

# Head and Neck - After Diagnosis Patient Concerns Inventory [PCI]

The amount of information patients and their family would like after the time of diagnosis of their cancer varies considerably. This Patient Concerns Inventory (diagnosis) is a checklist to help patients and their family raise issues that they want to talk about with the doctors, nurses and allied health professionals. *Tick as many or as few as you wish to help you remember what you want to discuss with our head and neck team.*

## Cause of cancer:

- Lifestyle issues (smoking/alcohol)
- HPV
- Other

## Treatment related:

- Investigations needed (MRI/CT)
- Investigation results
- Cancer treatment: what choices of treatment are available
- Treatment intent: cure or palliation
- Clinical trials - contributing to research
- Nutrition/feeding tube/PEG
- What are the side effects/toxicity/complications of treatments
- Surgery: length of stay in hospital, neck dissection, laser, free flap
- Radiotherapy: mould room, number of treatments, sore mouth and skin
- Chemotherapy: number of treatments, deafness, nausea
- What is the chance of cure
- When will I know I am all clear - when will I know treatment has been successful
- What treatments are available if the cancer comes back

- How long am I likely to live
- Waiting time for commencement of treatment
- Duration of treatment
- Dental check up

## What will I be like:

- What are the main issues that patients find important e.g. speech, swallowing
- What sort of 'quality of life' do patients report

## Follow-up:

- What sort of follow up do I need/how often/ scans/tests
- Patient and Carer Support Group/meet other patients

## Social care and Social well being:

- Carer
- Dependants/children
- Finance/money
- Benefits/what's free and what's not
- Time off work
- Home care/District nurse
- Recreation
- Relationships
- Speech/voice/being understood
- Support for my family

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### Psychological, emotional and spiritual well-being:

- Appearance
- Angry
- Anxiety
- Coping
- Depression
- Fear of adverse events
- Intimacy
- Memory
- Mood
- Self-esteem
- Sexuality
- Spirituality/religious aspects
- Personality and temperament

### Physical and functional well-being:

- Activity
- Appetite
- Bowel habit
- Chewing/eating
- Coughing
- Dental; health/teeth
- Dry mouth
- Energy levels

- Fatigue/tiredness
- Hearing
- Indigestion
- Mobility
- Mouth opening
- Mucus
- Nausea
- Pain in the head and neck
- Pain elsewhere
- Regurgitation
- Salivation
- Shoulder
- Sleeping
- Smell
- Sore mouth
- Swallowing
- Swelling
- Taste
- Vomiting/sickness
- Weight

### Other (please state):

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### Here is a list of professionals on the Multidisciplinary Team (MDT) who are around to help you. If you need to know more about their roles and how they can support you please ask.

- |                            |   |                              |                               |
|----------------------------|---|------------------------------|-------------------------------|
| - Dental hygienist         | - Speech (swallow) and language therapist | - Oncologist/ Radiotherapist | - Financial advisor           |
| - Dentist                  | - Occupational therapist                  | - Clinical Nurse Specialist  | - Chaplain                    |
| - Oral rehabilitation team | - Nursing staff                           | - Social worker              | - Clinical psychologist       |
| - Dietician                | - Audiologist                             | - General practitioner       | - Emotional support therapist |
| - Physiotherapist          | - Surgeon                                 |                              |                               |

Thank you for your time. All information is confidential. We have found that the PCI has helped patients express issues in their clinic.

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