

QUESTIONS
to ask when you
or someone you love
has cancer



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Informed People Do Better

Throughout the cancer journey, every person facing cancer has many questions—about the cancer itself, treatment options, cost, clinical trials, what happens after treatment, etc.

Studies show that people with cancer who are informed (have the facts they need) about their illness and treatment options usually do better than those who are not. Being

informed gives you some control over the disease and your treatment. Most patients feel better when they know what's going on.

If you are like most people facing cancer, or any serious illness, you may not know all the questions to ask.

This is a booklet of questions. It includes questions to ask your doctor and others who are helping you face cancer. Cancer care is complex. There are many new words and things to learn. Most doctors are busy. Knowing the questions to ask will help you and your doctor make the best choices for your care.

At times, it will seem like there is too much to take in. Include a family member or trusted friend to help you to talk with your doctor, ask questions, and weigh the choices that are right for you.

The questions in this booklet have been collected from health care providers and patients and from many online sources, including: the National Coalition for Cancer Survivorship; Cancer Care; People Living With Cancer; Cancer Survivors Online; the American Cancer Society; MamasHealth.com; About.com; and Susan G. Komen for the Cure.

How to use this booklet:

This booklet has hundreds of the frequently asked questions about cancer care. **You may not need all of the questions listed here.** To use the booklet most efficiently:

- Find the topic you need in the Table of Contents
- Read some of the most-asked patient questions on that topic
- Mark any questions you would like to ask
- Find note sheets in the center of this booklet to write down what the doctor said.
- If you think of other questions, write them in the “Other questions I have” box.
- Look-up words you don’t know in the Word List at the back of the booklet.

Tips when talking with your doctors

- Before each visit, write a list of questions.
- If you don’t know what something means, ask the doctor to explain, draw a picture or give an example.
- Repeat what the doctor said to make sure you got the right message (“So you said that my choices to treat my cancer are...”).
- Bring a notebook or a tape recorder to the visit so you can review what the doctor said later.
- Bring a family member, friend, or Cancer Patient Navigator to the visit to help you ask, listen, or write.
- Ask for brochures and other sources of things you should know.
- Be patient.

We hope this booklet will help you ask the questions to get the information you need to make thoughtful and informed choices.

*We also include a few sections on **Questions to ask YOURSELF** to help you weigh the many personal decisions in this journey.*

Questions to ask when you find out you may have cancer

1. What is cancer?
2. How do you know I might have cancer?
3. What do you need to do to find out if it is cancer?
4. Where can I go if I want to know more about cancer?
5. How do I know if what I found on the Web or hear from friends or magazines is correct?
6. What type of cancer might I have?
7. Do doctors know what causes this type of cancer? Was it something I did, or something I came into contact with, or something else?
8. Is this type of cancer something I got from my parents? Can other members of my family get it too?
9. How many people get this type of cancer each year?
10. Is cancer curable? Can I become cancer-free?

Other questions I have:

Genes and Inherited Cancer Risk

Every cell in your body contains genes. Genes are the instructions that the body's cells use to do their work. Some genes are key in the development of certain cancers (e.g., *BRCA1* and *BRCA2* for breast cancer). Sometimes people are born with a change in one of these genes, an inherited mutation that can be passed on to children. Inheriting a cancer gene with a mutation may increase a person's risk for cancer. Genetic testing gives people a chance to learn if their cancer is something they got (inherited) from a parent.

Only 5% (1 in 20) to 10% (1 in 10) of cancers are known to be inherited but genetic testing is one way to find out if your family has a role in your cancer or your chances of getting cancer.

Answers to these questions will help you better understand the relationship between genes and inherited cancer risk.

Questions to ask your doctor about genetic testing:

1. Should I get cancer genetic testing to see if I got this from one of my parents?
2. Should I talk with a cancer genetic counselor? If yes, why? And when?
3. How is the test done?
4. When should I get the test? Will the test change the treatment I get for my cancer?
5. What are the benefits and risks of genetic testing?
6. What does our family need to think about if I get this test? If they find I have an inherited gene mutation that is causing my cancer, does that mean they have it too? Am I supposed to tell my family if the test is positive?

—continued

—Genetic Testing continued from page 4

7. How much does genetic testing cost? Will my insurance pay for it?
8. Will my test results be confidential, private? Who will see my results? What are my options if I learn from the test that I have a mutation in a cancer gene?
9. If I have a cancer gene mutation, will I get cancer? Does it mean my family members (e.g., daughter, son, sister, mother) will get cancer too? What can we do? Where can we/they go for testing and counseling?
10. What does it mean if my test is negative? Does that mean I will not get cancer?
11. If my test is positive, will that affect my job or health care insurance (employer or insurance discrimination)?

Adapted from Susan G. Komen's Questions to Ask Your Doctor About Breast Cancer, www.komen.org

Other questions I have:

Questions about tests to find out if you have cancer

1. What do you need to do to find out if it is cancer?
2. What kinds of tests do I need to take?
3. What will these tests tell me?
4. Who will give me the test?
5. Why do you want to do this test?
6. How good is the test? Are there other tests?
7. What are the next steps if the test shows I have cancer?
8. What will happen if I do not have the test?

Other questions I have:

Questions about tests and procedures after you are told you have cancer

1. Will I be harmed if I take this test? What are the risks?
2. Will the results change the kind of treatment I get?
3. What will you learn from the test?
4. Why do I need to have this test?
5. What will the test involve?
6. Will the test be painful?
7. Will I need to go to the hospital for the test?
8. Can you walk me through the steps of the test?

—continued

—Tests and Procedures continued from page 6

9. How do I prepare for the test?
10. How much will the test cost?
11. Will my insurance cover this test?
12. When will I get the results? How will I get the results?
Will you call me or will you send a letter?
13. Is this test being done to confirm what we know now or to learn more about my cancer?
14. Will you support me if I want to ask some other doctors about my case (get a second opinion)?
15. If I decide to ask other doctors about my case (get a second opinion), how can I make an appointment? Will my insurance cover a second opinion? Will I have to repeat any tests or procedures?
16. What is a “tumor board” and how can they help me make choices about my treatment?
17. What should I tell my family and friends when they ask me about my illness? Is there someone who can help me think through this?

Other questions I have:

Questions about staging and prognosis

1. What do doctors mean by “stage” of cancer? What does the stage number tell you? What if my cancer is not staged?
2. How is staging used to decide what treatment I will get?
3. Is my cancer slow growing or fast growing? How do you know?
4. Is my cancer just in one place or is it in other places in my body?
5. What are the chances my cancer will get worse?
6. What are my chances of beating this cancer (my prognosis)?
7. How many people survive this kind of cancer I have?
8. What does “remission” mean? If my cancer goes into “remission,” does that mean I am cancer-free?

Other questions I have:

Questions to ask yourself before choosing treatment

1. Is this the doctor I want to handle my case?
2. Am I comfortable with him/her?
3. Do I know enough to make the best choice?
4. How much do I really want to know? What information is helpful?
5. Who should I take with me to the doctor’s office to help me remember things and ask questions if I am nervous?
6. Should I ask another doctor about my case?
7. Who should I talk to if I’m not sure about what to do?

—continued

—*Before Choosing Treatment continued from page 8*

8. Which hospital do I want to go to for treatment?
9. How much do I want to share with my family about my illness, my treatment, and my chances for living through this?

Other questions I have:

Questions about treatment

1. What are the ways they treat the kind (and stage) of cancer that I have?
2. What treatment do you think is right for me? Why?
3. Will I need surgery? Radiation? Chemotherapy?
4. What is the goal of this treatment? Is it to cure (to be cancer-free) or to control my symptoms?
5. Why do you think this treatment is better than the others?
6. Is this the treatment given to most people with my kind of cancer?
7. Is this treatment needed?
8. Are there other treatments I should think about? Which?
9. Tell me about clinical trials that research new treatments. Should I be thinking about a clinical trial? (see next section)
10. If this treatment works, what are the chances this cancer will slow down or go away?
11. How often will I have to go for treatment and for how long?
12. How many “rounds” of treatment do you think I will need?

—*continued*

—*Treatment continued from page 9*

13. What are the names of the drugs I will take? What are they for?
14. Explain radiation treatment to me and why I need it or not.
15. I hear that treatments like radiation and chemotherapy can be “rough.” What are the side-effects of this treatment?
16. Do patients find this treatment painful? What can you do to make it less painful?
17. What is the “good news” (benefits) and the “bad news” (risks) of the treatment I am getting?
18. What will happen if I choose not to have one or all of the treatments?
19. Can I keep working while I am having radiation or chemotherapy or both?
20. Can I be put on a treatment program that allows me to work too?
21. How will you know that my treatment is working?
22. If I feel sick, does that mean the treatment is working?
23. What can I do to be ready for treatment?
24. What can I do to reduce some of the side-effects?
25. Are there any special foods I should or should not eat?
26. Can I drink alcohol?
27. Are you aware of all the other medicines I take for my other illnesses (like diabetes, heart disease, asthma, allergies, etc.)? Can I still take them during my cancer treatment? Does having this treatment mean I can't have kids? What are my options?
28. What is the best time to contact you (and best number) if I get really sick from the treatments or if I have more questions?
29. Do I have a type of cancer that would be better treated at a cancer center outside of Hawai'i?
30. Should I let my other doctors know about this treatment?
31. How will you make contact with my other doctors about my case?
32. Even if I do all this treatment, what are the chances my cancer will come back?

Other questions I have:

Questions to ask about clinical trials (research)

1. What are clinical trials? Why is it research?
2. Why is it important to be in a clinical trial?
2. Will a clinical trial help cure my cancer?
3. If I am in a clinical trial, who will be my cancer doctor?
4. What happens if I decide to join a clinical trial and my cancer gets worse?
5. Will the clinical trial pay for all of my cancer treatments?
6. Will it cost me money to join a clinical trial?
7. Where can I get more information on clinical trials?
8. Is there a clinical trial in Hawai'i now for my type of cancer?

Other questions I have:

Questions to ask if you decide to join a clinical trial

1. What is the purpose of the test? Research?
2. How do I join a clinical trial?
3. What will be involved if I join? How long is it?
4. What is an Informed Consent Form? Why must I sign it?
5. Will they tell me exactly what treatment they are researching?
6. What are all the steps of the clinical trial?
7. What are all the benefits and harms or risks if I join?
8. Will my cancer doctor watch over me in the clinical trial or is it someone else? Will the research doctor keep in touch with my other doctors?
9. What if I want to stop being part of the clinical trial after I have joined?

Other questions I have:

Questions to ask about radiation therapy

1. What is radiation therapy? Why is this a good treatment for the kind of cancer I have?
2. Can I get too much radiation? Will it harm me or the parts of my body that do not have cancer?
3. Who is the doctor for these treatments?
4. Who should I talk to if I have questions about radiation?
5. Can I work while I'm getting treatment?
6. Do I have a choice of places where I can get radiation treatment?
7. How long will each treatment take?
8. What actually happens during the treatment?
9. How many sessions will there be?
10. Will the treated area of my body need special care?
11. What will it do to my skin? What can I do to deal with that?
12. What other side-effects can I expect?
13. What should I do if I have side-effects?
14. What side-effects should I report to the doctor?
15. Will the treatment harm me in any way?
16. Are there other treatments that would give me the same results?
17. What will happen if I don't have radiation therapy?
18. Do I need to be on a special diet before, during, and after these treatments?
19. What day-to-day things should I be doing or not doing while having these treatments?
20. How much will this cost?
21. Does my insurance cover this treatment?

Other questions I have:

Questions to ask about chemotherapy

1. Can you explain to me in simple terms what chemotherapy is and how it works for the kind of cancer I have?
2. Do all cancer patients get the same chemotherapy drugs?
3. Can you write down the names of the drugs I am getting?
4. How will the drugs be given to me and by whom?
5. How often will the drugs be given?
6. How long will each drug treatment take?
7. What do you mean by a “series of treatment.”
8. Will I need more than one series?
9. What are the changes I might see in my body, my hair, my energy level, and my appetite?
10. What can I do if I have these changes or side-effects?
11. Which side-effects should I report to the doctor right away?
12. How long will the side-effects last?
13. Can I take my other medications at the same time?
14. Can I drink alcohol while I am getting this treatment?
15. Can you give me advice about eating and keeping my energy up?
16. What should I be careful about before, during, and after the treatments?
17. What harmful things could happen to me because of these treatments?
18. Are there other treatments that have the same outcomes?
19. What will happen if I decide not to have this treatment?
20. How much will these treatments cost?
21. Does my insurance cover this treatment?

Other questions I have:

Questions to ask your surgeon before an operation or surgery

1. Why do you want to do this surgery?
2. What are the goals of this surgery? Will it cure my cancer or will it slow down the cancer?
3. What other treatments can you use instead of surgery?
4. How many of these or similar operations have you done?
5. Will there be other doctors helping with the surgery? What is their role in my care?
6. Who will do my follow-up care after the surgery?
7. Would you describe in simple terms the process from start to finish? How should I prepare? What exactly will the surgeon do? What happens right after surgery? What will my recovery be like?
8. What about the medicines or supplements (like aspirin) that I take now?
9. How long will the operation take?
10. Does this surgery have to be done in a hospital?
11. How long will I be in the hospital?
12. How long will it take me to get back to normal?
13. How much will this change my body looks?
14. How much will this operation change how my body acts or functions?
15. Are there other procedures that cause fewer body changes than the one you suggest?
16. What harms might the surgery cause me?
17. What are the harms to me of the other possible treatments?

—continued

—*Before an Operation continued from page 15*

18. What are the chances that I might die or be disabled because of the surgery?
19. Do you feel the good outweighs the bad? Why?
20. What might happen if I wait or delay the operation?
21. What will happen if I don't have the surgery at all?
22. How much will it cost? Is the surgery covered by my insurance?
23. After this surgery, what will I have to deal with? More surgery? Other treatments? Chemotherapy? Blood transfusions?
24. Who can I see for a second opinion or to learn more?
25. How can my family prepare and help me during the surgery and after?

Other questions I have:

Questions to ask about medicines for the surgery (anesthesia)

1. What medicines will I be given for this surgery so that I don't feel any pain (anesthesia)?
2. Will this medicine numb just a part of my body or will I get medicine that will "put me out" and make me unconscious (general anesthesia)?
3. Is general anesthesia necessary for this operation?
4. Who will give me the medicine? How will they give it?
5. Who needs to know about any allergies I have or other medicines and supplements that I am taking now?
6. Should I take my other medications before this surgery?
7. What are the chances that I will react badly to the anesthesia?
8. How long before I wake up from the surgery?
9. What side-effects might I get from anesthesia? What can I do to lessen them?

Other questions I have:

Questions to ask if I need to go to the hospital

1. Who can explain to me what to expect in the hospital?
2. What might I expect from the time I sign in to the time I leave?
3. What is scheduled to happen to me for the time I am there?
4. When I am a patient, who can I talk to when there are delays or when I don't understand what is going on?
5. What if I have questions about a test or medicine they are giving me when my doctor is not there?
6. Do I have to stay in bed, or can I walk around?
7. How often will my doctor visit me while I am in the hospital?
8. When can people visit me? Are there rules about visits?
9. Can a family member sleep over in the room with me?
Are there chairs or fold-out beds for that purpose?

Other questions I have:

Notes to use when you meet with your doctor or health care provider.

The Question is On...
(Page and Number)

What my Doctor said...

(SAMPLE)

Page 7, Question 12

(SAMPLE)

Test will be back in couple of days.

Dr.'s office will call with the results.



The Question is On...
(Page and Number)

What my Doctor said...



Questions to ask your doctor before leaving the hospital

1. How active can I be when I get home?
2. Will I need to stay in bed at home? For how long?
3. Will I be able to care for myself?
4. When can I drive a car? Have sex? Go to the beach? Lift things?
5. Will I have to follow a special diet or meal plan?
6. What side-effects can I expect once I leave the hospital?
7. What side-effects should I report to you and when?
8. When can I go back to work?
9. What medicine should I continue to take?
10. What exercise should or can I do each day?
11. How often will I see you after I return home?

Other questions I have:

Questions to ask yourself before using “unproven” treatments or treatments not recommended by a doctor

1. Why am I thinking about using this kind of treatment?
2. What do I really know about this treatment other than what friends have told me?
3. If this treatment is so good, why are doctors not using it?
4. What chances am I taking by using this treatment?
5. Did I ask my doctor if I can take this at the same time as other prescription medicines or during the cancer treatments that I am getting now (like radiation or chemotherapy)?
6. If this treatment does not work or makes me worse, who is responsible?
7. Is there a way my doctor and I can talk about this?
8. What are the extra costs of this treatment?
9. Are there other approved treatments that I could try instead?

Other questions I have:

Questions to ask about symptoms and side-effects

1. What are some common symptoms of this type of cancer?
2. What are some risks or side-effects of the treatment I am getting?
3. How can I prevent or reduce symptoms and side-effects?
4. Where can I learn more about coping with symptoms and side-effects?
5. What may make the symptoms and side-effects worse?
6. If my symptoms or side-effects get worse or new ones arise, what should I do?
7. What symptoms or side-effects should I report right away?
8. If I do feel sick, does that mean the treatment is working?
9. Is the symptom or side-effect I have something that can be cured or controlled?

Other questions I have:

Questions to ask about nutrition

1. How will my cancer or the cancer treatment affect my weight?
2. Is this a good time for me to lose weight? Gain weight?
3. What should I do if I lose or gain weight?
4. How will I know if I'm eating or drinking enough?
5. I follow a diet now for another health problem (diabetes, gout, high blood pressure, etc. Should I change that diet now that I have cancer?
6. Are there any foods that I am not allowed to eat during cancer treatment or with the cancer medicines I take?
7. I hear about special foods and diets, like goji berries & noni, that claim to help my cancer. Is it OK to try them?
8. How do I know if I need to speak to a food expert (dietician)? How do I find one?
9. Where can I learn more about what to eat during and after treatment?
10. Sometimes I have trouble swallowing. What can I do?
11. My food tastes like metal. Is this normal? What can I do to make it better?
12. Sometimes I don't have the energy to cook. What should I do?
13. My mouth is really sore, and it is hard to eat. What should I do?
14. The smell of food makes me feel sick. What can I do?
15. My bowel habits have changed since I got sick. Is there something I can eat or take that will help?
16. What are supplement drinks? Should I be having them?
17. What is 'alternate feeding'? Will I need that?

Other questions I have:

Questions to ask about palliative care

1. What is palliative care? Is it the same as hospice care?
2. How can palliative care help me and my family?
3. When would I need it?
4. If I need palliative care, does this mean I'm dying?
5. How can I find someone who is an expert in this kind of care?
6. How can I get this kind of service?
7. To get palliative care, do I need to stop my cancer treatment?
8. Will my cancer doctor's role change if I get this kind of care?
9. Can I get this care at home or do I have to be in the hospital?
10. Can I get this kind of care at night or on weekends when I have pain or other symptoms?
11. If I am in pain, what can be done for me to make me feel better?
12. What can be done if I have other symptoms or side-effects that make me feel bad?
13. Can I get hooked (addicted) on pain pills or pain medicines?
14. What side-effects are caused by drugs that relieve pain?
15. Are there patients that you would not give this kind of care to?

Other questions I have:

Questions to ask about support and support services

1. Would you tell me about Cancer Patient Navigators?
How can they help me and my family while I have cancer?
2. Is there someone like a Cancer Patient Navigator, Social Worker or Patient Advocate that I can talk to?
3. Where can I learn more about coping with my cancer and cancer treatment?
4. Where can I find help and support to deal with all these new thoughts and feelings (sadness, anger, confusion, hopelessness)?
5. Where can I get financial help to pay for cancer care?
6. Where can I get financial help paying my bills and living expenses if I am having money issues?
7. Where can I get legal advice or financial counseling?
8. Who can answer questions and help me sign up for health insurance?
9. If I have to fly or travel far to get my cancer care, where can I get help with travel costs, housing or childcare?
10. Where can I find help with transportation services so I can get to my medical appointments?
11. What are some things I can do to help my family and myself cope with this and all the changes it brings?
12. Where can my children and teens go to learn more about cancer and what I am going through?
13. Where can I find stories or accounts of patients or families who grew stronger during this tough time?

Other questions I have:

Questions to ask about social and mental health issues

1. What and how much should I share with others (family, friends, co-workers) about my cancer and things to come?
2. Is it good for family members, including children, to know what's going on? Is it better for them not to know?
3. Where can I go for help with bills, legal advice and counseling?
4. Is it normal to feel angry, sad, or scared?
5. What can I do about all of my feelings and mood changes?
6. How can I deal with the changes happening to my body? The way I look? My lack of energy? How I feel about myself?
7. Will I lose my interest in romance and sex? What if my partner is turned off because of my illness?
8. Some of my friends seem scared or distant since I've gotten cancer. How can I talk with them about this?
9. How can I get myself and my family to think about the possibility of death? What can I do if they deny it or won't even talk about it?
10. How do I maintain the quality of life I want right now and still take care of my responsibilities to family and friends?
11. Who can help me cope better?
12. Why do I sometimes feel guilty about having cancer?
13. Some people say that cancer is a punishment. Is this true?
14. I sometimes feel crazy and/or angry with my family and friends. Is this normal? What can I do about this?
15. How can I relax and let my body heal when there are so many stressful things happening to me?
16. How can I get my spouse or lover to talk with me about what is happening and how he or she feels about my illness?

—continued

—Social and Mental Issues continued from page 25

17. What can I do when I feel angry or upset with my doctor?
18. What can I do if I feel I am being treated unfairly by the hospital, insurance company, doctor or therapist?
19. How can I deal with friends who try to persuade me to look into cures, diets, religions or therapies?

Other questions I have:

Questions to ask when cancer is terminal

1. Are there any other treatments that will make me feel better or help me live longer?
2. For people that have the same cancer I have, how long do they usually live?
3. What are some ways that others like me have handled this?
4. Are there services that can help me cope with this?
5. Do you have any advice on how to talk about this with my family?
6. What do I still have control over? (Care options, pain relief, etc.)
7. What can I expect?
8. What papers or information do I need to give to you and other members of my health care team?
9. If I'm not able to talk or make decisions, who will make decisions for me?

—continued

—Terminal Cancer continued from page 26

10. How will my daily life (eating, drinking, toileting, etc.) change?
11. Will the dying process hurt? What can I do to stay pain-free?
Who can help me if I'm uncomfortable or in pain?
12. Do I have to go to the hospital to die, or can I die at home?
13. Can I get care that will reduce my symptoms (palliative care)?
14. Is palliative care covered by my health insurance?
15. Can I get end-of-life care (hospice) to help me and my family through the last stages of my illness?
16. Is hospice care covered by my health insurance?
17. Where can I learn more about the dying process?
18. What should I, or my loved ones, report to you? What do you need to know in order to care for me during this time?
19. What are the signs that death is near?
20. What should my loved ones do if I die at home?
21. What will happen to my body if I die at the hospital?
22. Even though I have cancer, can I still be an organ donor?
23. Even though I have cancer, can I still donate my body to the medical school to help in the training of medical students?

Other questions I have:

Questions to ask about living with cancer (After-Treatment)

1. What happens to me now that my cancer treatments have ended?
2. How long will it take for me to get back to my normal routine and feel more like myself?
3. When will I stop thinking about cancer?
4. Will my life change?
5. Are there programs that can help me adjust?
6. If I need help in the home, where can I get help?
7. For the kind of cancer I have/had, what are the chances of it coming back? What are the chances that I will get a new cancer?
8. What are long-term effects of the cancer treatments I've had?
9. Am I likely to get some other cancers because of the type of treatment I received?
10. What body changes or signs should I watch for that might tell me my cancer is coming back?
11. What can I do to lower my chances of the cancer coming back?
12. What should I do to stay healthy?
13. Will I need more treatment of any kind?
14. My cancer treatments are done, but I'm still having some side-effects. How long will these side-effects last? Will they ever go away?
15. What problems should I report to my cancer doctor?
16. What problems should I report to my regular doctor?
17. Who will be my regular doctor now?
18. What does my regular doctor need to know now that I'm done with cancer treatment?
19. Are my cancer care records going to my regular doctor?

—continued

—*Living with Cancer (After Treatment) continued from page 28*

20. Can we make a 1-2 year plan so I know which doctors, follow-up services, tests, and medicines I need and how often I need them?
21. What kind of records should I keep about my cancer treatment and history?
22. Can you write me a thorough summary that I can keep and share with doctors I visit in the future?
23. When can I go back to work or school?
24. Is there anything I should know or do before traveling?
Is it ok to travel by plane?
25. My partner and I would like to have a baby. Is it ok to get pregnant now?
26. Is there anything else I should be asking?

Other questions I have:

Word List

cancer - Cancer is a disease in which cells that are not normal grow out of control. Cancer cells can start in many parts of the body. They can spread to other parts of the body. There are more than 100 kinds of cancer.

chemotherapy - Chemotherapy is cancer treatment that uses drugs to kill cancer cells and stop them from growing.

clinical trials - Clinical trials are research studies in which people help doctors find ways to improve health and cancer care. A clinical trial may test how people react to new ways of screening, finding, preventing or treating a disease.

consent form - A consent form is a legal paper that you review and sign. It allows the doctor or researcher to move forward with treatment or research. The consent form must include needed facts about what is going to happen to you (like possible side-effects, as well as possible benefits). By law it must be written in a way that you can understand.

cure - Cancer is cured when all signs of the cancer are gone, and there is no chance that it will come back.

diagnosis - The process to find out what your health problem or disease, such as cancer, is. Doctors look at signs and symptoms that you have by doing a physical check-up and sometimes by doing tests to provide more details.

gene - A gene is a unit of heredity that is passed from parent to child.

general anesthesia - General anesthesia refers to drugs given to a patient before surgery, so the patient will not feel the pain of the surgery. When getting general anesthesia, the patient loses feeling and awareness for a limited time. The patient may feel like he or she is in a very deep sleep.

genetic testing - A test that looks at DNA to see if there is a mutation that might increase someone's chance of getting a disease like cancer.

health care provider - A health care provider is a licensed or certified person that provides health care services, like doctors, nurses, dieticians, social workers, pharmacists, treatment therapists and technicians.

health care team - The health care team is a group of health care professionals that treat and support people with cancer. The team may include your doctor, nurse, dietitian, pharmacist, radiation therapist, social worker, and others.

hospice - Hospice is a program that provides special care for people who are near the end of their life. Hospice may be provided at home, in the hospital, or in another facility.

informed consent - Informed consent is a process in which a person is told about treatment, research, or genetic testing so that he or she can decide to take part in it or not. Through the process, the patient should understand the harm (risks), benefits, and costs of the treatment, research or testing before they decide to take part or not. The patient should also learn more about the people in charge and how to contact them if they have questions or complaints.

inherited gene mutation - A gene mutation is a mistake or change of the information in a gene. An inherited gene mutation is a mutation that is passed from a parent to child.

operation - An operation refers to a surgery or medical process to take out or fix a part of the body or to find out if disease is present. An operation is sometimes called a surgery.

palliative care - Palliative care is also called comfort care, support care or symptom management. This care is given to prevent or relieve the side-effects caused by treatment and lessen the suffering caused by cancer and other life-taking diseases. A patient can get this care with other cancer treatments.

prognosis - A prognosis is a guess (prediction) about the likely outcome of a disease. Your prognosis provides answers to questions like: Will I be able to live a normal life? Will I be cured? Will I die?

radiation therapy - Radiation therapy is a treatment for cancer that uses high-energy radiation to kill cancer cells and shrink tumors. There are x-ray machines outside the body that provide this treatment or sometimes radioactive material can be placed in the body near cancer cells. Other names for this are: radiotherapy, irradiation, and x-ray therapy.

remission - Cancer is said to be “in remission” when the signs and symptoms lesson or go away.

stage (cancer stage) - The stage of one’s cancer refers to the extent of a cancer within the body. Cancer stages are 0, 1, 2, 3, and 4. A stage 1 cancer tumor is small and contained in one area. A cancer at stage 3 or 4 has spread to other parts of the body. The type of treatment you get depends on the stage of the cancer.

surgery - Surgery refers to a medical process to take out or fix a part of the body or to find out if disease is present. Surgery is sometimes called an operation.

symptom - A symptom is a sign of illness or condition that may feel like an illness or disease. Common symptoms during cancer treatment are fever, fatigue, nausea, vomiting, weight loss and pain. Patients should tell their doctor about their symptoms. Some may be easy to treat.

terminal cancer - Terminal cancer is cancer that cannot be cured.

transfusion - A transfusion is blood that is put in your body using an IV (intravenous) system.

treatment - Treatment is given to fix or manage a health problem and can be in many forms, like pills, surgery, radiation therapy, etc.

tumor - A tumor is a lump or large group of cells (mass). Tumors can be found to be cancer (malignant tumor) or found not to be cancer (benign tumor). A tumor is also called a neoplasm.

tumor board - A tumor board is a panel of cancer doctors who discuss their patients. Cancer care is complex, so doctors discuss various treatment options for their patients to make sure he or she is getting the best care. Members of a tumor board may include the doctors who provide cancer treatment with drugs (medical oncologists), surgery (surgical oncologists) and radiation (radiation oncologists)

“unproven” treatments - Unproven treatments are treatments that have not been proven by science to work. Some examples of “unproven treatments” are: eating acai berries and goji berries and using or taking shark cartilage and noni.

Sources: Malecare; Cancer Care Nova Scotia; National Cancer Institute; American Cancer Society; and Susan G. Komen for the Cure

Cancer Care Doctors

Oncologist: A doctor who treats cancer.

- **Medical Oncologist:** An oncologist who treats cancer with drugs (e.g., chemotherapy, hormonal therapy, biological therapy). A medical oncologist often is the main doctor for someone who has cancer. They may also give supportive care and may organize treatment given by other doctors.
- **Radiation Oncologist/Radiotherapist:** A radiologist with special training in the treatment of cancer using radiation.
- **Surgical Oncologist:** A surgeon with special training in the treatment of cancer using surgery.

Hematologist: A doctor with special training in diseases of the blood and blood-forming tissues.

Pathologist: A doctor who studies cells and tissues under a microscope to find out what disease a person has.

Physiatrist/Rehabilitation Specialist: A doctor or other health care expert that helps people regain function lost due to an illness or injury and return to daily life.

Some others on your team:

Cancer Patient Navigator: A person with special training to help cancer patients find and reach services and resources that they need during their cancer journey. Navigators can be based in the community, clinic, or hospital.

Case Manager: A trained health care worker that helps plan and manage the care for a patient before, during, and after treatment. A case manager can help patients with managing treatment plans, getting health insurance approvals, and finding support services.

Oncology Nurse: A nurse who specializes in treating and caring for people who have cancer.

Registered Dietitian/Nutritionist: A health care expert who can answer questions about nutrition and help plan diets for cancer patients with special food needs.

Social Worker: A professional trained to talk with people and their families about emotional or physical needs and to find them support services.

Sources: National Cancer Institute; American Cancer Society; livestrong.org; cancer.net

We hope you found this booklet of questions helpful in your journey.

We appreciate any feedback from you on:

- How you or your family used this book
- If you found the book helpful
- Ways you think we can improve this booklet.

Send comments and feedback to:

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Please contact us for more copies of this booklet.

In Appreciation

‘A ‘ohe hana nui ke alu ‘ia.

No task is too big when done together by all.

‘Olelo No‘eau 141 (MK Pukui)

It takes many hands to do this work. Mahalo piha to all who have helped with ideas, field testing, editing and constant encouragement. You represent the spectrum of agencies and groups that this booklet was made for, including the Native Hawaiian Health Care Systems, The Queen’s Medical Center, the Thoracic Tumor Clinic, Hawai‘i Medical Center, the Breast and Cervical Cancer Control Programs, and most important, the Cancer Patient Navigators and the Cancer Survivors and their families. ***Mahalo no kou kokua!***

HO‘OKELE I KE OLA
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