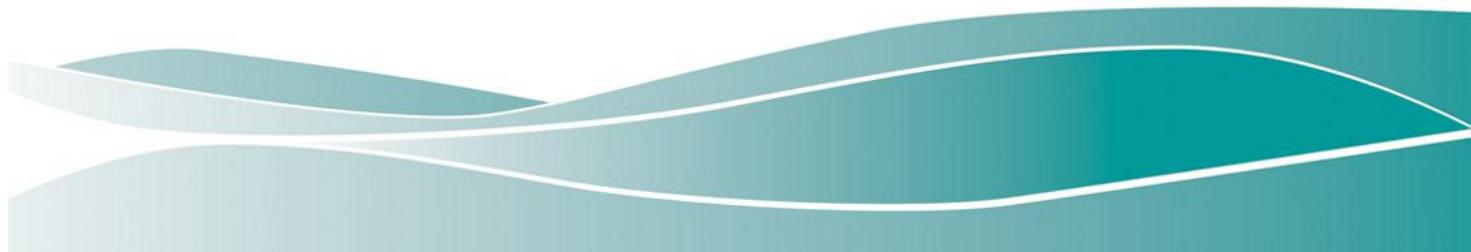
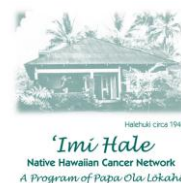




MANAGING YOUR CANCER CARE RECORDS



HO'OKELE I KE OLA
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Contents

What to Include in a Patient Record	4
Managing a Cancer Care Record	5
Your Personal Information Form	6
Your Personal Health History Form	7-8
Your Health Team Form	9
Your Medical Team Form	10-11
Your `Ohana Team Form	12-13
Health Insurance Information Form	14
Preparing for Appointments	15
Appointment Notes Form	16-17
Hospitalization Information Form	18
Outpatient Procedure Information Form	19
Chemotherapy Schedule Form	20
Radiation Schedule Form	21
Pharmacy Information	22
Keeping Track of Your Medicines	23
Medication Record Form	24-25
Your Legal Documents	26
Your Journal or Diary	27
Getting a Second Opinion	28
Getting Copies of Your Medical Records	29
Your Bills and Payments Log	30-31
Quick Contact List	32

What to Include in a Patient Record

- Personal Information
- Personal Health History
- Your Health Team
 - Medical Team
 - ‘Ohana Team
- Health Insurance Information
- Appointment Notes, including Questions to Ask the Doctor and Others
- Hospitalization and Outpatient Procedure Information
- Your Test Results
- Chemotherapy and Radiation Schedules
- Pharmacy Information
- Medication Record
- Your Legal Papers
- Second Opinion Information
- Your Bills and Payments
- Notes

Forms in this Patient Record Packet were developed by ‘Imi Hale or adapted from several organizations dedicated to helping people with cancer. These include:

- **The Lance Armstrong Foundation**, through its LIVESTRONG program, offers information, tip sheets and multiple forms for cancer patients.
- **The Wellness Community** provides lots of information and organization tools for cancer patients. Some of their materials are provided.
- **CancerCare.org** provides lists of questions you may want to ask your doctor.

Managing a Cancer Care Record

You have a right to copies of all the paperwork about your healthcare and treatment.

Under the Health Insurance Portability and Accountability Act of 1996 (also called HIPAA), you have the right to get copies of your medical records, x-rays, biological slides, and other stuff related to your cancer.

We recommend that you keep a Patient Record. When you share your record with a health care provider, they don't have to ask you the same questions over and over again. Each provider will know what the other provider is doing. Your family and Navigator can help you better because all your paperwork is in one place. Keeping a Patient Record can help reduce your stress and save time.

Organize your Paperwork.

- Get something big enough to carry your information, like a 3-ring binder. Use dividers to sort your information.
- Buy plastic-pocket pages that allow you to insert test results and information the doctor gives out. Do not have loose papers!
- Organize records in the order that things happened. The earliest note should be first.
- Your Navigator has “forms” that can help you track your treatment. Because everyone's cancer is different, and everyone's treatment is different, your Navigators should only give you the forms that you need.

Create two copies of your Patient Record, just in case one is lost. Take one with you to all appointments, and keep the other at home or in a safe place.



Decide who can have access of your cancer care information. As a person with cancer, you may need help with your records. Think about who can help you collect, organize and update your cancer care information? Who will have access to this information? Where will the information folder be kept so the right people have access to it?

Your Personal Information

Full legal name: _____

Home Address: _____

Home 📞: _____ Work 📞: _____ Cell 📞: _____

Employer: _____ Job Title: _____

Work Address: _____

Personal Identification (Driver's License, State ID, etc) _____

Father's name: _____

Mother's full maiden name: _____
(and whether she took your father's surname)

Marital status: _____

Spouse/Domestic Partner's name: _____

Home 📞: _____ Work 📞: _____ Cell 📞: _____

Other contact person(s):

Name: _____ Relationship to you: _____

Home 📞: _____ Work 📞: _____ Cell 📞: _____

Name: _____ Relationship to you: _____

Home 📞: _____ Work 📞: _____ Cell 📞: _____

Name: _____ Relationship to you: _____

Home 📞: _____ Work 📞: _____ Cell 📞: _____

Your Personal Health History

Use this form to record your past health history. Print out a copy and take it with you to your doctor appointment to help keep your doctor up-to-date.

1. I was in the hospital for (list conditions).

Date

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

2. I have had these surgeries

Date

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

3. I have had these injuries, conditions, and illnesses:

Date

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

4. I have these allergies (list type of allergy—food, medicine, etc.—and reaction):

5. I have had these immunizations (shots):

For adults	Suggested age	Date(s) received
Influenza	Every year starting at age 65	_____
Pneumococcal	Once at age 65	_____
Tetanus (Td)	Every 10 years	_____

6. I take these medicines / supplements (bring with you, if possible):

7. My family members (parents, brothers, sisters, grandparents) have / had these major conditions:

8. Other notes about your past health and health care.

Source: Choosing a Doctor. *Your Guide to Choosing Quality Health Care*. AHCPR
Publication No, 99-0012, July 2001. Agency for Healthcare Research and Quality, Rockville, MD.
<http://www.ahrq.gov/consumer/qntascii/qntdr.htm>

Your Health Team

Keep a list of all your health care providers, including:

- Family Doctor
- Cancer Doctor (oncologist)
- Surgeon
- Radiation Oncologist
- Chemotherapy Nurse
- Social Worker
- Dietitian
- Any other doctor providing health care for you (not just cancer care).
 - Heart Doctor (cardiologist)
 - Diabetes Doctor (diabetologist, endocrinologist)
 - Etc.
- Complementary and Alternative Medical Care Providers
 - Traditional healers (Kahuna lā`au lapa`au, lomilomi, etc.)
 - Chiropractor
 - Acupuncturist
 - Others
- `Ohana and other care givers
- Spiritual and Religious Workers

Cancer Patient Navigator _____

Agency/Address _____

Work 📞: _____ Cell 📞: _____ (E-mail) _____

Helps me with: _____

MEDICAL Team

Family Doctor or Internist:

Name: _____ Office Hours: _____

Nurses/Staff names: _____

Address: _____

Other offices: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Other phone numbers: _____

Office Hours:

NOTES:

Other Non-Cancer Doctors, Traditional Healers, and Therapists

Name: _____

Specialty: _____ Office Hours: _____

Nurses/Staff names: _____

Address: _____

Other offices: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Other phone numbers: _____

NOTES:

Name: _____

Specialty: _____ Office Hours: _____

Nurses/Staff names: _____

Address: _____

Other offices: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Other phone numbers: _____

NOTES:

Cancer Care Doctors:

Name: _____ Office Hours: _____

Nurses/Staff names: _____

Address: _____

Other offices: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Other phone numbers: _____

Office Hours:

NOTES:

Name: _____

Specialty: _____ Office Hours: _____

Nurses/Staff names: _____

Address: _____

Other offices: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Other phone numbers: _____

NOTES:

Name: _____

Specialty: _____ Office Hours: _____

Nurses/Staff names: _____

Address: _____

Other offices: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Other phone numbers: _____

NOTES:

‘OHANA Team (family, friends, pastor, others)

Name: _____

Relation to me: _____ E-mail: _____

Home 📞: _____ Work 📞: _____ Cell 📞: _____

Helps me with: _____

Name: _____

Relation to me: _____ E-mail: _____

Home 📞: _____ Work 📞: _____ Cell 📞: _____

Helps me with: _____

Name: _____

Relation to me: _____ E-mail: _____

Home 📞: _____ Work 📞: _____ Cell 📞: _____

Helps me with: _____

Name: _____

Relation to me: _____ E-mail: _____

Home 📞: _____ Work 📞: _____ Cell 📞: _____

Helps me with: _____

Name: _____

Relation to me: _____ E-mail: _____

Home ☎: _____ Work ☎: _____ Cell ☎: _____

Helps me with: _____

Name: _____

Relation to me: _____ E-mail: _____

Home ☎: _____ Work ☎: _____ Cell ☎: _____

Helps me with: _____

Name: _____

Relation to me: _____ E-mail: _____

Home ☎: _____ Work ☎: _____ Cell ☎: _____

Helps me with: _____

Name: _____

Relation to me: _____ E-mail: _____

Home ☎: _____ Work ☎: _____ Cell ☎: _____

Helps me with: _____

Name: _____

Relation to me: _____ E-mail: _____

Home ☎: _____ Work ☎: _____ Cell ☎: _____

Helps me with: _____

Health Insurance Information

Primary Insurer: _____

Subscriber Name: _____

Subscriber Number: _____ Group Number: _____

Benefits: Medical Dental Drug Vision

Insurer Contact Information: _____

Other Insurer: _____

Subscriber Name: _____

Subscriber Number: _____ Group Number: _____

Benefits: Medical Dental Drug Vision

Insurer Contact Information: _____

Other Insurer: _____

Subscriber Name: _____

Subscriber Number: _____ Group Number: _____

Benefits: Medical Dental Drug Vision

Insurer Contact Information: _____

Make photocopies of your insurance card(s). Keep them in a plastic-pocket page in this binder. Each doctor's office will want a copy.

Preparing for Appointments

Use the following **Appointment Notes** Form to arrange and prepare for your visit to the doctor.



Before your appointment:

- ✓ Confirm your appointment
- ✓ Confirm location and how you will get to the appointment
- ✓ Bring all the paperwork your doctor wants to see
- ✓ Complete any lab tests/blood work ahead of time
- ✓ Write a list of questions you or your family may have for the doctor on the form and bring the form to the appointment so you don't forget to ask.

At your appointment

- ✓ Bring someone who can help you ask questions and get answers.
- ✓ Write down what the doctor tells you and what he wants you to do after the appointment. (Or have your *kokua* (caregiver) write down this information for you.)
- ✓ Write down the next appointment date with this doctor/health care provider. (Or have your *kokua* write down this information for you.)

Appointment Notes

With: _____

Date: _____ (Day) _____

Location: _____

Time: _____ AM PM

To Do before the appointment:

Appt. confirmed 24 hrs. before

- Put appointment on calendar
- Get lab work by this date: _____
- Arrange transportation to appointment
- Get directions to the office/place
- Decide who will go with me: _____
- Bring these things: _____

Other: _____

Questions I need to ask:

1. _____
2. _____
3. _____
4. _____

Things I need to do after the appointment:

1. _____
2. _____
3. _____
4. _____

<p>Next Appointment? Date: _____ Time: _____</p>

Appointment Notes

With: _____

Date: _____ (Day) _____

Location: _____

Time: _____ AM PM

To Do before the appointment:

Appt. confirmed 24 hrs. before

- Put appointment on calendar
- Get lab work by this date: _____
- Arrange transportation to appointment
- Get directions to the office/place
- Decide who will go with me: _____
- Bring these things: _____

Other: _____

Questions I need to ask:

1. _____
2. _____
3. _____
4. _____

Things I need to do after the appointment:

1. _____
2. _____
3. _____
4. _____

<p>Next Appointment? Date: _____ Time: _____</p>

Hospitalization Information (1 sheet per hospital stay):

Hospital Name: _____

Address: _____

Other offices: _____

Phone & Fax: _____ E-mail: _____

Other phone numbers: _____

Reason for stay (surgery, chemotherapy, radiation, other): _____

Admission date: _____ Discharge date: _____

Admitting doctor: _____

Discharge doctor: _____

Doctors who came to see me while there:

Name: _____ Specialty: _____

Name: _____ Specialty: _____

Name: _____ Specialty: _____

Name: _____ Specialty: _____

Take home information:

- Discharge Summary
- Instructions for care
- Appointment with doctor
- Medicines to take
- Diet instructions
- Copies of tests for next appointment

Admission date: _____

Discharge date: _____

NOTES:

Outpatient Procedure Information (1 per procedure)

Facility Name: _____

Address: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Other phone numbers: _____

Type of procedure (diagnostic test, outpatient surgery, radiation set up, chemo start, other):

_____ Date: _____

Doctor: _____ Nurse: _____

Others Name: _____ Role: _____

Name: _____ Role: _____

Name: _____ Role: _____

Name: _____ Role: _____

Take home information:

- Discharge Summary
- Instructions for care
- Appointment with doctor
- Medicines to take
- Diet instructions
- Copies of tests for next appointment

NOTES:

Chemotherapy Schedule

Oncologist: _____

Facility Name: _____

Address: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Staff and their phone numbers: _____

Plan for Chemo: _____

Chemo Schedule:

Date and Time	Date and Time	Date and Time

Possible side effects _____

Between visits, I should call the doctor if: _____

Radiation Schedule

Radiation Oncologist: _____

Facility Name: _____

Address: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Staff and their phone numbers: _____

Plan for Radiation: _____

Radiation Schedule:

Date and Time	Date and Time	Date and Time	Date and Time

Possible side effects _____

Between visits, I should call the doctor if: _____

Pharmacy Information:

Pharmacy Name: _____

Address: _____

Other locations: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Other phone numbers: _____

Medicines I get from this pharmacy:

1. _____ Prescription # _____
2. _____ Prescription # _____
3. _____ Prescription # _____
4. _____ Prescription # _____
5. _____ Prescription # _____

NOTES:

Pharmacy Name: _____

Address: _____

Other locations: _____

Phone ☎: _____ Fax ☎: _____ (E-mail) _____

Other phone numbers: _____

Medicines I get from this pharmacy:

1. _____ Prescription # _____
2. _____ Prescription # _____
3. _____ Prescription # _____
4. _____ Prescription # _____
5. _____ Prescription # _____

NOTES:

Keeping track of your medicines:

1. Directions on HOW and WHEN to take your medicines can be confusing so write down how your doctor says that you should be using your medications.

Caution: If the prescription says to take the medicine with meals, be certain to find out whether that means one pill with some food at approximately the same time each day or literally one pill at each meal. There is a huge difference between one pill and three pills.

2. Sometimes your physician will give you a trial bottle or sample bottle to get you started. This bottle may not have the usage instructions on it, so it is important to write that information down in your personal notes.
3. Transfer all the prescription information to a single sheet (see form attached).
4. Share that list with your doctor so that he knows what you are already taking. It is likely that you will have more than one doctor for your cancer care and one doctor may not know what your other doctor has prescribed for you.
5. Make sure to have a list of your non-prescription medicines (medicines that you can buy yourself without a doctor's prescription).
6. From time to time, have your pharmacist review all of your prescription and non-prescription medications and preparations to be certain that there are no bad interactions among them. Your pharmacist likely has a computer with up to date information that your individual doctors may not be aware of, especially about medications that other doctors may be prescribing for you.

Medication Record

Name of medication	FROM WHO/WHERE (Doctor, Kahuna, or Over-the Counter)	When/how do I take it?	Warnings and side effects
Name: _____ Stop this medication when: _____ _____		<input type="checkbox"/> Before breakfast <input type="checkbox"/> With breakfast <input type="checkbox"/> Before lunch <input type="checkbox"/> With lunch <input type="checkbox"/> Before dinner <input type="checkbox"/> With dinner <input type="checkbox"/> At bed time	
Name: _____ Stop this medication when: _____ _____		<input type="checkbox"/> Before breakfast <input type="checkbox"/> With breakfast <input type="checkbox"/> Before lunch <input type="checkbox"/> With lunch <input type="checkbox"/> Before dinner <input type="checkbox"/> With dinner <input type="checkbox"/> At bed time	
Name: _____ Stop this medication when: _____ _____		<input type="checkbox"/> Before breakfast <input type="checkbox"/> With breakfast <input type="checkbox"/> Before lunch <input type="checkbox"/> With lunch <input type="checkbox"/> Before dinner <input type="checkbox"/> With dinner <input type="checkbox"/> At bed time	
Name: _____ Stop this medication when: _____ _____		<input type="checkbox"/> Before breakfast <input type="checkbox"/> With breakfast <input type="checkbox"/> Before lunch <input type="checkbox"/> With lunch <input type="checkbox"/> Before dinner <input type="checkbox"/> With dinner <input type="checkbox"/> At bed time	
Name: _____ Stop this medication when: _____ _____		<input type="checkbox"/> Before breakfast <input type="checkbox"/> With breakfast <input type="checkbox"/> Before lunch <input type="checkbox"/> With lunch <input type="checkbox"/> Before dinner <input type="checkbox"/> With dinner <input type="checkbox"/> At bed time	

Name: _____ Stop this medication when: _____ _____		<input type="checkbox"/> Before breakfast <input type="checkbox"/> With breakfast <input type="checkbox"/> Before lunch <input type="checkbox"/> With lunch <input type="checkbox"/> Before dinner <input type="checkbox"/> With dinner <input type="checkbox"/> At bed time	
Name: _____ Stop this medication when: _____ _____		<input type="checkbox"/> Before breakfast <input type="checkbox"/> With breakfast <input type="checkbox"/> Before lunch <input type="checkbox"/> With lunch <input type="checkbox"/> Before dinner <input type="checkbox"/> With dinner <input type="checkbox"/> At bed time	
Name: _____ Stop this medication when: _____ _____		<input type="checkbox"/> Before breakfast <input type="checkbox"/> With breakfast <input type="checkbox"/> Before lunch <input type="checkbox"/> With lunch <input type="checkbox"/> Before dinner <input type="checkbox"/> With dinner <input type="checkbox"/> At bed time	
Name: _____ Stop this medication when: _____ _____		<input type="checkbox"/> Before breakfast <input type="checkbox"/> With breakfast <input type="checkbox"/> Before lunch <input type="checkbox"/> With lunch <input type="checkbox"/> Before dinner <input type="checkbox"/> With dinner <input type="checkbox"/> At bed time	
Name: _____ Stop this medication when: _____ _____		<input type="checkbox"/> Before breakfast <input type="checkbox"/> With breakfast <input type="checkbox"/> Before lunch <input type="checkbox"/> With lunch <input type="checkbox"/> Before dinner <input type="checkbox"/> With dinner <input type="checkbox"/> At bed time	

Your Legal Documents

It is important to make your own wishes known about health treatment. Some people are OK with letting their doctor or family member make health treatment decisions for them. But often, people with cancer feel better once their own wishes are known. Talk with someone close to you about what kind of care you want. The more you know, the more prepared you will be.

Advance Directives are legal papers that tell the doctors what to do if you cannot tell them yourself. You can decide ahead of time, how you want to be treated. Advanced Directives may include a living will, durable power of attorney, and Physician's Orders for Life-Sustaining Treatment (POLST).

- **Living Will.** A living will is a document that lets people know your wishes regarding medical care if you can't speak for yourself. It relieves your family of the guilt and conflict that can come with having to make these types of decisions.
- **Durable Power of Attorney for health care** lets you name someone to make decisions for you in case you cannot. This person is someone you choose and is called a "health care proxy". It should be a person you trust.
- **Physician's Orders for Life-Sustaining Treatment (POLST)** tells health care providers, including emergency responders, what treatments you'd like to receive as you near the end of your life. Your health care provider may have copies of the form, or you can download the form and bring it to your next appointment. Your provider will explain the form to you and give you more information about your treatment options.

Do you need a lawyer? A lawyer is not always needed to fill out these documents. But you may need a **notary public**. Each state has its own laws about advance directives.

What if you and your family do not agree? Your family members may have different opinions from you, but you have the final decision. It is important to talk early. If you cannot agree, ask someone for help. You might talk to a member of your church, other people dealing with cancer, a trusted family friend, or a hospice worker.

Advance directives: Completed? Yes No

Give copies of your advance directive to your health care team, the hospital medical records department, and the person you choose as your durable power of attorney for health care.

I have designated this person as my power of attorney:

Name: _____ Relationship _____

Address: _____

Home ☎: _____ Work ☎: _____ Cell ☎: _____

Your Journal or Diary

Many patients have found a journal or diary helpful.

- ✓ Coping with the challenges of having cancer by providing a place to vent
- ✓ Provides a document of your emotional and physical changes
- ✓ A place to express thoughts and feelings that are sometimes difficult to say out loud or discuss with someone
- ✓ Provides a document of your cancer care

Each person has a preference about what kind of journal or diary to keep. Some write volumes daily, while others jot down brief notes. Find something that matches your style.

Getting a Second Opinion

Requesting a second opinion is normal, and your doctor should not be offended. Your doctor should appreciate that you are gathering all the information you need to make informed decisions throughout your treatment.

Sometimes you can get different opinions. If there is a difference of opinions, you can consider getting a third consultation.

Getting the most out of a second opinion:

1. Arrange to have a complete set of your medical records and medical reports to share with the doctor making the second opinion. This should include any of the following that you have:
 - MRI – Magnetic Resonance Imaging
 - CT Scan – Computer Tomography
 - PET Scan – Positron Emission Tomography
 - Pathology slides
 - Lab Results

How to get records:

- a. Ask your doctor or nurse where to get copies of your tests and reports.
 - b. The Pathology Lab may need 48 hours notice to make copies of your slides.
 - c. There may be a charge for getting copies of your slides so ask.
2. Write down questions you want to ask the doctor and bring the list of questions to the meeting.
3. Bring a friend or family member with you to help you take notes. If it is alright with the doctor, you can record the meeting so that you can refer to the tape when you discuss this later with your family.

What if the opinions of both doctors are different? What if they disagree on how to treat you?

If you get different opinions on your treatment, discuss the pros and cons with the doctor you are most comfortable with. It is standard practice to take the opinion you learn from a “second opinion doctor” back to the first doctor. This happens all the time.

Source: *Frankly Speaking About New Discoveries in Cancer. Special Focus on Colorectal Cancer.* The Wellness Community 2005.

Getting Your Medical Records:

You may need to request a copy of your complete Medical Records if you:

- Seek a second/third opinion
- Apply for disability or extended leave at your job
- Apply for Social Security disability
- Go for evaluation/treatment at a different facility

Doctors prepare reports of each visit. There should be a report for each time you see a physician, physical therapist, or another provider. There should be a report for each checkup, lab test, x-ray, surgery, chemotherapy visit, radiation visit, hospitalization, etc.

If possible, collect copies as you go. Even then, you may have to request your complete Medical Record. Things to get include:

- The note that's added to your chart at each visit to a physician, physical therapist, or other provider for a checkup or treatment
- Each set of lab results
- A written report of each imaging procedure (listed next)
- Imaging films: x-rays, CT scans, MRIs, PET, etc. Remember, these must be kept flat and stored in a cool place. Some results are provided on a CD/DVD
- Each written pathology report
- Discharge summary of each hospitalization
- Tissue blocks and specimen slides.

Getting Your Record. You have the right to your Medical Record. Some facilities may ask you to pay for a copy of your Medical Record. Usually, if your physician requests a copy of your Medical Record, it will be provided at no cost.

Your Bills and Payments

✓ **Collect All your Receipts:**

- your co-payments (the portions that you pay for)
- your prescription payments

You may need to come up with one or more of these receipts on very short notice. Keep them well organized.

✓ **File the bills by provider, with most current bill on top.**

✓ **Log all payments you make and to who (form provided).**

Payments made for my cancer care:

Date Paid	HOW?	Paid to who and what did you pay for	Invoice number

Quick Contact List

Name: _____ Work ☎: _____

Cell ☎: _____

Email: _____

Name: _____ Work ☎: _____

Cell ☎: _____

Email: _____

Name: _____ Work ☎: _____

Cell ☎: _____

Email: _____

Name: _____ Work ☎: _____

Cell ☎: _____

Email: _____

Name: _____ Work ☎: _____

Cell ☎: _____

Email: _____

Name: _____ Work ☎: _____

Cell ☎: _____

Email: _____

Name: _____ Work ☎: _____

Cell ☎: _____

Email: _____

Name: _____ Work ☎: _____

Cell ☎: _____

Email: _____