









It can't be me The reluctant cancer patient

Nancy Franke Wilson

Who am I?

- Master of Science, Health Science and Public Administration
- Consultant; communications, policy, project management, etc
- Plant-based eater
- Yogi
- Wine student
- Tea geek
- Advocate
- Wife, mother, sister, aunt, cousin, friend, volunteer
- Executive Director, MOHC

Minnesota Oral Health Coalition



Our Mission

To strengthen Minnesota's oral health community through partnerships, resources, and outreach.

Our Vision Optimal oral health for all Minnesotans.

The Minnesota Oral Health Coalition is made possible by a grant from the Delta Dental of Minnesota Foundation.















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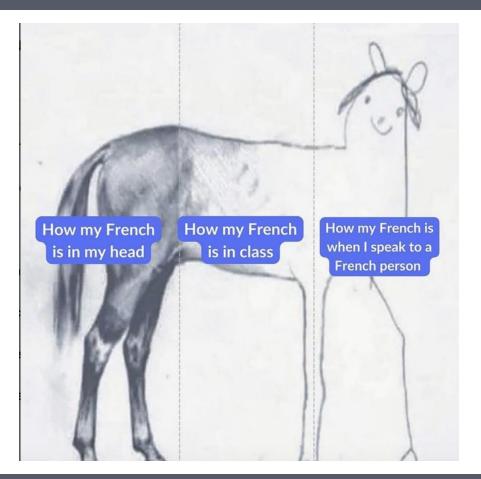
VOLUNTEERING HELPS ME MAKE A DIFFERENCE FOR ANIMALS BECAUSE I CAN BE A FRIENDLY FACE WELCOMING PEOPLE TO TRY PLANT BASED, COMPASSIONATE LIVING LOVE THE PEOPLE AND WHAT THE ORGANIZATION STANDS FOR. IN A WORLD OF INTOLERANCE AND **MEANNESS, CAA IS** ACCEPTING AND NONJUDGEMENTAL TOWARD **ALL LIVING BEINGS. WE JUST** HAVE FUN!

Nancy Franke Wilson,











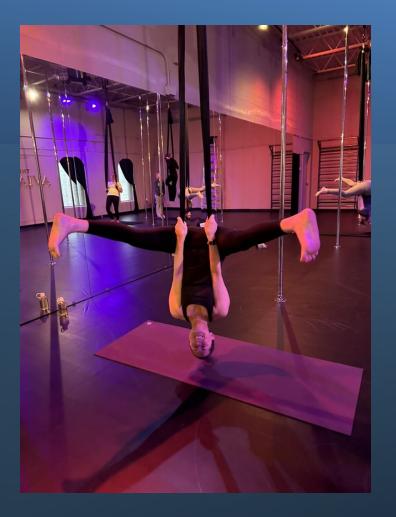


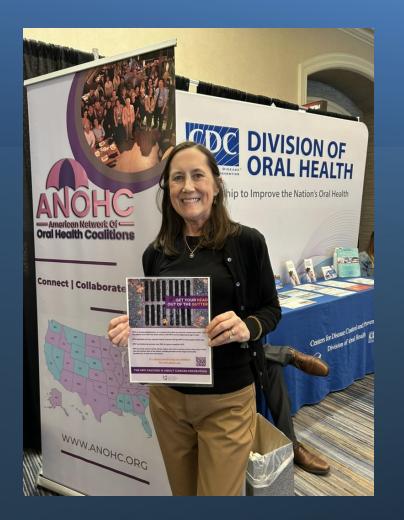




Exit 🕀

Thank you for visiting. Safe journey home!







"Your problem is how you are going to spend this one and precious life you have been issued. Whether you're going to spend it trying to look good and creating the illusion that you have power over circumstances, or whether you are going to taste it, enjoy it and find out the truth about who you are."

Anne Lamott



The Reluctant Cancer Patient

- HPV-related
- Squamous cell carcinoma p16+
- or -
- Cancer of the Oropharnix (p16 [HPV]-positive)
- Jugulodigastric
- Head & neck cancer

HPV and Oropharyngeal Cancer

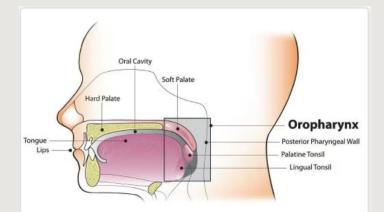


Diagram of the oral cavity and oropharynx. The oral cavity includes the lips, the labial and buccal mucosa, the front two-thirds of the tongue, the retromolar pad, the floor of the mouth, the gingiva, and the hard palate. The oropharynx includes the palatine and lingual tonsils, the back one-third base of the tongue, the soft palate, and the posterior pharyngeal wall.



Symptoms of Oropharyngeal Cancer

- long-lasting sore throat
- earaches
- hoarseness
- swollen lymph nodes
- pain when swallowing
- unexplained weight loss
- some people have no symptoms

What Is HPV?

- HPV is the most common STI
- Oral HPV is transmitted to the mouth by oral sex, or possibly in other ways.
- Sexual transmission is the most documented, but there have been studies suggesting non-sexual courses. The horizontal transfer of HPV includes fomites, fingers, and mouth, skin contact (other than sexual).
- More than 90 percent of sexually active men and 80 percent of sexually active women will be infected with HPV in their lifetime.

How do I know if I have HPV?

- There is no test to find out a person's "HPV status"
- Also, there is no approved HPV test to find HPV in the mouth or throat
- There are HPV tests that can screen for cervical cancer (pap smear)
- CDC estimates that there were 43 million HPV infections in 2018. In that same year, there were 13 million new infections.

How long does it take for HPV to turn into cancer?

- Research has found that it can take 5 to 10 years for HPVinfected cervical cells to develop into precancers and about 20 years to develop into cancer.
- HPV is so common that almost every sexually active person will get HPV at some point if they don't get vaccinated.

2024 Cancer Care Conference

HPV and Cancer

- HPV can cause cervical and other cancers, including cancer of the vulva, vagina, penis, or anus.
- HPV can infect the mouth and throat and cause cancers of the oropharynx (back of the throat, including the base of the tongue and tonsils). This is called oropharyngeal cancer.
- HPV is thought to cause 70% of oropharyngeal cancers in the United States.



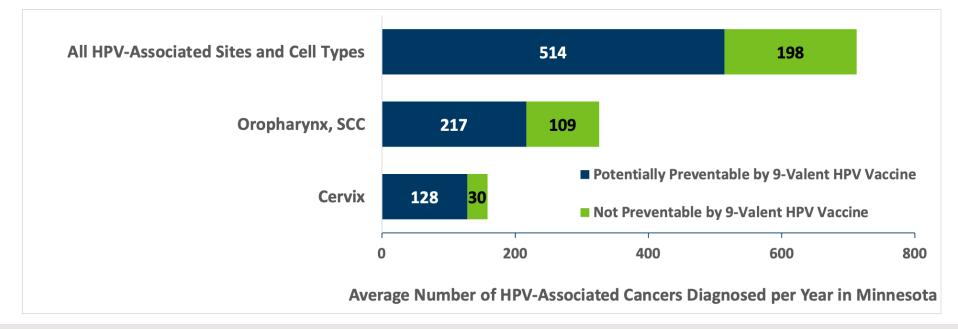
HPV Vaccination

- HPV vaccine is recommended for routine vaccination at age 11 or 12 years. (Vaccination can be started at age 9.)
- ACIP also recommends vaccination for everyone through age 26 years if not adequately vaccinated when younger.
- HPV vaccination is given as a series of either two or three doses, depending on age at initial vaccination.
- For adults ages 27 through 45 years, clinicians can consider discussing HPV vaccination with people who are most likely to benefit.

HPV Vaccination and Cancer

- The HPV vaccine was developed to prevent cervical and other cancers of the reproductive system.
- The vaccine protects against the types of HPV that can cause oropharyngeal cancers, so it may also prevent oropharyngeal cancers.
- HPV vaccination can prevent over 90% of cancers caused by HPV, as well as anal, vaginal, cervical, and vulvar precancers (abnormal cells that can lead to cancer).

Estimated annual number of HPV-associated cancers of the oropharynx and cervix prevented by Gardasil 9 vaccination, Minnesota 2015-2019



Screenings for Head & Neck Cancers

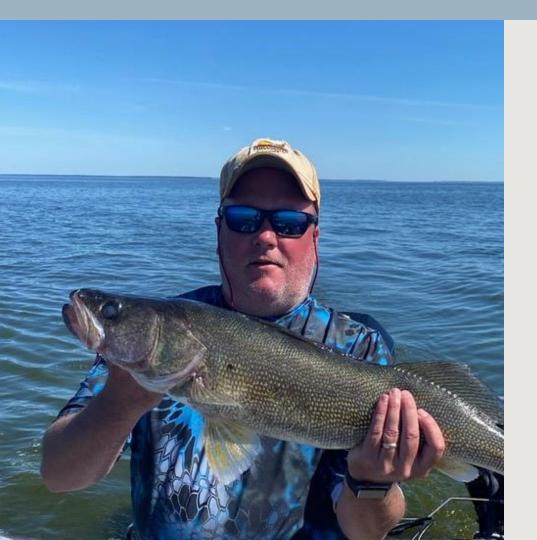
- Currently, there are no screening tests that work well to find head and neck cancer.
- A screening physical exam is part of a regular dental exam. It checks your neck, mouth, and oropharynx.
- The oropharynx is the middle section of your throat, including your soft palate, base of your tongue, and tonsils

Treatment

- Surgery
- Radiation
- Chemotherapy
- Targeted medicines and immunotherapy

My story





My husband retired March 31, 2023

April 16 - 19, 2023



National Oral Health Conference

THE PREMIER MEETING FOR DENTAL PUBLIC HEALTH

April 19, 2023

I saw my General Practitioner



My 60th birthday in Paso Robles, CA

April 26 - May1, 2023



May 6, 2023 Birthday dinner with friends



Then things moved quickly

- May 15, 2023 saw 1st ENT
- May 23, 2023 needle biopsy and CT scan
- May 25, 2023 saw 2nd ENT
- June 1, 2023 surgery to remove lymph node

The diagnosis



The "C" word

• HPV-related sqamous cell carcinoma p16+

- or -

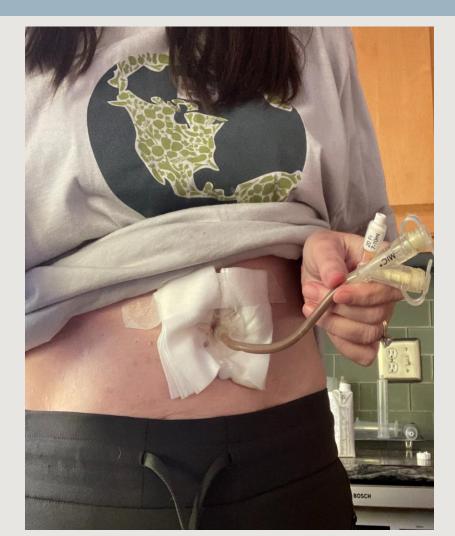
• Cancer of the Oropharnix (p16 [HPV]-positive)

2nd Surgery

- July 6, 2023
- Removed 35+ lymph nodes
- Tissue from back of tongue and throat

Radiation

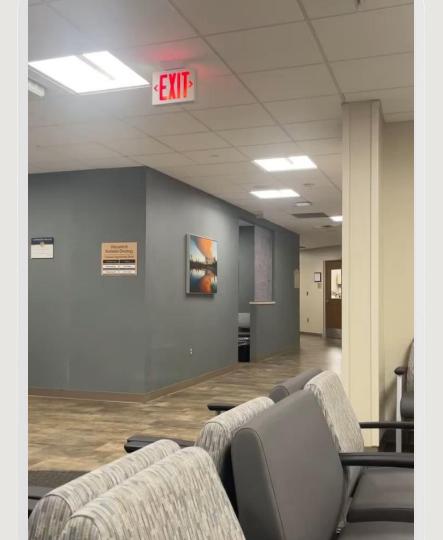
• 5 days a week for 6 weeks



During and after radiation

- Feeding tube
- No saliva
- Eating hurt
- Mucous
- Choking
- Nothing tasted good

- Vomiting
- Sputum (SPYOO-tum) or Expectorate
- Fatigue
- Depression
- Swelling in the neck



Final tests

- December 11, 2023: CT scan
- December 12, 2023: PT scan
- December 15, 2023: All clear
- May 13, 2024: Follow-up



And now this





Kicking and screaming

- Not ME
- Cancer isn't my disease
- Cancer is not a gift



Gratitude

- Health care professionals
- Healthcare system
- People make all the difference



"your purpose is not the thing you do. it's the thing that happens in others when you do what you do."

Dr. Caroline Leaf

2024 Cancer Care Conference

2024 May 17

THANK YOU!

For Listening



10 MINUTE BREAK – BE BACK BY 10:30AM

Cervical and Ovarian Cancer

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Trauma-Informed and Fat-Friendly Approaches

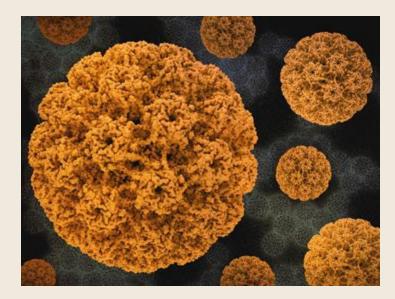
Tanya Baity, CNM

Objectives

- → Review current cervical cancer screening guidelines
- → Discuss upcoming changes to cervical cancer screening
- → Review symptoms of ovarian cancer

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- → Discuss who and when to screen for ovarian cancer
- → Review how trauma and weight-bias create barriers to cancer screening and detection
- → Discuss strategies healthcare providers can use to address these barriers



Cervical Cancer Screening

Individuals with a cervix, HIV negative, no prior abnormal screening

USPSTF, ACOG

- → Cytology every 3 years ages 21-29
- → Cytology+HPV every 5 years ages 30-65 (Or Cytology alone every 3 years still acceptable)

ACS

- → Primary HPV screening every 5 years ages 25-65
- → Cytology for HPV+ samples only

WHO

- → HPV screening every 5-10 years ages, prioritize ages 30-50
- → HPV+ may triage with cytology or proceed directly to treatment

UK

- → HPV primary screening, every 3-5 years ages 25-50, every 5 years ages 50-65
- → Cytology for HPV+ samples only

https://www.acco.parg/clinical/clinical-guidonce/proctice-advisory/articles/2021/04/updated-cervical-concer-screening-guidelines https://www.uspreventiveservicestaskforce.org/visost/recommendation/cervical-concer-screening https://acsjournals.anlinelibrarywiley.com/doi/full/10.332/conc.21628 https://ris.who.int/distream/handle/10645/342365/78824003824-eng.pdf?sequences] https://www.gov.uk/guidonce/cervical-screening-parame-overview

Widespread Agreements



- → Don't screen anyone under 21
- → Stop screening at age 65 unless there are other risk factors
- → Don't screen anyone who has had a total hysterectomy unless they had CIN3 or cervical cancer prior to surgery
- → Patients with HIV or other immunosuppression need increased screening

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→ Get those HPV vaccinations!

USPSTF Under Review

- → Effectiveness of various testing strategies
 - Self collecting vaginal samples?
- → Harms of various testing strategies
- → Variations by population

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Race, ethnicity, gender identity, HPV vaccination status?

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Story Time:



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Ovarian Cancer - Who to Test?

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Symptoms

Typically new onset, occurring almost daily, bothersome enough to seek care

- → Abdominal/pelvic pain, bloating, fullness
- → Difficulty eating
- → Urinary urgency/frequency
- → Increased abdominal size
- → Constipation
- → Abdominal mass

Family Family History/Genetics

- → 1st degree relatives with breast, ovarian or colorectal cancer
- → Familial Lynch syndrome primarily GI tract cancers but also genitourinary
- → Known genetic mutations

https://www.acco.prg/-/media/project/acco_racoorg/clinicd/files/committee-opinion/articles/2019/12/hereditary-concer-syndromes-and-risk-assessment.pdf https://www.upto.dote.com/contents/early-attection-of-epithelial-ovarian-concer-rate-of-symptom: recoonition?search=Ovarian%20concer%20symptome&source=search result&selectedTitle=1%7E150&usage_type=default&display_rank=1#H 8563498

Ovarian Cancer

- → Offer genetic counseling / screening based on family history
- → Standard screening includes pelvic/transvaginal ultrasound + CA125

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→ Guidelines recommend against routine screening of low risk, asymptomatic patients (leads to more interventions but no decrease in mortality)

https://www.cancer.org/cancer/types/ovarian-cancer/detection-diagnosis-staging/detection.html#-text=There%20are%20no%20recommended%20screening.risk%20af%20developing%20avarian%20cancer. https://www.cancer.ov/types/ovarian/score.org/uspst/recommendation/ovarian-cancer-screening. https://www.cancer.ov/types/ovarian/score.org/uspst/recommendation/ovarian-cancer-screening.

Making it Trauma Informed and **Fat-Friendly**

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Can I have a baby elephant made of pure light that tells you true secrets about the universe?

> "81% of women and 43% of men report some form of sexual harassment or assault in their lifetime"

Not Surprisingly...

- → Individuals with a history of childhood trauma, especially (but not only) sexual trauma, are less likely to get routine cervical cancer screenings.
- → Having a stress-related diagnosis prior to developing cancer increases risk of mortality
- → Individuals with PTSD (and possibly depression) have increased rates of ovarian cancer
- → Having more adverse childhood experiences (ACEs) increases a person's risk of cancer in general
- → Fat people are less likely to get screened for cervical cancer and more likely to die from it
- → Fat people report longer lapses of time between onset of ovarian cancer symptoms and diagnosis
- → Fat people may have higher rates of some ovarian cancers, and increased risk of mortality from ovarian cancer.
- Medical providers may be giving inadequate chemotherapy doses or surgical treatments to fat people with ovarian cancer

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ips://ons.org/onf/S0/k/adverse-childhood-experiences-and-preventive-cerviced-concer-screening-behavior#:-text=In%20_his%20_study%20%20%20hioher, received%20rercommendee%20cervicd%20cerce%20screeningps://acsiournals.onlinelibrary.wilev.com/doi/full/0.1002/cncr.34036 https://pubmed.ncbi.nlm.nih.aov/3726414/ https://pubmed.ncbi.nlm.nih.aov/31488422/#:-text=Women%20with%20hig%20TSD%20symptoms.Cl%20%2009%203.5]). ps://pubmed.ncbi.nlm.nih.aov/2449316/ https://www.cdc.aov/cancer/aces/index.htm.https://pubmed.ncbi.nlm.nih.aov/308358/ https://pubmed.ncbi.nlm.nih.gov/37080502/ https://www.aynecologiconcology-online.net/article/S0090-8258(2301596ibstract#:text=Women%20with%20symptoms/20weipht%20ads20weight: https://pubmed.ncbi.nlm.nih.gov/and/articles/PMC3308358/ https://pubmed.ncbi.nlm.nih.gov/and/articles/PMC3308350/ https://www.aynecologiconcology-online.net/article/S0090-8258(2301596ibstract#:text=Women%20with%20symptoms/20weipht%20ads20weight: https://obayn.onlinelibrary.wiley.com/doi/10.1002/ligo.13870

The Most Basic Basics



- → Assume everyone has trauma
- → Ask permission before touching someone
- → Use the least restrictive positions
- → Meet people with their clothes on
- → Ditch your assumptions

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- → Don't look at a patient's weight if it isn't relevant
- → Ask permission before discussing weight or diet
- → Educate yourself

A Trauma-Informed GYN Exam

- \rightarrow Is the exam necessary?
- → Could it wait until the second visit?
- → Are there less invasive testing options?
- → Shared decision making
- → Be realistic about pain
- → Support person if desired
- → Comfort object, music?
- → No stirrups
- → Keep own clothes on as much as possible
- → Placing their own speculum
- → Pre-medication if desired
- → Safe words "Stop" and "Out"
- → Let the patient set the pace



https://www.uptodate.com/contents/health-care-for-female-trauma-survivors-with-posttraumatic-stress-disorder-or-similarly-severesymptoms?search=trauma%20informed%20care&source=search result&selectedTitle=1%7E24&usage type=default&disday rank=1#H19272% Image credit Tanya Baity, CNM

Take It A Step Further

- → Seek out additional training on trauma informed care.
 - https://www.traumainformedcare.chcs.org/
 - <u>https://www.samhsa.gov/sites/default/files/programs_campaigns/child</u> <u>rens_mental_health/atc-whitepaper-040616.pdf</u>
 - Specific to midwifery / GYN care <u>https://www.feministmidwife.com/</u>
- → Read more about the harms of weight bias.
 - https://onlinelibrary.wiley.com/doi/full/10.1111/obr.12266
 - <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4677673/pdf/nihms7387</u>
 <u>44.pdf</u>

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- → Learn all about Health at Every Size
 - https://asdah.org/haes/
- → Binge a funny but very informative podcast
 - https://maintenancephase.buzzsprout.com/1411126
- → Read the research about how ineffective dieting is
 - <u>https://www.healthline.com/nutrition/do-diets-make-you-gain-weight#dieting-industry</u>

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Thanks!

Connect with metbaity@famhealthcare.org

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LUNCH! 11:30AM - 12:30PM

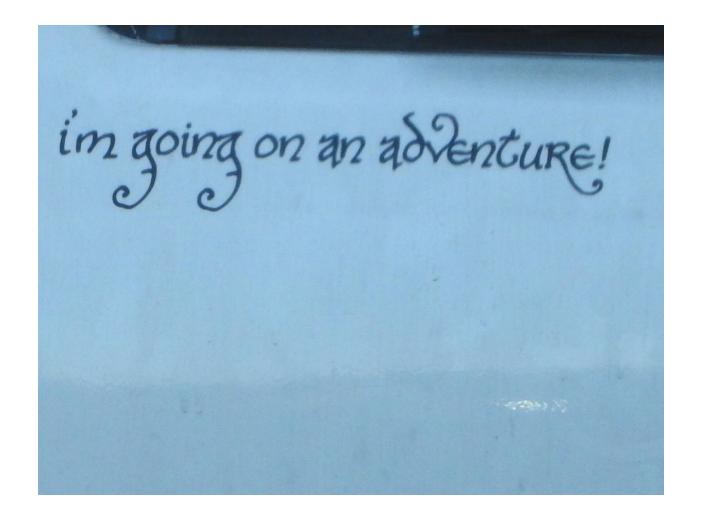




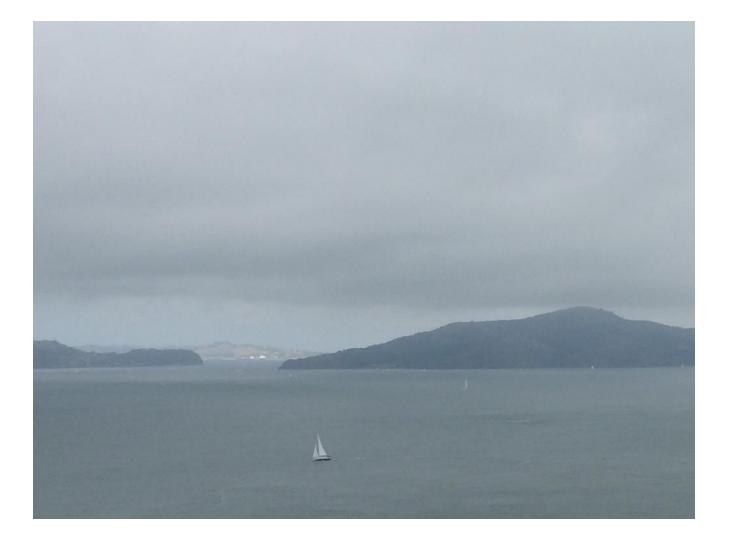
10 MINUTE BREAK -BE BACK BY 1:45PM











THANK YOU!





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