

Fear of recurrence concerns following head and neck cancer

Aintree University Hospital **NHS**
NHS Foundation Trust

Where quality matters

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This information leaflet has been developed for patients, carers and families who have been treated following a diagnosis of head and neck cancer.

What is fear of recurrence?

Fear of recurrence (FOR) is the fear associated with the possibility that cancer will return or progress in the same place or in another part of the body. It is a natural reaction to the diagnosis and treatment.

Is fear of recurrence common?

To a lesser or greater degree all patients experience fear of recurrence at sometime in their cancer journey. Fear of recurrence is the most frequent issue that patients wish to talk about when asked in their clinic consultation.

When do patients experience fear of recurrence?

Patients tend to experience fear of recurrence after their treatment has been completed. Developing fear of recurrence is not dependent on age, time since treatment, extent of the cancer or type of treatment. Fear of recurrence and anxiety are normal reactions to the end of treatment. These feelings may come and go, they may be strong and difficult to deal with, some can find it difficult to sleep and find it difficult to concentrate. Fear and anxiety often lesson over time, however sometimes fear of recurrence can extend over longer periods.

How do recurrence fears affect some patients?

Some patients notice that their concentration is affected, that they have difficulties planning for the future and there is reduced communication between family members. Patients with fear of recurrence can be more prone to panic attacks and other physiological effects of anxiety and depression. After treatment some people are physically and emotionally exhausted, this can cause them to feel low at times. Usually, as they begin to get better and find they are able to get on with their usual activities, these feelings will lessen.

However, some people find that they don't feel better and their symptoms persist. If you are concerned about a symptom contact your consultant's secretary and ask for your appointment to be brought forward.

Are there signs that fear of recurrence may be problem?

- When minor pains, headaches or cold symptoms cause a strong fear that cancer has recurred.
- Thoughts of recurrence occur frequently, as soon as you wake up through to going to sleep at night.
- There are long term sleeping problems (more than a few weeks).
- Having little to no appetite for prolonged periods.
- Severe inability to concentrate or carry out usual routines.

How do I know when cancer recurrence may be a problem and not just a fear?

Patients should be aware of the risk factors and signs that cancer may have in fact recurred. If you want to know more about these then talk to your healthcare professional, as they will be able to tell you what the risk factors are.

Not only can this help to ensure that you know what the signs are, but it can also help to alleviate fears that minor pains or other symptoms are signs of cancer returning. In most cases of the tumour coming back following head and neck cancer, it returns at the primary site (where it first was) or in the neck.

Patients experience similar symptoms as the first time notably increasing pain and functional problems, or a new swelling /lump in the mouth or neck.

Is there extra support for patients with recurrence fears?

When contacting your healthcare team or Doctor about your fears of recurrence discuss any of these services that you feel may help you best:

- A Clinical Nurse Specialist
- Emotional Support Therapists
- Head and Neck Counselling Services

Are there any websites I may find helpful?

Relaxation websites

- <http://www.getselfhelp.co.uk/>
- <http://www.getsomeheadspace.com/>

Support groups

- www.cancerchat.org.uk – Share your experience and feelings with others who know what you may be going through.

Voluntary work

- <http://www.ncvo-vol.org.uk/>
- <http://www.do-it.org.uk/>

What can I do to try to help me deal with recurrence fears?

- Talking to your friends or loved ones about your concerns can help to relieve the fears you may be experiencing. Having someone to talk to openly about fear of recurrence can reduce anxiety.
- Discover new or old hobbies that you enjoy doing, this is an essential part of treatment as the more you enjoy doing things the more likely that your fear and anxiety will subside.
- It is important to notice success at carrying out normal routines, keeping a diary noting how often you are feeling able to carry out things that you enjoy can be a great help in seeing how your fears are reducing over time.
- Relaxation techniques have been found to be beneficial in reducing fear and anxiety.
- Strongly consider carrying out voluntary work, as helping others can be rewarding and can often help patients on their path to recovery.
- Find a cancer support group in your area, support groups provide a safe environment to talk about feelings and experiences with others who may be going through the same situation as you.
- Talk to your healthcare team, doctor or a professional therapist if you feel your fear or recurrence has become a problem and is severely affecting your life.

Further information on fear of recurrence

- www.livestrong.org
- www.cancer.org
- www.cancer.net

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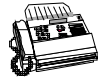
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