



# Paths to Survivorship

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We collected the following printable guides from the Paths to Survivorship booklet in the Bag It bag for your convenience and personal use.

## Questions about Your Cancer Care

Print the list of question(s) that is relevant to you and add it to your *My Companion Guidebook*, along with any other questions you want to ask. (You can also make an extra copy to give to your healthcare team.) Bring your guidebook with you to your appointments. Be sure to write down the answers you receive to your questions.

- Your Diagnosis
- Your Cancer Treatments
- Your Follow-Up Care
- Late and Long-Term Side Effects of Cancer Treatment
- Living with Chronic Cancer
- Advanced Cancer
  - » Your Cancer and Treatment Choices
  - » Symptoms and Side Effects
  - » Transition from Cancer Treatment to Hospice Care

## Self-Advocacy

- Tips for Self-Advocacy
- Survivorship Checklist

## Questions to ask your healthcare team about your diagnosis

1. What is my specific diagnosis?
2. Where is the cancer located? Has it spread?
3. What is the size and stage of my cancer? What are the different types of stages?
4. Are more tests needed at this time to fully diagnose my cancer or determine treatment options?
5. What treatment options do you recommend?
6. What are the goals for treatment?
7. Who will be on my healthcare team?
8. What is the best way to reach you for non-urgent questions or concerns?
9. Where can I find more information on my diagnosis and treatment? Where can I find support services in my area?
10. Is participation in a clinical trial an option for me?

## Questions to ask your healthcare team about cancer treatments

1. What are the expected short-term and long-term benefits of this treatment?
2. How will we know if the treatment is working?
3. When does the treatment need to start? How long will the treatment last?
4. If drugs are part of my treatment, what drugs are they and what will they do?
5. Where, how, and how often will the treatment be given?
6. What short-term side effects might I experience during this treatment?
7. How do you anticipate I will feel during treatment?
8. How may I need to modify my work schedule or lifestyle?

## Questions to ask your healthcare team about cancer treatments (continued)

9. Do you expect any changes in my appearance as a result of treatment?
  
10. What side effects or symptoms do I report immediately, and to whom?
  
11. Are there any long-term risks or late effects of treatment?
  
12. How much will the treatment cost? Is it covered by my insurance?
  
13. Who do I talk to about insurance and/or obtaining financial assistance?
  
14. How might my treatment impact my family or friends? Are there any resources my caregivers should be aware of?

## Questions to ask your healthcare team about follow-up care

1. Will I receive a Treatment Summary and Survivorship Care Plan?
2. What follow-up care do I need? With whom and how often?
3. Do I need any follow-up tests? If so, how often?
4. What symptoms or side effects should I report and to whom?
5. Are there late or long-term side effects or health issues I should be aware of?
6. Are there helpful survivorship programs or resources you can recommend for me, my caregiver, and family?

## Questions to ask your healthcare team about late and long-term side effects

1. What can be done to manage any side effects that continue after treatment?
2. What are the most common late and long-term effects that may develop based on my treatment plan?
3. What should I do if I notice a late side effect?
4. What screening tests do you recommend based on my cancer history?
5. Are there other doctors or specialists I should see, such as a cardiologist or endocrinologist?

## Questions to ask your healthcare team about living with chronic cancer

1. What are my extended treatment options? What is the goal of each treatment?
2. What clinical trials are open to me? Where are they located, and how do I find out more about them?
3. How long do you think I can live with extended treatment?
4. What side effects are possible based on the cancer treatment I receive?
5. How will this treatment affect my daily life? Will I be able to work, exercise, and perform my usual activities?
6. How long will I continue to receive extended treatment?
7. How long do you think extended treatment can help me live?

## Questions to ask your healthcare team about living with chronic cancer *(continued)*

8. What specialists will I need to see?
  
9. What follow-up tests will I need? How often will I need them?
  
10. How will I know if the extended treatment is working or if the cancer is getting worse?
  
11. If I'm worried about managing the costs of long-term cancer care, who can help me?
  
12. Where can I find emotional support for me and my family?



# Advanced Cancer

## Questions to ask about your cancer and treatment choices

1. How long can I live with my advanced cancer?
2. Are there tests I should have now to better understand the extent of my cancer?
3. What's the best we can hope for by trying another treatment? What's the goal?
4. What are my treatment choices? Which do you recommend for me and why?
5. Would a clinical trial be right for me?
6. What kind of care will I receive to keep me comfortable if I decide not to have active treatment for my cancer?

## Questions to ask about symptoms and side effects

1. What are the possible side effects and other downsides of this treatment? How likely are they?
2. How can I manage the symptoms of my advanced cancer or the side effects of its treatment?
3. Can you refer me to a palliative care specialist to help me cope with my side effects?

## Questions to ask about making the transition from cancer treatment to hospice care

1. How do I decide whether to continue or stop cancer treatment?
2. When should I consider having hospice care?
3. How can I make sure I have the best quality of life possible—that I am comfortable and free of pain?
4. Can I have hospice care in my home, or do I have to go to a special facility?
5. How can I get help with financial and legal issues (for example, paying for hospice care or preparing a will or an advance directive)?
6. How can I get help with my spiritual needs?

# Tips for Self-Advocacy

## Get Informed

- Learn from reputable sources so you can speak knowledgeably and make sound decisions about your cancer care.
- Ask the right questions about your cancer, goals of care, the benefits, risks and side effects of treatment options.
- Understand your health insurance coverage and the cost of your care.
- Stay informed along the way.

## Get Organized

- Get copies of your medical records.
- Use *My Companion Guidebook* to record, store and track your medical info and schedules. Bring it to your appointments.
- Prepare for doctor visits. Write your questions and info to share. Bring someone with you (in person or virtually) to help.

## Know Yourself

- What is important to you?
- What are your goals of cancer treatment?
- What are your personal hopes, strengths, needs, concerns, and preferences?
- What help do you need?
- Listen to your body.

## Speak Up

- Confidently, directly yet kindly, and honestly.
- Ask questions until you fully understand the answers.
- Voice concerns until you are understood.
- Report changes in your physical, emotional and mental wellbeing.
- Know how to ask for the help you want, and accept the help offered.

## Build Your Team

- Find a cancer care team that is a good fit for you and where you can receive the best quality care possible.
- Add support to lean on: family, friends, neighbors, groups in your area.
- Connect with others living with cancer. Try a support group, peer mentor, or an online community.

## Know Your Rights and Protections

Under federal, state and local laws:

- As a patient or caregiver.
- On the job.
- For health and disability insurance.
- For benefit(s) eligibility (public/employer).
- Related to your finances.
- For estate planning.

## Take Action

- Get involved. Be an active member of your healthcare team.
- Ask your doctor for supportive/palliative care.
- Create advance directives no matter your prognosis.
- Look into financial resource to help with medical and non-medical expenses.
- Tap into resources offered for every aspect of cancer.
- Plan for "what if" scenarios.

## Decision Making and Problem Solving

- Work with your healthcare team to make informed choices about your care.
- Consider getting a second opinion.
- Communicate, communicate, communicate.
- Find solutions and negotiate to overcome challenges. Be persistent and follow up.
- Ask for input and help from trusted sources along the way.

# Survivorship Checklist

Type of cancer: \_\_\_\_\_ Date: \_\_\_\_\_

Other info: \_\_\_\_\_

## Treatment

- |   |   |   |
|---|---|---|
| <input type="checkbox"/> Surgery                | <input type="checkbox"/> Immunotherapy        | <input type="checkbox"/> Supportive/Palliative Care |
| <input type="checkbox"/> Chemo (IV, port, oral) | <input type="checkbox"/> Stem Cell Transplant | <input type="checkbox"/> Physical Therapy           |
| <input type="checkbox"/> Radiation Therapy      | <input type="checkbox"/> Clinical Trials      | <input type="checkbox"/> Occupational Therapy       |
| <input type="checkbox"/> Hormone Therapy        | <input type="checkbox"/> Biomarker Testing    | <input type="checkbox"/> Other _____                |

## Support System

- |   |  |   |
|---|--|---|
| <input type="checkbox"/> Spouse/Partner | <input type="checkbox"/> Neighbors                   | <input type="checkbox"/> Support Group/Peer Support |
| <input type="checkbox"/> Family         | <input type="checkbox"/> Religious/Spiritual Advisor | <input type="checkbox"/> Survivorship Program       |
| <input type="checkbox"/> Friends        | <input type="checkbox"/> Navigator/Patient Advocate  | <input type="checkbox"/> Other _____                |
| <input type="checkbox"/> Nurse          | <input type="checkbox"/> Social Worker/Counselor     |   |

## Concerns and Side Effects

- |   |  |   |
|---|--|---|
| <input type="checkbox"/> Physical             | <input type="checkbox"/> Genetic Testing     | <input type="checkbox"/> Caregiver/Family Support |
| <input type="checkbox"/> Emotional Well-Being | <input type="checkbox"/> Fertility/Sexuality |   |

## Wellness and Support Activities

- |  |   |   |
|--|---|---|
| <input type="checkbox"/> Healthy Diet                          | <input type="checkbox"/> Religious Faith/Spirituality | <input type="checkbox"/> Yoga/Tai Chi/Stress Management   |
| <input type="checkbox"/> Nutrition Counseling                  | <input type="checkbox"/> Exercise/Physical Activity   | <input type="checkbox"/> Meditation/Relaxation Techniques |
| <input type="checkbox"/> Stopping Smoking                      | <input type="checkbox"/> Healthy Weight               | <input type="checkbox"/> Individual Counseling            |
| <input type="checkbox"/> Limit Alcohol                         | <input type="checkbox"/> Journaling                   | <input type="checkbox"/> Other _____                      |
| <input type="checkbox"/> Continued Education/<br>Self-Advocacy | <input type="checkbox"/> Acupuncture/Massage          |   |
| <input type="checkbox"/> Support Groups/Peer Support           | <input type="checkbox"/> Volunteering                 |   |
|  | <input type="checkbox"/> LIVESTRONG at the YMCA       |   |

## Practical Matters

- |   |  |
|---|--|
| <input type="checkbox"/> Life Planning (powers of attorney & wills) | <input type="checkbox"/> Financial (medical costs, household expenses)               |
| <input type="checkbox"/> Insurance (health, disability)             | <input type="checkbox"/> Practical (child care, meals, in-home care, transportation) |
| <input type="checkbox"/> Work/Legal Rights                          |  |

## Ongoing Care/Follow-up Care

- |  |  |
|--|--|
| <input type="checkbox"/> Extended Treatment _____      | <input type="checkbox"/> Late/Long-Term Side Effects                                 |
| <input type="checkbox"/> Oncology Follow-up Care       | <input type="checkbox"/> Physical Therapy  |
| <input type="checkbox"/> Supportive/Palliative Care    | <input type="checkbox"/> Occupational Therapy  |
| <input type="checkbox"/> Primary Care/Family Physician | <input type="checkbox"/> Treatment Summary & Survivorship Care Plan<br>(see page 65) |
| <input type="checkbox"/> Care By Specialists           | <input type="checkbox"/> Survivorship Program  |
| <input type="checkbox"/> Dental Care                   | <input type="checkbox"/> Other _____   |
| <input type="checkbox"/> Vision Care                   |  |