Cancer Survivor Care Plan

What's Next?
Life After Cancer Treatment

A project of:
minnesota cancer alliance
working together to eliminate the burden of cancer

The Minnesota Cancer Alliance is pleased to provide this survivorship care plan: *What's Next? Life After Cancer Treatment*. This booklet is a road map of sorts, a way to help you record where you've been and provide information to help you plan the next part of your cancer journey.

This booklet is designed to help you:

- create a concise history of your cancer treatment experience
- provide a platform for dialog with your care providers
- manage your follow-up medical care
- gain an awareness of side effects in both the short and long-term
- provide tools and direction for self-care involving physical, emotional and practical issues

Karen Karls is a cancer survivor from Grand Rapids, Minnesota. She has some thoughts to share on cancer and the use of this booklet.

It's cancer.

The words set your world spinning and fill you with fear. Soon your life is centered on doctors, tests, and treatments. You learn what comes next and who to go to with questions.

Then comes your last big treatment, and you are left wondering, What next?

A survivor care plan would have helped me with this question. A care plan is a history of your cancer journey. It is a place to note the stages of your treatment, long-term side effects and what to expect from your follow-up care.

It's been 11 years for me, and the exact treatment dates have faded from my memory. With a care plan, I can find these details without having to go through all of my records.

A survivor care plan is for the future –
an empowering reminder that you still have control of your life.
Cancer happened to you, but it does not have to define who you are.

– Karen Karls

TABLE OF CONTENTS

This publication was supported by CDC Cooperative Agreement Number 5U58DP000802-03. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

SUMMARY OF CANCER TREATMENT

Having detailed information about the cancer treatment you receive is important.

Use this section to write notes about your diagnosis, treatment, and care team. This will be useful to future doctors and others who may need to know your cancer history.

Please update this section as you learn more details about your cancer journey.

Every person's cancer experience is different, so parts of the booklet may not apply to you.

PERSONAL INFORMATION:

Name _____

Address _____

Phone _____

Date of birth _____

People who supported me through my diagnosis and treatment:

Name	Relationship	Phone	Signed a "release of information" form? *Note

**Note if you signed a form that gives this person access to your medical records, this form needs to be renewed every year.*

I have completed a Health Care Directive: ❒Yes ❒No

Where my Health Care Directive is located _____

A Health Care Directive (also known as a Living Will or Durable Power of Attorney for Health Care) is designed to assist a person in communicating their wishes about health care, should they be unable to make or communicate decisions. It is a document in which a person may name someone to make decisions for them and/or provide information about care they would or would not like to receive in the event that they cannot speak for themselves.

PEOPLE IN MY FAMILY WITH CANCER

Relative	Name	Type of cancer	Age at diagnosis
Mother			
Father			
Sibling			
Sibling			
Mother's mother			
Mother's father			
Father's mother			
Father's father			
Child			
Other			

GENETIC COUNSELING

Genetic testing will tell you if cancer runs in your family. Most cancers do not run in the family. Only a small number of people will need genetic counseling.

Did my care team suggest genetic counseling? ❒Yes ❒No

I received genetic counseling. ❒Yes ❒No If yes:

1. Date I met with the genetic counselor _____

2. Type of genetic test I had _____

3. Date of test _____

4. Results of test _____

MEDICAL CARE TEAM

General Care

Family doctor _____

Office or clinic name _____

Address _____

_____

Phone _____ Fax _____

Cancer Surgery

Cancer surgeon _____

Office or clinic name _____

Address _____

_____

Phone _____ Fax _____

Cancer Care

Cancer doctor (oncologist) _____

Nurses _____

Office or clinic name _____

Address _____

Phone _____ Fax _____

MEDICAL CARE TEAM

Radiation

Radiation doctor _____

Nurses _____

Office or clinic name _____

Address _____

_____

Phone _____ Fax _____

Other Specialist

Name and title _____

Office or clinic name _____

Address _____

_____

Phone _____ Fax _____

Hospital or Clinic

Hospital or clinic name _____

Address _____

_____

Phone _____ Fax _____

MEDICAL CARE TEAM

Hospital or Clinic

Hospital or clinic name _____

Address _____

_____

Phone _____ Fax _____

Other Care Providers	Name	Contact Information
Social worker		
Psychologist		
Psychiatrist		
Dietician		
Genetic counselor		
Physical therapist		
Spiritual advisor		
Rehabilitation therapist		
Complementary and Alternative Medicine care providers (chiropractor, acupuncturist, massage therapist, etc.)		
Other(s)		

CANCER DIAGNOSIS

Type of cancer _____

Date I learned I had cancer _____ Stage _____

Hospital or clinic that found the cancer _____

Comments _____

_____

I have a copy of my pathology report: ❒Yes ❒No

Where my pathology report is located _____

CANCER TREATMENT SUMMARY

Some of the treatments may not apply to you.

1st Surgery

Type of surgery _____

Date of surgery _____

Where surgery was done _____

Doctor who did the surgery _____

Describe any problems you had after surgery _____

_____

_____

I have a copy of my surgery record: ❒Yes ❒No

CANCER TREATMENT SUMMARY

2nd Surgery

Type of surgery _____

Date of surgery _____

Where surgery was done _____

Doctor who did the surgery _____

Describe any problems you had after surgery _____

_____

_____

I have a copy of my surgery record: ❒Yes ❒No

3rd Surgery

Type of surgery _____

Date of surgery _____

Where surgery was done _____

Doctor who did the surgery _____

Describe any problems you had after surgery _____

_____

_____

I have a copy of my surgery record: ❒Yes ❒No

CANCER TREATMENT SUMMARY

1st Course of Radiation

Where I received treatments _____

Dates: from _____ to _____

Area of body treated _____

Number of treatments _____ Total dose _____

Describe any problems you had from the radiation _____

_____

_____

2nd Course of Radiation

Where I received treatments _____

Dates: from _____ to _____

Area of body treated _____

Number of treatments: _____ Total dose _____

Describe any problems you had from the radiation _____

_____

_____

I have a copy of my radiation therapy summary: ❒Yes ❒No

CANCER TREATMENT SUMMARY

Port Information

Hospital where port was placed _____

Date port was placed _____

Area of body _____

Type of port (brand and company) _____

_____

Describe any problems you had with the port _____

_____

_____

I have a copy of my port information: ❒Yes ❒No

Clinical Trial Information

You may join a clinical trial at any point in your cancer journey.

Name of clinical trial _____

Dates of trial _____

Hospital or clinic where trial was done _____

Name of contact person _____

Describe any problems after the trial _____

_____

I have a copy of the details from my clinical trial: ❒Yes ❒No

CANCER TREATMENT SUMMARY

Chemotherapy, Biotherapy, Hormone Therapy (and other drugs received as part of my cancer treatment)

Where I received therapy_____

Drug name	How often	Start date	End date

CANCER TREATMENT SUMMARY

Chemotherapy, Biotherapy, Hormone Therapy

Describe any bad reactions or problems from treatments

I have a copy of my therapy records: ❒Yes ❒No

Bone Marrow or Cord Blood Transplant

Type of transplant:
❒Autologous (you received cells that you donated)
❒Allogeneic (you received cells that someone else donated)

Hospital name _____

Date of transplant _____

Other Procedures and Treatments

Name	Hospital or clinic	Dates
Blood transfusion (red cells or platelets)		
Dialysis		
Biopsy		
Other		

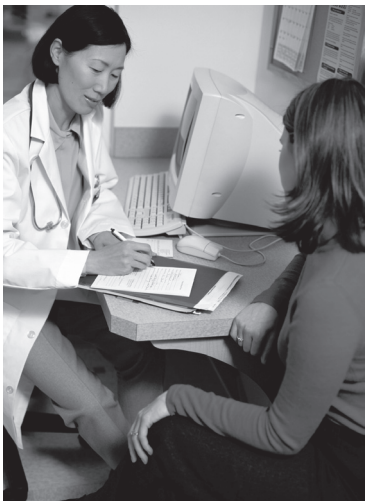
AFTER TREATMENT CARE

This section explains the care you will need after you finish your cancer treatment. It lists questions you may want to ask your doctors. It also helps you think about the support you might need as a cancer survivor.

After your treatment ends, you will still see your doctor for regular care. You should know:

- What tests and clinic visits you will need
- How often you will need them
- Where to go for tests and exams

Many patients visit their cancer doctor every few months for several years. During clinic visits, your care team will check your health and answer your questions.



AFTER TREATMENT CARE

Long-term Issues

Ask your doctor what side effects you might have after your treatment has stopped:

❒Appetite (hunger) changes	❒Breathing problems	❒Bone pain
❒Change in concentration	❒Dental concerns	❒Change in ability to have children (fertility)
❒Headaches	❒Hearing changes	❒Heart problems
❒Hormone changes	❒Low energy	❒Memory changes
❒Pain	❒Sadness	❒Sexual health changes
❒Skin changes	❒Changes in sleep patterns	❒Swollen arms or legs (lymphedema)
❒Urinary problems	❒Worry	❒Numbness of hands or feet
❒Other (list)		

AFTER TREATMENT CARE

Questions to Ask

How long can side effects last after treatment has stopped?

Who should I call if I have any of these side effects?

How can I manage these side effects?

Other

AFTER TREATMENT CARE

	How often should I see my doctor?	Purpose of visit
Family doctor		
Cancer doctor		
Surgeon		
Other specialist(s)		

Comments _____

_____

_____

Now that I am finished with my cancer treatment:

When should I call my cancer doctor (oncologist)?_____

_____

When should I call my family doctor?_____

_____

When should I call other doctors or care providers involved in my care?

_____

_____

_____

_____

AFTER TREATMENT CARE

Scans and X-rays (MRIs, PET Scans, CT Scans, etc.)

Which tests will I need, and how often?_____

_____

Who will order the tests?_____

Dates of tests _____

How will I get my test results?_____

Lab tests & blood draws

Which tests will I need, and how often?_____

_____

Who will order the tests?_____

Dates of tests_____

How will I get my test results?_____

Other After-Treatment Tests

Which tests will I need, and how often?_____

_____

Who will order the tests?_____

Dates of tests _____

How will I get my test results?_____

AFTER TREATMENT CARE

Advice from Your Care Team

❒Screening tests (to check for cancer): _____

_____

❒Eating habits: _____

_____

❒Exercise – what kind should I do? _____

_____

❒Healthy weight programs: _____

_____

❒Sunscreen: _____

_____

❒Immunizations: _____

_____

❒Help to quit smoking and tobacco: _____

_____

❒Support groups: _____

_____

❒Counseling (individual, couples, family): _____

_____

❒Sleep: _____

_____

❒Complementary and alternative medicine: _____

_____

❒Preventing osteoporosis (weak bones): _____

_____

❒Other: _____

AFTER TREATMENT CARE

Other Concerns

Below is a list of topics to think about after you finish treatment.

Topic	My concern	Person who can help
My relationships		
Legal issues		
Spiritual issues		
Money problems		
My job		
My rights at work		
Financial (money) planning		
Estate planning		
Long-term care		
Health insurance		
Nutrition		
Emotional support		
Health changes		
Lifestyle changes		
Fear of cancer return (recurrence)		
Other		

RESOURCES

American Cancer Society 1-800-227-2345
www.cancer.org

Cancer Survivors Network
www.acscsn.org

National Cancer Institute 1-800-4-CANCER
www.cancer.gov [1-800-422-6237]

Life After Cancer Treatment
www.cancer.gov/cancertopics/life-after-treatment

Notes

Minnesota Cancer Alliance
Minnesota Department of Health
85 East Seventh Place
P.O.Box 64882
St. Paul, MN 55164
Phone: 651-201-3608
Fax: 651-201-3603
e-mail: communications@mncanceralliance.org
http://www.mncanceralliance.org

A project of:
minnesota cancer alliance
working together to eliminate the burden of cancer