MAKESENSECAMPAIGN

FAQ discussion guide for head and neck cancer patients



Introduction

A diagnosis of head and neck cancer can be shocking and in the following weeks will have you navigating through your medical system. During this time, conversations with your healthcare professionals will be intense and, sometimes, short, but you must feel empowered to ask questions and get the answers you need to move forward.

To help you, the *Make Sense* campaign has developed this discussion guide. The following guide has been developed with input from previous head and neck cancer patients and healthcare professionals around Europe; it gives you the tools you need to make your transition through diagnosis and post-treatment as smooth as possible.

The following pages includes questions you may want to ask your doctor and other specialists who will be a part of your multidisciplinary team. The guide is comprehensive and has been developed keeping in mind the wide-range of people who are affected by this type of cancer. Feel free to pick and choose which questions you need answers to.

The guide is divided into five sections; each section focusing on different stages of the treatment pathway, from diagnosis to post-treatment and recurrence. We recommend you print the entire document and bring the relevant section to your consultations. We understand that everyone's journey through head and neck cancer is different, so please treat this document as a guide, and if you have any additional questions or require additional information, do discuss with your healthcare team.

An overview of your multidisciplinary team

You will be working closely with a variety of healthcare professionals from diagnosis through to treatment, and these healthcare professionals will make up your multidisciplinary team. The multidisciplinary team is a group of specialist healthcare professionals from a variety of disciplines; each member provides specific services for the management and treatment of your cancer. The multidisciplinary team will vary depending on your diagnosis, as well as the healthcare system in your country.

Use this space to write down contact details of all the healthcare professionals in your multidisciplinary team					

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Post-diagnosis: treatment plan

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The first appointments after your diagnosis can be a difficult time, as you are still adjusting to the news of your diagnosis, and at the same time, there will be a lot of important information for you to absorb.

Bring these questions to your consultations to help you understand your treatment plan and its impact on your daily routine.

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- What is my treatment plan and what are my options?
- How much choice do I have regarding my treatment options?
- How long will my treatment last?
- How often will I need to come to the hospital for my treatment?
- Is there anything I should do to prepare for my treatment?
- Will I undergo any tests/assessments prior to starting my treatment?
 - If so, what will they be?
- Can I bring someone with me to all my appointments and treatment sessions?
- Which other doctors/healthcare professionals will be involved in my treatment?
- Will I be undergoing any other tests, and if so, what do the results of these tests mean for my family and me?
- Is my cancer HPV positive, and what does my HPV status mean for my treatment plan?
- What side effects can I expect during my treatment?
 - How should I manage these side effects?
- Will the treatment be painful?
 - What can I do for pain management?
- How will my treatment plan affect my current routine/lifestyle, and how do you suggest managing these changes? (Table on page 6 and 7 contains further questions regarding routine/lifestyle)
- Is there someone I can talk to about how I am feeling during my treatment?
- If I am unable to arrange my own transport to the hospital, what support will I receive?
- Is there an option to join a clinical trial?







Diet

- How will my diet/eating habits be affected?
- Are there certain foods I should avoid eating?
- Am I able to drink alcohol during my treatment?
- Am I able to smoke during my treatment?
- Are there any new foods/additional supplements I should incorporate into my diet?
- What challenges should I expect during my treatment, and how could I manage these?
 - Pain
 - Fatigue
 - Inflammation
 - Difficulties eating and drinking

Day-to-day activities

- Are there any activities I can do to help with my recovery?
- Should I limit any type of activities?
- Should I make any changes to my current fitness plan?
- Should I be tracking any specific side effects related to my fitness, and let you know (tiredness, pain etc.)?
- How will my sleeping be affected, and how can I manage this?
- Should I avoid spending extended periods of time in the sun?
- If my cancer is HPV positive am I infectious to others?
 - Can I kiss my loved ones?
 - Can I share cutlery?
- Will I be able to take care of myself or will I need additional support (preparing food, travelling to the hospital etc.)?

Family

- Will my treatment affect the time I spend with my children and/or grandchildren?
- Will I be able to keep carrying out my parental responsibilities (picking children up from school, helping with homework, going to parents evening etc.)?
- Will there be any effects to my sex life?
 - If so, how can these be managed and will they be long lasting?





Post-diagnosis treatment plan (continued)

Social

- How will my surgery or treatment affect eating and drinking?
- Am I able to socialise as usual?
- How will my surgery or treatment affect my speech?
- Will there be any changes to my mood/attitude?
 - If so, what type of support can you offer?

Starting/growing a family

- Will I still be able to have a child?
- How long should I wait before trying to become pregnant or father a child?
- Will my diagnosis affect my pregnancy?



- When will I be able to return to work?
- Are there any long-term/permanent effects that will affect my ability to work?
- What information should I give my employer to arrange time off work for treatment?
- Is there anyone I can speak to about my current work situation, and help me explain things to my employer?
- Is there anyone I can speak to about my potential unemployment?
 - Who can I speak to for advice on my economic situation during and after the completion of my treatment?





Use this space to write down any of your own questions that you may have before your consultation and/or notes during your consultation					

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Specialist questions

long will I need to stay in hospital following r surgery? What are the possible outcomes of surgery? What is the rehabilitation process a

Specialist questions



You will see a variety of different doctors throughout your treatment/ post-treatment process. This section has been created to help you ask relevant questions during your consultations. I look or your lan? How I I expect est manag

Questions for your Surgeon

- How many procedures will I need?
- Can you tell me more information about the procedures?
- Is there anything I should do to prepare for surgery?
- How long will I need to stay in hospital following my surgery?
- What are the possible outcomes of my surgery?
- What is the rehabilitation process and how long is my recovery time?
- Will my swallowing be impaired after surgery?
- Will my speech be different following surgery?
- Will I look different after surgery?
- Will my surgery affect my ability to carry out day-to-day activities?
 (e.g. driving if I have an eye removed)

Questions for your Oncologist

- What is my treatment plan?
- How long will my treatment last?
- Should I expect any side effects, and if so, how can I best manage these?
- Can I have a family member or friend accompany me during my treatment?

Questions for your Radiation Oncologist

- How many sessions will I need?
- Can you explain what will happen in these sessions?
- How long will my treatment last?
- Should I expect any side effects, and if so, how can I best manage these?
- Can I have a family member or friend accompany me during my treatment?
- Will I need to take any medication?
- Will I become radioactive?



Discussion guide with your Psychologist

Understanding your symptoms

Select a number (5 – very frequently, 1 – never) to rate how often you have experienced the following before meeting with your psychologist:

Changes to my personality	1	2	3	4	5
Issues with work	1	2	3	4	5
Changes in mood	1	2	3	4	5
Difficulty sleeping	1	2	3	4	5
Little interest in socialising	1	2	3	4	5
Trouble managing daily activities (shopping, cleaning, driving etc.)	1	2	3	4	5
Difficulty concentrating (reading, watching TV etc.)	1	2	3	4	5
Difficulty adjusting to a new self-image	1	2	3	4	5
Relationship challenges	1	2	3	4	5
Issues with sex life	1	2	3	4	5

Questions for your Psychologist regarding a treatment plan (if recommended)

- What is my treatment plan?
- How long will my treatment last?
- What can I do in my daily routine to ease symptoms?
- Do I need to take some psychotropic drugs to ease my psychological symptoms?
- Should I be exercising, if so, how often?
- Are there any mental activities I should be doing (brain exercises, meditation etc.)?
- Are there any signs or symptoms that my family or I should look out for to ensure my mental well-being?
- Will we continue to meet after I have completed my treatment?
- Could my mental health impact my ability to return to work?



Questions for your Regular Healthcare Contact (For example: nurse, social worker, healthcare assistant etc.)

- What can I do to help myself transition back to my normal daily routine?
- What activities would you recommend I do to help improve my social life?
- Are there any resources you would recommend, for example courses or books, to provide information and advice?
- Where can I find information on public/state health support?
- What is the number of a hotline I can contact with any questions?
- How can I talk to my family/friends about my cancer?
- Are there any support groups for the struggles I am facing?
- If I feel like my family are struggling emotionally, what can be done to help them?
- What support will I receive from the healthcare system?
- Can you advise on support options for financial implications?
- What support is available if I am struggling to complete normal daily tasks (food shopping, cooking, getting ready in the morning etc.)?
- Will we continue to meet after I have completed my treatment?
- Who is going to help coordinate all of my appointments with the various specialists throughout my treatment?
- Based on the changes advised by my care team, what can I do to adapt to my new lifestyle?
- Where am I able to receive a benefits claim and/or travel expenses from?
- If I have more questions, who is best to contact? How do I contact them?

Questions for your Dietician

- How will my eating habits be affected?
- What foods should be added and/or restricted from my diet?
 - Short-term
 - Long-term
 - Permanently
- Would you recommend any additional food supplements/nutritional tablets?
- Will I be able to eat in public?



Questions for your Speech Therapist

- How do you expect my speech to be affected in the short and long term?
 - Am I going to lose my speech?
 - Will I be able to speak up again?
- How long will my treatment last? Will I require a treatment plan? If so:
 - When is it advisable to start my treatment?
 - How long will my treatment last?
 - What are we going to do in speech therapy?
- Can my family members attend speech therapy sessions?
- How will my speech therapy sessions combine with other treatments?
- What type of exercises can I do outside of our appointments to help with my rehabilitation?
 - How frequently should I do these exercises?
 - How long should I continue these exercises?
 - What else, other than exercises, can I do outside the appointments to help with my rehabilitation?
 - How will I make myself understood after surgery?
- Which symptoms, if any, should I flag to you if they arise?
- What should I avoid that may impact my speech moving forward? For example:
 - Particular food or drink
 - Speaking for long periods of time
- What are the next steps after my treatment plan?
- Is there a chance of complications with my speech in the future? What can I do to reduce the chances of any such complications?
- Will I be able to return to work after treatment?
- Are there any support groups you can recommend?

For additional information and advice on eating and drinking following treatment, access 'Making Meals Make Sense', a cookbook developed by the *Make Sense* campaign in collaboration with patients, survivors, nutritionists and head and neck cancer experts.

https://makesensecampaign.eu/files/documents/Making-Meals-Make-Sense-Cookbook.pdf





Questions for your **Dentist**

- Will I require dental procedures?
- What would these procedures involve?
- How long is treatment likely to take?
- How often should I see my dentist after chemotherapy and radiotherapy?
- Should I make any changes to my dental routine?
- Should I alter my diet?
- What toothpastes and/or mouthwashes do you recommend?
- What foods should I avoid to prevent dental decay and gum disease?



Use this space to write down any of your own questions that you may have before your consultation and/or notes during your consultation					

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check-up

someone about how I am feeling, who shoul speak to? Do you recommend any cancer

Treatment: check-up



For every treatment check-up, fill in the below questionnaire beforehand. This will help let your doctor know how you are feeling and assist them to make more informed decisions about your care options. ng the short-ter should I consult a

Managing side effects

Below are details for you to fill in before your check-up

Indicate where you have been experiencing pain, and on what scale (5 – severe, 1 – mild)

1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

Are you experiencing any of the following symptoms?

- Dry mouth
- Dribbling
- Jaw aching
- Loss of taste
- Speech/Swallowing difficulties
- Inflammation
- Other



Select a number (5 – very frequently, 1 – never) to rate how often you have experienced the following:

Changes in mood	1	2	3	4	5
Difficulty sleeping	1	2	3	4	5
Little interest in socialising	1	2	3	4	5
Trouble managing daily activities (shopping, cleaning, driving etc.)	1	2	3	4	5
Difficulty concentrating (reading, watching TV etc.)	1	2	3	4	5
Difficulty adjusting to a new self-image	1	2	3	4	5
Relationship challenges	1	2	3	4	5
Issues with sex life	1	2	3	4	5

- Do you have any concerns about the following:
 - Diet
 - Fitness/Sleeping
 - Family life
 - Starting a family
 - Social activities
 - Work
 - Self-image
 - Sex life



	ou have any other concerns or anything additional you want to discuss please see a note here:
	u have indicated any concerns for the above, bring the table from the section t-diagnosis: Treatment Plan' to your next check-up to discuss further with your for.
•	Do you recommend any cancer rehabilitation services? If so, which services? - Family counselling - Home care services - Speech and swallowing therapy - Psychological therapy - Nutritional planning - Pain management - Other Please indicate



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Post treatment

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Post treatment



Finishing your treatment is a huge milestone, and it is important you feel equipped with all the relevant information as you move into the next phase of your care. Bring these questions to your initial post treatment consultation to understand what additional follow-up care and services may be available to you.

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- What short-term, long-term and permanent effects should I expect?
 - For which effects should I consult a doctor?
- What challenges should I expect following the completion of my treatment and how could I manage these?
 Note: Some of the challenges you may experience that you should raise with your doctor may include:
 - Fatigue
 - Soreness
 - Dry mouth
 - Dribbling
 - Jaw aching
 - Loss of taste
 - Speech/Swallowing difficulties
 - Inflammation
 - General pain
 - Other
 Please indicate



- How should I manage my pain?
- How will my daily routine be affected post treatment, and how do you suggest managing these changes? (Please refer to the table in the 'Post Diagnosis: Treatment Plan' section, which contains further questions)
- How frequent will my follow-up visits be?
- Who will be leading my medical care after I finish treatment?
- What can I do to lower my risk of cancer coming back after treatment?
- How likely is it that I will need to undergo further treatment/tests?
- What symptoms should I look out for that may show that my cancer is coming back?
- Who will be my main point of contact if I have any questions?
- If I feel like I need to talk to someone about how I am feeling, who should I speak to?
- Do you recommend any cancer rehabilitation services? If so, which services?
 - Family counselling
 - Fertility planning
 - Home care services
 - Speech and swallowing therapy
 - Psychological therapy
 - Nutritional planning
 - Pain management

- Other

- Back-to-work planning

Please indicate							



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- Inflammation
- Other
 Please indicate



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Relationship challenges	1	2	3	4	5
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- Do you have any concerns about the following:
 - Diet
 - Fitness/Sleeping
 - Family life
 - Starting a family
 - Social activities
 - Work
 - Self-image
 - Sex life



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chance of further recurrence? Along with treatment, will I require palliative care? Will I have the same amount of follow-up visits as

Recurrence

If your cancer recurs, your treatment options will depend on a number of factors, including the location of the cancer, what treatments you have had before, as well as your state of health at the time. Each situation is different, so it is important to ask the right questions to understand your treatment options and ensure you will be effectively supported throughout your treatment. o preventure?
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Questions for your doctor

- What does this recurrence mean for me?
 - Is my prognosis different this time?
- Will I undergo the same treatment as before?
- How long will my treatment last?
- How often will I need to come to the hospital for my treatment?
- Which other doctors/healthcare professionals will be involved in my treatment?
- Is there an option to join a clinical trial?
- What side effects can I expect during my treatment, and will they be similar to the side effects I had during my previous treatment?
 - How should I manage these side effects?
- Will the treatment be painful?
 - What can I do for pain management?
- What are the expected outcomes of my treatment?
 - Will my cancer respond to treatment?
 - Will I experience a prolonged benefit from this treatment?
 - Is my cancer curable?
 - Is there a chance of further recurrence?



Questions for your doctor (continued) >>>

- How do I decide whether to continue or stop cancer treatment?
- When should I consider having palliative treatment?

If you are seeing any specialists during your treatment, please read the 'Specialist Questions' section on pages 9–15, for prompts to ask questions relevant to your diagnosis.



Use this space to write down any of your own questions that you may have before your consultation and/or notes during your consultation					

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chance of further recurrence? Along with treatment, will I require palliative care? Will I have the same amount of follow-up visits as

Palliative care

Following treatment for a recurrence, you may find that you need to transition to palliative care to help you achieve the best quality of life for you and your family. These questions are to help you get the most information regarding the services available at home and the hospital, to help you make the best decision for your care.

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Questions for your palliative care team

- Who are the members of the palliative care team and what do they do?
- What does palliative care offer?
- How long will palliative care last for?
- Can I receive palliative care in my home, or do I have to go to a special facility?
 - Am I able to be admitted to palliative care hospital for a short time and then go home again?
 - Are there differences between home and hospital palliative services?
- What pain and symptom management options are available?
 - What symptoms may occur in the future and what should I do if they arise?
- What palliative care services are available (e.g. physiotherapy, massage, spa etc.)?
- What will my quality of life be like?
 - What can I expect in the future?
 - What is my life expectancy?

If you have any specific questions regarding your routine/lifestyle, please read the 'Post-diagnosis: treatment plan' section on pages 4–8.



Use this space to write down any of your own questions that you may have before your consultation and/or notes during your consultation						

For more information please contact us:



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Make Sense Campaign

