CANCER SURVIVORSHIP CHECKLIST

What you need to know when you are in treatment for head and neck cancer.

NAME

AGE

CANCER TYPE

COMMUNICATION WITH MY HEALTH CARE TEAM

Get a full explanation of my diagnosis and care plan.

Share with my doctor what is most important to me, so my goals, values, and cultural practices may be included in my treatment plan.

Establish my preferred form of communication (online portal, texting, phone call, or hard copy).

Select one health care team member and ask them to serve as my point of contact for communicating decisions, protocols, or overall updates to all other health care team members. Establish who, when, and how to contact my care team coordinator if I have questions or concerns.

Discuss any medications or supplements I am taking and how they will interact with my treatment.

Discuss my treatment options, including the benefits and side effects (both short- and long-term) of each.

Schedule all necessary appointments and get a copy.

Ask my surgeon to draw a picture showing the range of structures impacted.

Take the picture to my radiation oncologist and ask for details about radiation targets, if applicable.

Present the picture to a cancer rehabilitation team who can develop a rehabilitation plan that addresses my individualized needs in treatment and beyond.

Ask about different feeding tube options and education on administering supplemental nutrition and hydration, if applicable.



Meet with an endocrinologist to establish baseline hormone function prior to surgery and treatment.

Seek a second (or third) opinion if it will make me feel more comfortable about my decisions.

Ask if there is an appropriate clinical trial available for me. Discuss the pros and cons of participating.

GET ORGANIZED

Get a calendar to keep track of my appointments.

Create a contact list with names of doctors, physician assistants, nurses, other support staff, family, preferred pharmacy, and emergency contacts.

Use a notebook to track all interactions with my health care team. Note the date and time, name of providers and any questions I may have. List any phone messages that I left and make notes of inbound and outbound calls.

Keep track of any new symptoms, side effects, or questions that arise to share with my care team.

Have a whiteboard and markers, legal pads and pens, or an electronic device to communicate with others if I am not able to communicate verbally.

Get comfortable clothing that is easy to put on and take off like button-up shirts, cardigans, and sweatshirts with zippers.

Use lightweight blankets, scarves or wraps to keep warm. These items gently provide protection when I am moving from place to place.

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CARE PLAN

Work with my health care team as early as possible to develop a written plan of care, including:

- A schedule of surgery dates, if applicable.
- Hospitalization length & types of accommodations.
- Frequency of treatments and tests.
- A pain management plan.
- Additional side effects I should expect and how to manage them.
- Any disruptions I should expect to my work, family, or other responsibilities.
- Resources I can use to understand the diagnosis and treatment better.

CAREGIVER(S)

Have a family member or friend attend appointments with me to provide support, ask questions, and take notes. Ask if audio recording the visit is permitted using a phone app or tape recorder.

Ask how a caregiver can get help learning how to care for me at home.

Discuss resources that can help my child(ren) understand my diagnosis, my treatment plan, the impacts my treatments might have on me, and what I might need from my family to return to my healthy self.

Discuss resources and support groups for my caregiver(s) and child(ren) to support their emotional or psychological concerns.

SUPPORTIVE SERVICES

Ask which of my appointments will require someone to drive me. If transportation is a problem, ask for support to help me find resources.

Ask about priority or free parking for ongoing appointments.

Meet with a dietician or a speech therapist to plan for challenges like tasting, chewing, swallowing, and adequate nutrition.

Radiation treatment may dry or burn my skin. Test skin moisturizers to ensure they don't sting, and apply them as needed. Skin dryness or burns can persist after treatment ends.

If I don't have balance issues or concerns about falling, make a plan to incorporate movement into daily activities like walking to the mailbox, walking the family pet, or walking around the block in the neighborhood for 10 minutes a day.

Discuss options for **cancer rehabilitation therapy** (physical therapy, occupational therapy, and speech & language therapy) to help prepare for treatment and proactively manage potential side effects.

Discuss options for **integrative oncology** (acupuncture, yoga, meditation, oncology massage, nutrition, exercise, and decongestive therapy) to manage my wellness and potential side effects like fatigue, lymphedema, and the experience of muscle tightness/spasms.

Discuss options for **palliative care** to support symptom management and maintain quality of life.

EMOTIONAL & MENTAL HEALTH

Seek people and places where I can discuss my emotional or psychological concerns related to my cancer diagnosis (including anxiety, depression, or other worries).

Ask for support or counseling for emotional, sexual, or relationship issues.

Identify support groups or patient advocacy groups where I can get support.

Ask to be connected to other cancer survivors who have gone through this before and would be willing to have a conversation.

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SHORT- AND LONG-TERM ORAL CARE

Be sure that my dentist is aware of my cancer diagnosis and treatment plan, and consult with a dentist specifically trained in head and neck cancer care (prosthodontist or dental oncologist).

Work with a prosthodontist to establish a baseline and to discuss prevention of tooth decay, gum and mouth sores, and complications due to dryness.

Schedule regular dental cleaning appointments.

Dry mouth can be addressed with saliva substitutes. There are many products available, so seek a recommendation from my oncology nurse/clinician, prosthodontist, or dentist.

If I have mouth sores or throat soreness because of treatment that makes eating difficult or painful, check with my dietician, speech therapist, or prosthodontist for support.

Stay hydrated! Avoid excessive amounts of caffeine and alcohol that will dry my mouth.

WORK & SCHOOL CONSIDERATIONS

Request information regarding my rights under the Family and Medical Leave Act (FMLA). This applies to caregivers.

Request information regarding my rights under the Americans with Disabilities Act (ADA).

Talk to my employer or school to accommodate my care plan.

If I am dealing with any discrimination at my work or school, discuss these issues with an attorney.

FINANCIAL HEALTH

Ask for information about the costs of treatment.

Ask for resources for financial support, if needed.

Discuss any concerns regarding getting or keeping health insurance.

Ask for information about fertility preservation and family-building options that are covered by insurance and grants.

Talk to my health insurance provider to enroll in any case management services or programs.

Discuss any concerns about applying for public disability or redeeming short- or long-term disability policies.

NOTES

Reference: National Comprehensive Cancer Network, Inc. (2022). NCCN Guidelines for Patients[®]: Survivorship Care for Cancer-Related Late and Long-term Effects. Retrieved from https://www.nccn.org/patients/guidelines/content/PDF/survivorship-crl-patient.pdf



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