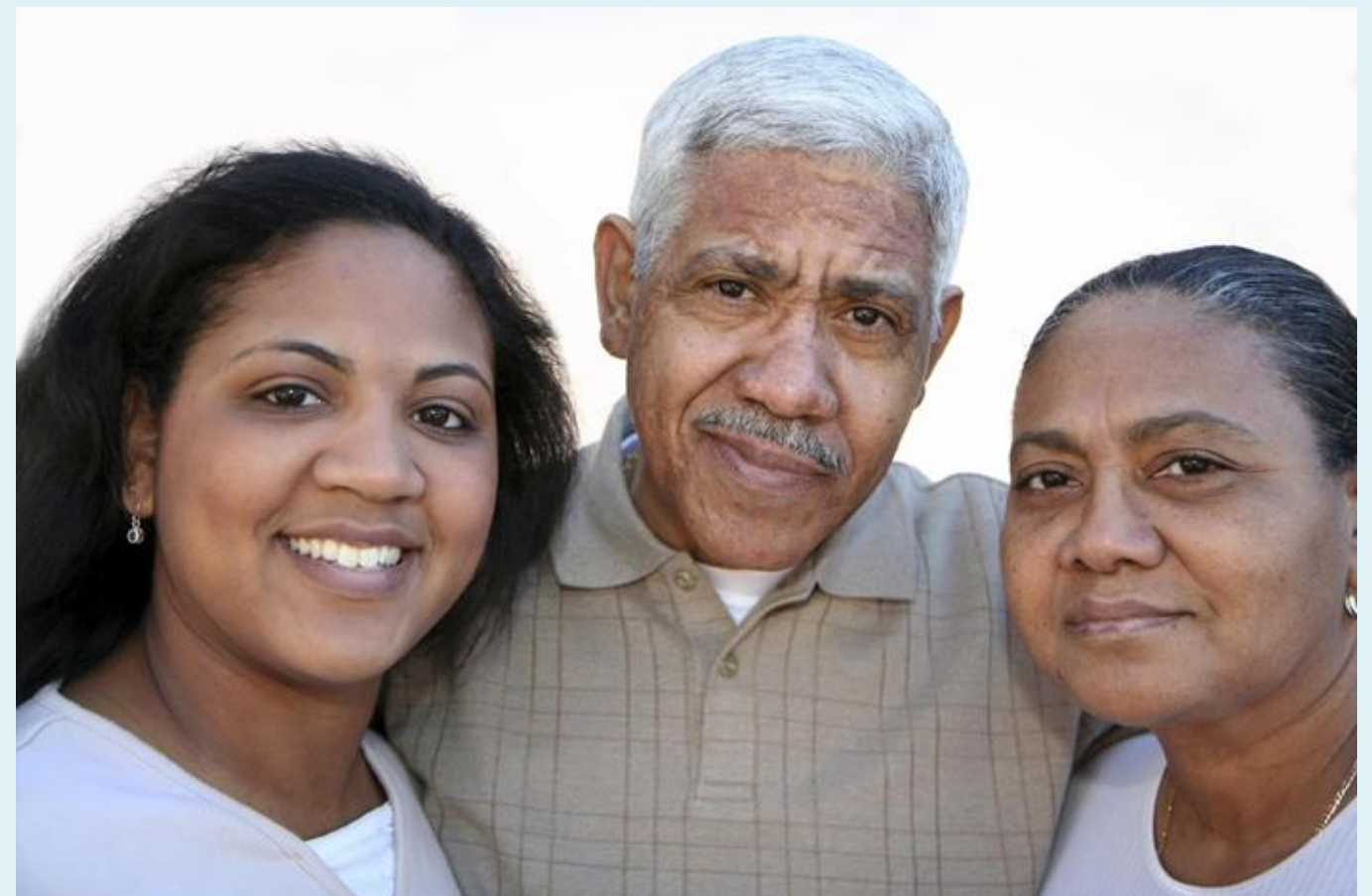
“My family history means I am doomed.”

Need

Structured risk assessment +
genetics/radiology referral

Team

PCP, genetics, radiology,
navigator



Different Fears Need Different Pathways

A one-size-fits-all script can increase anxiety.

Survivor surveillance

Fear

Recurrence, scan anxiety, body cues

Need

Surveillance plan + coping plan for triggers

Team

Oncology, primary care, behavioral health



Fatalism is Often Learned Uncertainty

Hear the layers UNDERLYING BARRIERS

- **Family experience** with cancer
- **Transportation** and time costs
- **Mistrust** or past dismissal
- **Fear of finding** something unaffordable

Less helpful

The Statement

"What can I do about it anyway?"

The Dismissal

"Don't think that way."

More helpful

VALIDATE & PARTNER

The Stance

"It makes sense that you feel powerless. Let's figure out what would make the next step possible and who can help with it."

***"What can I do anyway?"* may be a meaning-making response to access barriers and family stories.**

The Stance: Validate, Orient, Offer Agency



Fear decreases when people feel seen and know what happens next.

Avoid the reassurance trap

"You'll be fine" can shut the conversation down.

"Most callbacks are not cancer, and we will help you through the next step" gives information plus support.

VALIDATE: *"That fear makes sense."*

ORIENT: *"Here is what this test can and cannot tell us."*

ASK: *"What part worries you most?"*

PLAN: *"What would make this doable?"*

FOLLOW: *"Who will call you and when?"*

When The Fear is Pain or The Procedure Itself

Preparation is often more helpful than reassurance alone.

What to ask

QUESTIONS TO EXPLORE

“What have you heard?”

“Have you had a painful mammogram before?”

“What helped you get through other medical tests?”



When The Fear is Pain or The Procedure Itself

Preparation is often more helpful than reassurance alone.



What to say GUIDANCE TO SHARE

“Some pressure is expected.”

“You can tell the technologist you are anxious.”

“Ask what will happen before each step.”

When The Fear is Pain or The Procedure Itself

Preparation is often more helpful than reassurance alone.

What to plan PRACTICAL STEPS

Schedule when less rushed

Bring a support person if allowed

Use slow breathing and grounding

Plan a reward afterward



When The Fear is “What if They Find Something?”

Callback anxiety is one of the moments when follow-through can break down.

NAVIGATOR CHECKLIST

Action steps for follow-through

Is the diagnostic appointment scheduled?

Does the patient know what the test is for?

Are transportation/cost barriers addressed?

Is there a plan for result communication?

A callback is not a diagnosis.

It is a request for more information.

SCRIPT FOR NAVIGATORS

“It is understandable that your mind goes straight to cancer. The next step is to get a clearer picture. Let’s make sure you know who is calling, what test is next, and when you should hear back.”

Dense Breasts And Hereditary Risk Need Careful Language

The wrong message can create panic; the right message creates a pathway.

SUPPORT TASK

Dense Breasts

“Dense breasts are common. Mammograms are still important. Extra imaging may help some people, but it can also increase false positives. This is a risk conversation, not a reason to panic.”

Reduce catastrophic interpretation

Support the risk-assessment conversation

Help the patient prepare questions

Keep uncertainty tolerable while referrals happen

GENETIC RISK COUNSEL

Family History

“Family history does not mean you are doomed. It means we should ask structured questions and decide whether genetics or high-risk screening is appropriate.”

Assess Inherited Risk Factors

Use pedigree mapping and clear patient scripts to guide family risk exploration.

Fear of Recurrence: Surveillance as Repeated Uncertainty

After breast cancer, screening may feel like returning to the scene of the trauma.

SURVEILLANCE Common triggers

- Mammogram or MRI appointment
- Aches, scars, swelling, fatigue
- Anniversaries and follow-up visits
- Stories of other recurrences

EXPECTED REACTION Normal fear

- Comes and goes
- Responds to information and support
- Does not dominate daily life
- Patient still attends follow-up

CLINICAL ATTENTION Concerning fear

- Persistent checking or avoidance
- Repeated reassurance seeking
- Panic before surveillance
- Sleep, work, relationships impaired

A Practical Coping Plan For Screening or Surveillance

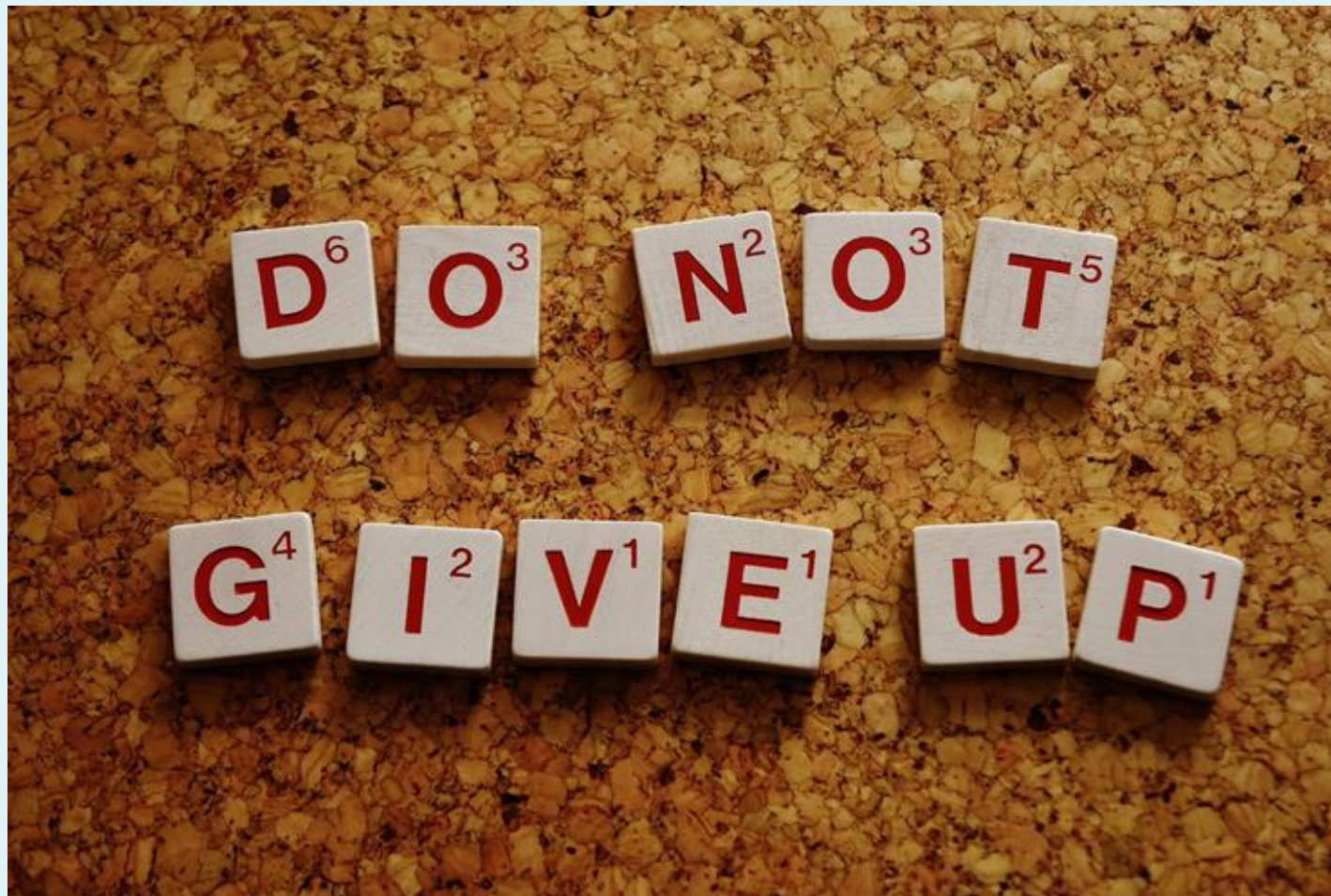


Preparation Before

- Write two or three questions
- Choose support person
- Plan transportation/time
- Name the fear out loud

A Practical Coping Plan For Screening or Surveillance

Coping is not “calming down” coping is making the next step doable.



Coping in Action During

- Tell staff you are anxious
- Ask for each step before it happens
- Use slow exhale breathing to calm your nervous system
- Grounding Exercise (Identify three things you can see, hear, and feel)

A Practical Coping Plan For Screening or Surveillance

FOLLOW-UP **After**

- Know when results are expected
- Limit repeated portal checking
- Plan a normalizing activity
- Call if no result by agreed time



How Family And Friends Can Help

Support should be practical, calm, and chosen by the patient.

Before Preparation

- Ask what would actually help
- Offer ride, childcare, or scheduling help
- Help write two or three questions
- Make a comfort plan together



How Family And Friends Can Help



APPOINTMENT DAY Support on-site

- Reduce logistics stress
- Sit nearby if invited
- Remind them they can tell staff they are anxious
- Support pausing, breathing, and asking questions

How Family And Friends Can Help



WAITING FOR RESULTS

Follow-up

- Know when results are expected
- Plan one check-in, not constant reassurance
- Encourage follow-up if no result
- Do something normal afterward

What Helps - And What Usually Backfires

Anxiety responds better to validation + agency than pressure or forced optimism.

TRY INSTEAD

Validation & Agency

- “It makes sense this feels scary. What part is hardest?”
- “What would make the next step doable?”
- “Would hearing stories help, or would that make it worse?”
- “Avoiding helps short-term. You deserve support getting through it.”
- “Surveillance can bring fear back. I’m here for this appointment too.”

USUALLY BACKFIRES

Pressure & Forced Optimism

- “Don’t worry. You’ll be fine.”
- “You have to do this.”
- “My aunt had breast cancer, and...”
- “If you ignore it, it won’t go away.”
- “You’re cancer-free — move on.”

**Family and friends are not responsible for convincing
— they help reduce fear, friction, and isolation.**

A Fear-Informed Workflow For Professionals

Make fear visible and make follow-through trackable.

STEP 01

Name the fear

- Pain
- Result
- Cost
- Recurrence
- Family story

STEP 02

Clarify risk

- Average risk
- Elevated risk
- Survivor surveillance

STEP 03

Identify barrier

- Transport
- Scheduling
- Childcare
- Coverage
- Trust

STEP 04

Next step

- Appointment
- Referral
- Questions
- Navigator handoff

STEP 05

Close loop

- Result
- Diagnostic follow-up
- Return screening plan

When Fear Needs More Than Education

Education helps normal uncertainty; treatment helps fear that is impairing or self-maintaining.

CONSIDER BEHAVIORAL HEALTH REFERRAL

When fear causes...

- Repeated cancellations or no-shows
- Panic symptoms before appointments
- Compulsive checking or reassurance seeking
- Sleep, work, relationship impairment
- Trauma reactions related to prior cancer care

TREATMENT FOCUS

Therapy may focus on...

- Uncertainty tolerance
- Exposure to avoided care tasks
- Cognitive restructuring of catastrophic thoughts
- Values-based action despite fear
- Coordination with oncology/primary care

WV Breast And Cervical Cancer Screening Program



EARLY DETECTION SAVES LIVES

Regular screenings are the most reliable way to detect breast and cervical cancers in their earliest, most treatable stages.

OUR MISSION

West Virginia Breast & Cervical Cancer Screening Program

To prevent unnecessary disease, disability, and premature death due to cancer of the breast and/or cervix.

LEARN MORE & ACCESS SERVICES

dhhr.wv.gov/bccsp

WV BCCSP Can Reduce Cost Barriers



COVERAGE BASICS

What BCCSP covers

- Breast screening for eligible WV residents
- Diagnostic follow-up when more testing is needed
- Patient navigation and referral/enrollment support

MRI ELIGIBILITY

MRI when eligible

- Reimbursement for screening breast MRI for high-risk clients and diagnostic MRI if indicated
- Requires program approval and preauthorization
- For those who are unable to have a screening MRI but require further screening, whole breast ultrasound is an appropriate option

MEDICAID PATHWAYS

If cancer is found

- Breast & Cervical Cancer Medicaid is available for eligible participants
- Applies to breast and cervical cancer
- Route early so cost fear does not stop clinical follow-up

QUICK ROUTING MESSAGE

“There may be a WV program that can help pay. Let’s check eligibility before cost becomes another reason to delay.”

WV BCCSP Contact: 1-800-642-8522 | 304-558-5388 | dhhr.wv.gov/bccsp

The Goal is Not Fearlessness



The goal is supported follow-through. People can be scared and still be supported into care.

For patients

You do not have to do this alone.

A compassionate navigation network ensures every individual has active guidance.

We focus on breaking down isolation during moments of vulnerability.

For professionals

Fear is clinical information.

Recognizing patient anxiety as a vital indicator helps clinicians tailor communication.

By doing so, we build deep trust and address critical barriers to medical adherence.

For systems

Navigation is anxiety care.

Replace dread with a plan.

Systems must build reliable pathways that transform abstract medical worry into structured, predictable, and reassuring steps.

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