

Native Hawaiian Breast Cancer Survivors
"Talking Story"

After Diagnosis: Now What?





Mahalo piha to our Native Hawaiian breast cancer storytellers. May their stories encourage us to care for and value ourselves, just as much as we care for and value our 'ohana.

Gloriann Akau, Hawai'i
Gwendolyn Pua Borrero, Lāna'i
Abigail H. L. Burgess, Moloka'i
Leni Hokoana English, Maui
Cindy Leimomi Goodness, O'ahu
Pele Hanoa, Hawai'i
Keikilani Harada, Kaua'i
Karen Joao, Moloka'i
Susan Kahawai, O'ahu
Daveanna M. "Steady" Kaowili, Maui
J. Mahealani McClellan, O'ahu
Beatrice H. Rosa, O'ahu



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Booklet Hui: Rie Leilani Kuhaulua, Gayle Haunani Mackura and JoAnn Umilani Tsark. Brochure Design: RinDesign. Illustration p.4: Kip Parker

Mahalo to Helen Friend for graciously allowing us to use her unique 'ulu quilt pattern.

Mahalo to all for providing valuable input.



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Start Here

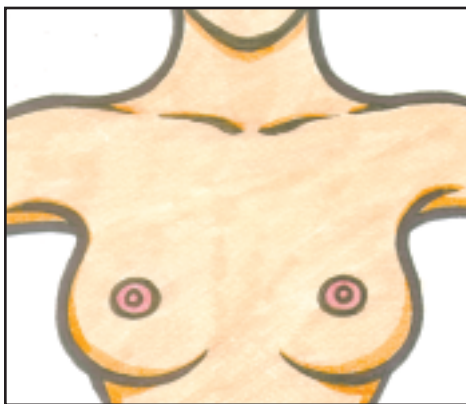
**The
path to
healing after
breast cancer diagnosis.**



Getting the Diagnosis

Take this booklet with you to your health care provider and fill it out together.

Ask your health care provider:
Where is my lump (tumor)?
Please show me where-



Health care provider includes doctors, nurses, la'au (herbal) practitioners and any others involved in your treatment and healing.

...[Don't] be afraid... we need treatment... we have to have it taken care of. Get it done and get it over with. *Pele Hanoa*. Diagnosed in 1996



***Breast cancer won't go away by itself.
Get treatment now!***

When you hear this big word CANCER, it's really scary...I had the cancer; it wasn't going away by magic. *Keikilani Harada* Diagnosed in 1996





Stages of Breast Cancer

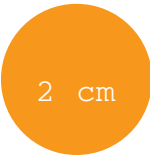
Which stage is my breast cancer?



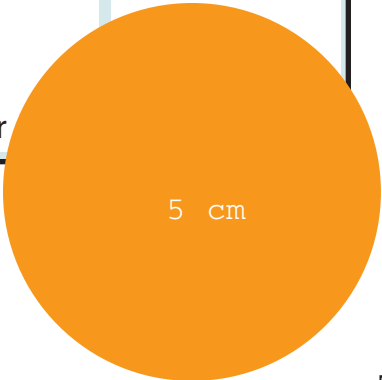
Ask!

Stage	Description	Notes
0 very early breast cancer	Found in a few layers of the cell.	
I early breast cancer	No bigger than 2cm. (see lump sizes below)	
IIA	No bigger than 2 cm. May have spread to the lymph nodes . (see pg.6)	
IIB	From 2cm to bigger than 5cm. Cancer has spread to the lymph nodes.	
IIIA	From 0.1cm to bigger than 5cm. Cancer has spread to lymph nodes.	
IIIB	Any size. Cancer has spread to chest wall or skin.	
IV	Any size. Cancer has spread to other	

0.1 cm



2 cm



5 cm

More Questions About the Diagnosis...



1 What does it mean if the cancer spreads to any lymph nodes? How about my cancer?

Lymph nodes are found under your arms and drain fluids from your chest to arm. Lymph fluids help to fight infections in your body.

2 My cancer is - (ask your health care provider to check)

ER Positive _____	PR Positive _____
ER Negative _____	PR Negative _____

ER means “Estrogen Receptor” and PR means “Progesterone Receptor.” Positive means your cancer depends on female hormones like estrogen or progesterone for growth.

I feel very comfortable with [my doctor]. At first I did not. He was young. Bushy hair and ponytail. But I can be really open with him when I go for my visit. [You’ve] got to feel comfortable with your doctor ... *Keikilani Harada* Diagnosed in 1996



It’s your choice, it’s your body ... [But to] refuse treatment because you hear stories about how you get sick and how you lose your hair, and how you throw up... don’t listen to all that. Sure, you may go through that, but it’s going to help you... *Bea Rosa*. Diagnosed in 1980



Treatment Recommendations

- Why are you recommending this treatment plan?
- How quickly do I have to make a decision about my treatment?
- What are clinical trials? Would you recommend one to me? Why or why not?



Treatments	<ul style="list-style-type: none">• What changes in my body and emotions can I expect if I have this treatment?• What about side-effects?
Surgery Lumpectomy (remove lump) Mastectomy (remove breast)	
Chemotherapy Use of drugs to kill cancer.	
Radiation Use of high energy x-ray to kill cancer.	
Hormonal Therapy Use of hormones to treat cancer	

(Ask your health care provider to fill in)

What treatments do my doctor recommend? Why?

1. _____
2. _____
3. _____



Making

Get information about the treatment that your health care provider has recommended.

Ask questions so you know what to expect.

Getting Support from 'Ohana & Friends

'Ohana (family)



"Ask a lot of questions and always try to bring someone with you to the visit with your doctor because you can't [always] remember what your doctor told you. Maybe your friend or your family can remember and can tell you."

Bea Rosa Diagnosed in 1980

"You have to ask questions and know what's going to happen... My daughter will ask questions and ask the doctor whatever she wants and she [takes] notes!"



Abigail Burgess Diagnosed in 1988

Breast Cancer Survivors

Talk-story with someone who experienced breast cancer. If you don't know any breast cancer survivors, you might ask a friend or 'ohana members if they know someone.



"A lady came to me and talked about what to expect because she had gone through it before and it was [a]... big plus for me."

Susan Kahawai Diagnosed in 1998

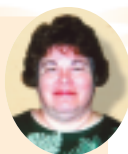
Also see these booklets: *The 'Ohana's Role in Supporting*

Decisions



Find out as much as you can about the kind of cancer that you have. You have... choices in terms of treatment. So I think it's important for us to be informed about our choices...

Mahealani McClellan. Diagnosed in 1991



It's okay to seek opinions from other doctors.

Other Sources of Support

Where support is available:	Some ideas:
Cancer Organizations Cancer Information Service American Cancer Society (phone numbers listed on pg 16)	Call and ask for up-to-date information on cancer and on support groups. Maybe your 'ohana or friends could call for you...
Internet www.cancercare.org www.komen.org www.cancer.org www.cancer.gov	You can get lots of information on the Internet. If you need a computer, try your local library or community center. Ask your 'ohana or friend or mo'opuna (grandchildren) to help you search and find information!
Local Bookstores	Find breast cancer books in the health section. If you don't have a health care provider, call the Native Hawaiian Health Care System on your island.



Treatment Details

Questions to ask your health care provider:



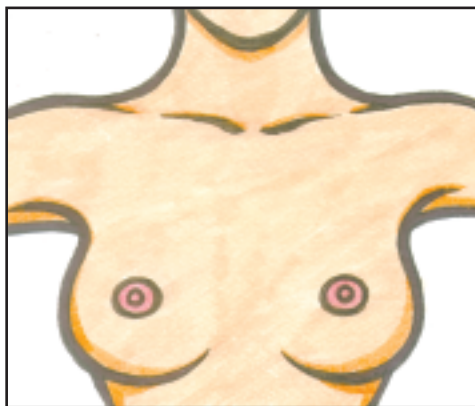
- If I choose surgery,

...how much of my breast will be removed?

...how long will I stay
in the hospital?

...will I need follow-
up care?

...when can I get
back to my normal
activities?



- If I choose radiation/chemotherapy/hormonal
therapy,

...when will I start my treatment? When will it
end? Start _____ End _____

...how long will each individual treatment last?
_____ hours _____ minutes

...how often will I need to come in for treatment?

...can I work during treatment?

...will I have any limitations in my daily living?



Things to Remember

Changes that some women feel during breast cancer treatment:

- 1 Physical Changes—breast removal, hair loss
Will you fill out a prescription for my wig or prosthesis if I need them?
- 2 Side Effects—nausea, tiredness, weakness, pain
Will you give me something for my side-effects?
- 3 Emotional changes—depression, sadness, denial, and acceptance

Is there anything you can recommend for my

Well, plenty times I do get depressed. But I kind of snap out of it. You can snap out of it if you just take a walk or you go work. You just go out or see somebody or do something.

Gwen Borrero Diagnosed in 1998



What else can I do to help my treatment work best?

Ask!

What are the best foods to eat during my cancer treatment:



Storytellers Share Advice



[The doctor] said 'Well we have to treat it.' I said 'Treat it!?' He said 'Yeah like chemotherapy...' I called my dad and my oldest sister. And they said 'Do what you have to do... Don't neglect it. Don't ignore it. Do what you got to do.' I said 'Yeah but I going get bald.' My dad goes 'And so what? Your hair only going grow back.' I said 'Okay. Fine.'

Daveanna "Steady" Kaowili Diagnosed in 1989



[My surgeon said] "You don't know it now but when you wake up and you see that one side is missing, it might really bother you." And I told him it wasn't going to bother me that ...[removing a breast] wasn't a matter to me... that he got it out was more important.

Leni English Diagnosed in 1998



It kind of hit me when I was in the shower and my hair was coming out in clumps. I think everybody must experience that in the shower. That's probably a good place to experience it [because] if you got to cry about it you wet anyway.

Susan Kahawai Diagnosed in 1998



I thought [having no breast] was a major issue too until my husband said, "Hey, I want you alive."

Karen Joao
Diagnosed in 1970



Getting Support



You can get a prosthesis; you can reconstruct your breast... At the American Cancer Society you can get a prosthesis and wigs... everything- you can get it. Call in and come in. *Bea Rosa*
Diagnosed in 1980

Ask your health care provider about...

Prosthesis

An artificial breast (“falsies”) you can wear under your clothing. Some come with special bras.



Wig or Hat

...Until your hair grows back.



I had a beautiful wig... better than my hair. And I put a pin and... nobody even knew that I was bald. They couldn't tell that I was sick.

Gwen Borerro Diagnosed in 1998



Reconstruction - putting a fluid-like sac or your own tissue to replace your breast by surgery. You will need to go to a plastic surgeon who will rebuild your breast.



After Treatment

You have to know that you did all that you can do before you can sit back and relax. *Gloriann Akau* Diagnosed in 1998



Health care providers cannot tell you if the cancer will come back, but will suggest frequent check-ups.

Health care provider suggestions for follow-up care:



...What I went through-it wasn't easy. It was an experience that I won't forget and it's an experience that makes you pretty much aware of how important life is. I'm very thankful because the most precious thing is not what you can buy—the most precious thing is your life. *Gwen Borrero*
Diagnosed in 1998



After I got over the shock I realized that... I wouldn't have gotten this disease if God didn't think I could handle this. *Cindy Goodness*
Diagnosed in 1999

Your Support Team

Primary Care Provider (doctor you see regularly)

_____ phone _____

Oncologist (cancer doctor)

_____ phone _____

Radiation Oncologist (gives radiation treatments)

_____ phone _____

Surgeon (performs biopsies and surgeries)

_____ phone _____

Nurse/nurse practitioner

_____ phone _____

‘Ohana & Friends

_____ phone _____

_____ phone _____

_____ phone _____

Spiritual Advisors & Others

_____ phone _____

_____ phone _____

Getting Support

It's important to get information on breast cancer so you know what's going on!

If you don't have a health care provider call the Native Hawaiian Health Care System for assistance and for additional breast cancer booklets in this series.

Kaua'i, Ni'ihau

Ho'ōla Lāhui Hawai'i

(808) 246-3511

O'ahu

Ke Ola Mamo

(808) 845-3388

Moloka'i

Nā Pu'uwai

(808) 560-3653

Lāna'i

Ke Ola Hou O Lāna'i

(808) 565-6608

Maui

Hui No Ke Ola Pono

(808) 244-4647

Hawai'i

Hui Mālama Ola Nā 'Ōiwi

(808) 969-9220

For up-to-date cancer information call or visit these web sites:

American Cancer Society

(800) 227-2345

www.cancer.org

Cancer Information Service

(800) 422-6237

www.cancer.gov

Susan G. Komen

www.komen.org

Breast Cancer Foundation

Cancer Care

www.cancercare.org