

2021 Virtual Advocacy Survivor-Caregiver Summit

CONNECTED + EMPOWERED

Gynecologic Cancer Literacy
Survivorship Primer: Quality-of-Life Matters
Power of Patient Advocacy

Saturday, September 25, 2021

8:00 am - 12:00 pm CT



IGCS



INTERNATIONAL
GYNECOLOGIC
CANCER SOCIETY



A Survivor-Caregiver Experience

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IGCS



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My Cancer Journey

Life before cancer



Diagnosis



Treatment



Post-treatment
Recovery



Second Cancer



Long-term Survival



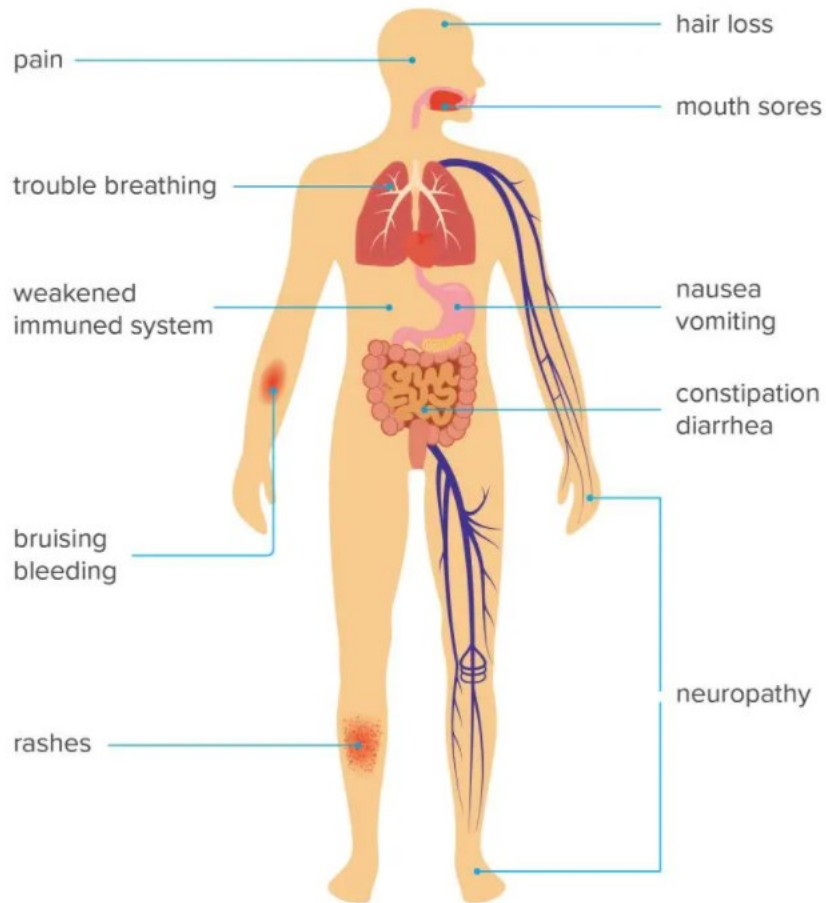
Recurrences/
Chronic Disease



Living well
(with or without cancer)

Active Treatment

Effects on the Body Chemotherapy



Surgery ♦ Radiation ♦ Chemo
Targeted Tx ♦ Immunotherapy

Managing Side Effects:
Temporary/permanent? Serious/manageable?

Getting through each day:
Energy, Sleep, Nutrition

SURVIVAL!

Post Treatment Recovery



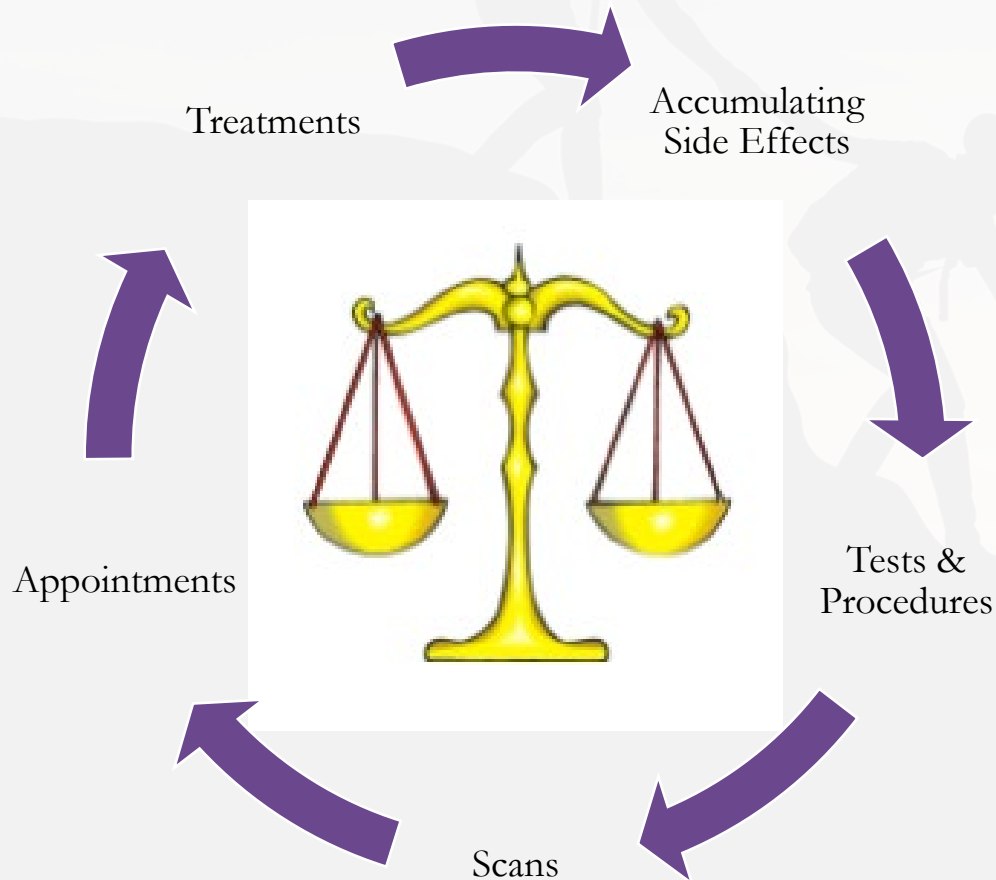
“New Normal”

Side effects: slowly resolving
What can I do to get stronger faster?

Difficulty staying positive
Uncertainty/Fear of recurrence
Should I make lifestyle changes?
Survivor Guilt

**Anxiety, Anxiety, Anxiety,
Anxiety, Anxiety,
Anxiety**

Management of Recurrences or Chronic Disease



<http://clipart-library.com/scale-cliparts.html>

Treatment goals change:

cure ♦ remission ♦ stable disease

Priorities can change:

work ♦ travel ♦ hobby ♦ event ♦ family

Finding balance:

Will treatment put brakes on cancer
but not be too hard on my body?
Hope for the best/Plan for the worst

Focus:

LIVING with cancer

Long-Term Survival

More birthdays!



Permanent and Late Side Effects
(Body changes, neuropathy, tinnitus)

Risk of recurrence & Scanzxiety

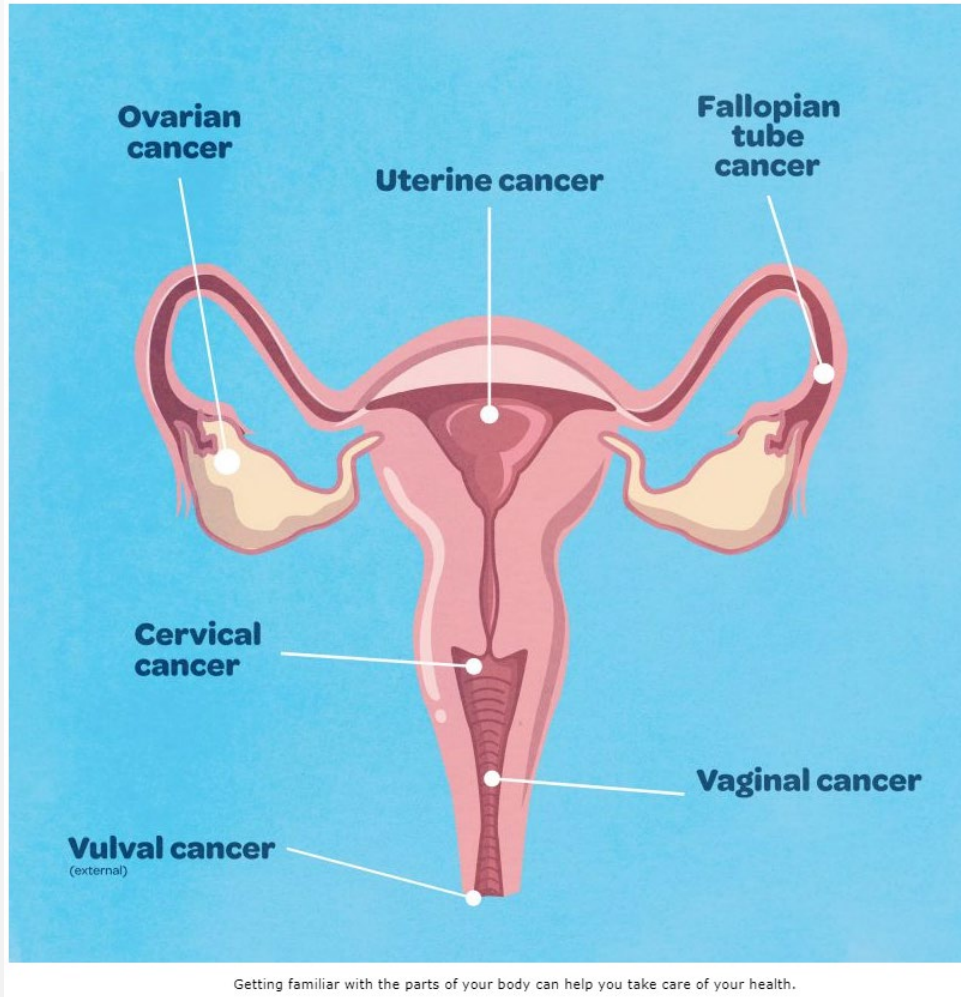
Risk of secondary cancers

Privilege of aging

Healthy living

Sexual health

Quality of Life and Sexual Health



Pain
Intimacy, Relationships, Guilt
Identity

Best advice I was given:

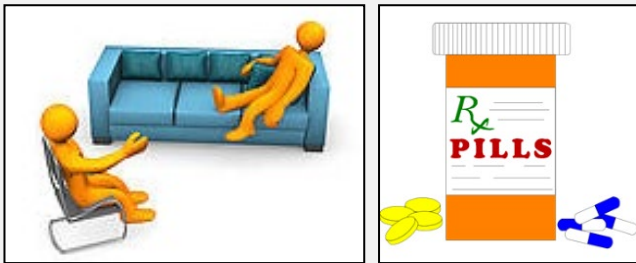
*“Stop having painful
intercourse.”*

*There are things we can do to
help
with the mechanics.”*

Honesty, Communication
Patience, Lubrication

Quality of Life and Mental Health

- All feelings and thoughts that come with a cancer diagnosis are normal and okay.
- It's okay to ask for professional help:
 - Any time
 - When mood/feelings get in the way of day to day functioning



Cancer-related Post-Traumatic Stress

- Repeated frightening thoughts.
- Being distracted or overexcited.
- Trouble sleeping.
- Feeling detached from oneself or reality



<http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0032735/>

Major Depression

- Feeling sad most of the time.
- Loss of pleasure and interest in activities you used to enjoy.
- Changes in eating and sleeping habits.
- Nervousness.
- Slow physical and mental responses.
- Unexplained tiredness.
- Feeling worthless.
- Feeling guilty for no reason.
- Not being able to pay attention.
- Frequent thoughts of death or suicide.

<http://www.ncbi.nlm.nih.gov/books/NBK66039/>

Improving Quality of Life: Who can help?

Self-Care

- Be kind and gentle to yourself
- Be proactive:
 - Tracking Side Effects
 - Staying ahead on meds
 - Activity
- Communication
 - Medical Team
 - Caregivers
 - Goals & Priorities
- Permissions:
 - Feelings
 - Thoughts
 - Asking for help

Medical Team

- **NURSES!**
- Reach out sooner rather than later
- When in doubt, call
- Manage anxiety and insomnia
- Referrals
 - Palliative care team
 - Psychosocial support
 - Sexual Medicine & Women's Health Clinic
 - Other specialists
 - Survivorship Clinic

Support Group

- Hope
- Everyone is different
 - Responses to treatment
 - Coping Strategies
 - Lifestyle choices
- Practical information
 - **NOTE:** Always check with medical team for possible interactions with current treatment
- Weight loss program
- When feeling ready:
 - Opportunities to give back and help others

Helpful Resources

Palliative Care

Palliative care is specialized medical care for people living with a serious illness.

This type of care is focused on providing relief from the symptoms and stress of the illness.

The goal is to improve quality of life for both the patient and the family.

<https://getpalliativecare.org/whatis/>

Heal Well A Cancer Nutrition Guide



<https://prod-io.livestrong.org/sites/default/files/rs/images-email/pdfs/livestrong-fertility/Meals-to-Heal-Heal-Well-Nutrition-Guide.pdf>

About Herbs, Botanicals & Other Products

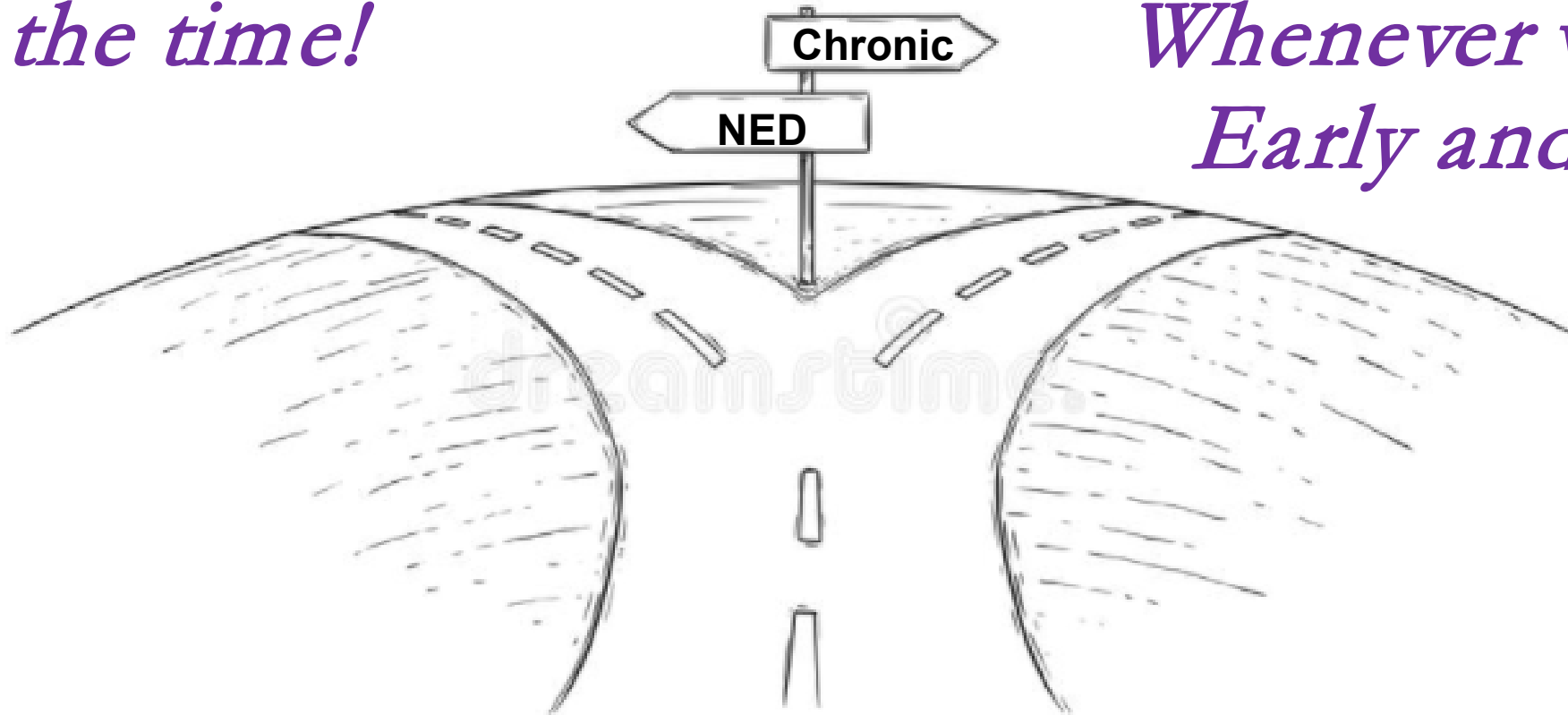


<https://www.mskcc.org/cancer-care/diagnosis-treatment/symptom-management/integrative-medicine/herbs>

When is
Quality of Life
most important?

When should
we reach out
for extra help?

All the time!



*Whenever we need!
Early and often!*

Thank you!



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