



MY UNEXPECTED JOURNEY

 Comprehensive
Cancer Control
Collaborating to Conquer Cancer
— NORTH CAROLINA —

A journal for a challenging health diagnosis.



**You Are Not Alone;
Moving Forward Together**



THE GOOD NEWS

- You are a Survivor from the time of diagnosis.
- People are living longer after a cancer diagnosis.

MY CONTACT INFORMATION

Name:

Address:

Mobile Phone:

()

Home Phone:

()

Emergency Contact(s) & Phone Numbers

Contact:

Phone:

()

Contact:

Phone:

()

Index

| | |
|-------------------------------------|----|
| My General Health Information | 5 |
| My Family Health History | 11 |
| My Appointments | 13 |
| My Health Care Team | 43 |
| My Next Journey | 48 |

MY UNEXPECTED JOURNEY

A journal for a challenging health diagnosis.

My Unexpected Journey: A journal for a challenging health diagnosis is a tool for you to record important information about your health history, current medicines, health care providers, treatments, health numbers, health tips, screenings, important names and numbers, and special instructions all in one place.

Take this Journal with you to your appointments so you will have the information you need during your visit. There is space for you to take notes, write down questions and answers and your next date to see a health care provider.



A daffodil is the flower of cancer survivors.

The North Carolina Comprehensive Cancer Control Program is working to support cancer survivors through partnership, education and improved access to treatment, palliative and other cancer resources and services.

Beginning Your Journey

Your cancer diagnosis has unexpectedly changed your world. With this sudden change in your life you may feel numb, in shock, afraid and worried about the future. The good news is that more and more people are living with their cancers and thriving in their lives with treatment or are living cancer free. More often now cancer research discovers new forms of treatment that can help move survivors into remission and living longer after a cancer diagnosis.

**You are not alone.
We can move forward together.**

To start your journey, record your important personal information, current prescriptions, non-prescription medicines and family health history in this Journal. Be sure to include vitamins, over the counter medications and herbal or supplements that you take. This will provide you easy access to information that your health care providers will ask for at your appointments. They will need to know this information to make sure there are no interactions with your cancer treatment.

Every person has similar and, yet, different experiences with their treatment. This is a new experience for you, your family and friends. Don't hesitate to ask questions about your treatment, any side effects you may notice and what other things you should do. Your health care team and support team are there to care for you and support you during your journey.

This Journal provides a section to record information about your treatments, questions to ask your medical providers and a place to take notes during your health appointments. It records your steps toward being a Cancer Survivor and learning to live beyond diagnosis and treatment.

One of the most important things you can do early in this journey is to identify one person or several people to support you. This may be any combination of a loved one, a special friend or a group of friends. They can be with you through cancer appointments, treatments and help with other things like fixing meals and running errands. There is a section in this Journal for you to list your support team with their contact information so if someone in the health care office asks you for their information, you will have it with you.



Know Your Numbers

[illegible]

Health Care

| Vaccine | Date | Date | Date | Date |
|--------------|------|------|------|------|
| COVID-19 | | | | |
| HPV | | | | |
| Pneumococcal | | | | |
| Seasonal Flu | | | | |
| Shingles | | | | |
| Tdap | | | | |
| | | | | |

| Vision | Date | Date |
|--------|------|------|
| | | |
| | | |
| | | |
| | | |
| | | |
| Dental | Date | Date |
| | | |
| | | |
| | | |
| | | |
| | | |



Health Care

[illegible]

Health Care

[illegible]

Prescription Drugs

[illegible]

Non-Prescription Medicines

[illegible]

My Family Health History

Know your family health history. A family health history can provide medical clues for you, your loved ones and your health care providers.

Medical conditions like cancer and other chronic diseases may run in a family. Knowing that one of these diseases runs in your family lets you and your family members take steps to reduce risks by eating a healthier diet, being more physically active and quitting tobacco use. This is important information for your health care provider.

Gather your family health history. You have already started with information on yourself. Write down any health information you know or can find out about your parents, grandparents, siblings, aunts and uncles in this journal. Talk with family members or even close friends of the family. Share it with other family members and encourage them to share it with their health care providers.



As you talk with family members, fill in the chart below with the name of your family member and his or her relationship to you, his or her birth date, if deceased, date and cause of death and any other major illnesses and/or diseases.

| Name/Relationship | Birth Date | Death Date | Cause of Death | Other Major Illness/Diseases |
|-------------------|------------|------------|----------------|------------------------------|
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

Appointment

Date:

Weight:

Page 10 of 10

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

Page 10 of 10

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

Page 10

Blood Pressure:

11/11/2019

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

Page 10

Blood Pressure:

11/11/2019

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

Page 10 of 10

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

Blood Pressure:

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

| |
|--|
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |

Appointment

Date:

Weight:

11/11/2019

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

11/11/2019

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

11/11/2019

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

This image shows a single sheet of white paper with horizontal blue lines for writing. A vertical red line runs down the left side, creating a margin. The paper is slightly wrinkled and has some faint smudges at the bottom left corner.

Appointment

Date:

Weight:

Page 10

Blood Pressure:

11/11/2019

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

Page 10 of 10

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

11/11/2019

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

Page 10

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

Page 10

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

Appointment

Date:

Weight:

Page 10 of 10

Blood Pressure:

Page 10 of 10

Diagnosis

Health Care Provider

Treatment Recommendation

Potential Symptoms/Side Effects

Follow-up Care Plan

Next Appointment

Page 10 of 10

Appointment Location

Reason for Appointment

Health Care Provider and Contact Information

Questions/Notes

[illegible]

MY GENERAL HEALTH TEAM

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

MY GENERAL HEALTH TEAM

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

MY GENERAL HEALTH TEAM

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

MY GENERAL HEALTH TEAM

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

MY GENERAL HEALTH TEAM

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

Name _____

Location _____

Contact Information _____

MY SUPPORT TEAM

Name _____

Relationship _____

Contact Information _____

Name _____

Relationship _____

Contact Information _____

Name _____

Relationship _____

Contact Information _____

Name _____

Relationship _____

Contact Information _____

Name _____

Relationship _____

Contact Information _____

Name _____

Relationship _____

Contact Information _____

Cancer Survivorship Journey



My Continued Journey in Cancer Survivorship

Congratulations, you are toward the end of your active cancer treatments! Or you just finished!

You may be wondering, “Now What” or “What Do I Do Next?” This is a new phase of your cancer journey where your cancer will move from being an acute illness to a chronic illness. It is time to plan for your cancer survivorship future!

Since cancer and cancer treatments effect each person differently, you will want to figure out what you need to explore for your new “normal.” You will have questions! What happens next? Do I need to continue long-term treatments? If you need them, you will need detailed information on the treatments like: what, how, when, where, how long. Will I have long-term side effects from the active treatments that I am finishing?

How do I feel physically and emotionally right now? I wonder how I will feel physically and emotionally in a few weeks, months or year. More and more questions will come to mind as you are moving through this journey. We have some tips on things to ask listed on the next pages. There are also spaces to write down your thoughts and answers.

**Ware are cheering you on!
Keep Thriving in Your Survivorship Journey!**

Questions to Ask

What kind of recovery can I expect?

1. Ask for a written care plan that includes details about the treatments you have had.
2. What are the possible future short- and long-term side effects of my treatment? What should I do about them? When should I call a health care professional? I feel lost. Who do I call?

Notes

| |
|--|
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |

Questions to Ask

What about future appointments and cancer tests?

1. Who will I see and where?
2. What is the reason for my appointment?
3. Schedule future appointments, if possible.

Future Appointments/Tests Potential Dates (who I will see and where)

| | |
|--|--|
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |

Questions to Ask

How will my future care be coordinated with my family doctor?

- 1. What future health screenings like mammograms, colonoscopies, LDCT, PSAs, etc. will I need?
- 2. How often should I have them?
- 3. When should I schedule them next?

| Future Health Screenings | How Often |
|--------------------------|-----------|
| | |
| | |
| | |
| | |
| | |
| | |
| | |

Notes

Questions to Ask

Don't forget your checkups!

- 1. How often do I need to visit my family doctor for routine health care?
- 2. How often do I need to have my eyes and teeth checked?
- 3. What about a counselor or nutritionist?

Notes

My Supports

Your support team continues to be as important in this phase of your cancer journey as it was during active treatment. Encourage these caregivers to explore with you the information you need and the answers to those questions. They may have questions that they would like to ask also.

Do you need to update your support group and their contact information?

Cancer Support Groups

As you know, having cancer is a very stressful experience. Any chance to connect with others in a support group can help you cope with the emotional as well as the physical aspects of cancer. Think of it as a safe place where you can be with folks that have been where you are. It is a space to work through feelings and learn from others how to cope with your new “normal.” They can also be a source of resources in your community. Your health care team can help connect you to cancer support groups in your area. There is space to record this information on the next page. The American Cancer Society is one group that sponsors cancer support networks throughout the country. Find more information on their support networks by searching American Cancer Society Support Groups or Cancer.net on the internet.

Yes, you are strong.
But remember you are NOT Alone.
Moving forward together.

My Supports

Collect information on support groups or patient advocacy groups where you can get support.

Your health care provider should have a list of community or national cancer support groups that can offer support or information on survivorship issues and challenges.

| Notes |
|-------|
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |
| |

Taking charge of my general health

► Discuss financial concerns with your health care provider.

- Inadequate financial resources to cover post-treatment needs.
- Problems for getting or keeping health insurance.
- Problems at work or school as a result of your diagnosis, care or treatments.

► Do a self check-in. Ask yourself: How is my emotional health?

- How do I feel about my cancer journey at this moment?
- Am I afraid, unsure or am I hopeful? Don't hesitate to ask for help with how you feel about your diagnosis and the cancer journey you are on. You are not alone.

► Seek support or counseling for emotional, sexual or relationship issues, if you need it. Don't be ashamed. You will find that you are not alone with this.

► Reach out to others. Volunteer, be an advocate for other cancer patients, help others. Find your strength in helping others. It will be good for your mental and physical well-being.

Remember, "I am not alone".

Taking charge of my general health

As a cancer survivor you will need to put your overall health first so you can help reduce risks for other problems like obesity, heart disease or diabetes.

► Take steps to help yourself be as healthy as you can! Renew your efforts to have a healthy lifestyle.

- Stop using tobacco if you smoke, chew or vape. Quitting takes practice. You can get support at QuitlineNC.com.
- Eat a healthy diet. Healthy food is fuel for your body. It can give you energy, build your immune system. Make a plan. What special eating habits can you follow? Not hungry? Tummy upset? Talk with your provider or dietician.
- Keep moving! Find a way to move to help your body be strong. Make a plan. How can you move your body today?



CANCER SURVIVORSHIP INFORMATION

Comprehensive Cancer Control Program

Cancer Prevention and Control Branch Chronic Disease and Injury Section

Division of Public Health

NC Department of Health and Human Services

5505 Six Forks Road, Raleigh, NC 27609

Mailing Address:

1922 Mail Service Center,
Raleigh, NC 27699-1922

Office: (919) 707-5300 | **Fax:** (919) 870-4812
<https://nccancer.dph.ncdhhs.gov>

Special thank you to the **Village of STRENGTH™ Program** of The Caraway Foundation for volunteering as a sampling of survivor and caregiver reviewers to assist in the development of the Unexpected Journey.

The **Village of STRENGTH™** program provides many resources to support those in North Carolina who are patients, SURVIVORS, caregivers of any chronic illness, i.e., cancer, stroke, heart attacks, lupus etc. Provide support groups, educational programs, and transportation support.

www.TheCarawayFoundation.org



NC DEPARTMENT OF
**HEALTH AND
HUMAN SERVICES**



**Comprehensive
Cancer Control**

Collaborating to Conquer Cancer
— NORTH CAROLINA —

NC Department of Health and Human Services • Division of Public Health
Cancer Prevention & Control Branch • <https://publichealth.nc.gov>
NCDHHS is an equal opportunity employer and provider. 4/21