



"What will I be like following head and neck cancer?" Advice sheets

Health related quality of life (HRQOL) information can help give patients and their carers an indication of 'what they will be like' post-treatment. This knowledge can promote realistic expectations and help patients come to terms with their outcome. The following 'what I will be like' information sheets give an approximation of the likely response in terms of HRQOL following treatment for head and neck cancer. The information is derived from data collated from a commonly used head and neck cancer specific quality of life questionnaire (UW-QOL). There are 12 domains comprising; activity, appearance, anxiety, chewing, mood, pain, recreation, saliva, shoulder, speech, swallowing and taste. The data was collected over 19 years at the Head and Neck Unit in Liverpool and focuses at a time around two years following diagnosis as this gives a very reasonable indication of HRQOL in longer-term survivorship. There were a total of 2624 patients and questionnaires were available from 1511 (65%).

The data has been split into 26 subgroups based on cancer site, stage and treatment. Page 2 describes the number of patients involved. Where numbers are small greater care has to be taken in generalising the data as patient responses can be different. The purpose of the advice sheets is just to give a rough indication when discussing HRQOL outcomes with individual patients and their families. The Merseyside and Cheshire Head and Neck Cancer Patient and Carer Research Forum helped in the design of the information sheets. The information sheets display the overall 'quality of life, percentage reporting a good outcome by domain and those with a 'significant problem' ¹, and a word cloud which gives an approximate display of how frequently domains were chosen as one of three domains most important. Appropriate Individual sheets can be given to patients when discussing outcomes.

Over time it is hoped to add more data, subgroups and treatments. There is additional 'what will I be like' information available via an online searchable dataset found at www.headandneckcancer.co.uk. We hope you find this resource helpful and welcome feedback.

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¹ Rogers SN, Lowe D Screening for dysfunction to promote MDT intervention using the University of Washington Quality of Life questionnaire (UW-QOL) Archives of Otolaryngology Head & Neck Surg.2009; 135: 369-375.

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The number of patients, survival at 2 years, number of questionnaire responses, and the time in relation to two years are given in the table below.

Some groups have very few numbers so caution is required when interpreting the findings. There are always differences between patients but the groups with more data will give a better indication of the 'likely' outcome. It is hoped that in the future it will be possible to add more patients and also add additional subgroups.

Survival rates vary and this influences the number of patients available to respond at two years.

Two years is a useful time point as 'what will I be like' tends to remain relatively unchanged from that time on and also most H&N cancer related deaths will have occurred.

Definition: Early is stage 1 and 2, Late is 'Advanced' stages 3 and 4.

STAGE/SITE/TREATMENT	Patients	Kapan-Meier % Survival (SE) at 24 months	Patients with UWQOL record *	Median (IQR) follow- up in months of UWQOL record**
1 EARLY/ORAL/SURGERY ONLY	601	87 (1)	423	24 (20-29)
2 EARLY/PHARYNGEAL/SURGERY ONLY	108	88 (3)	74	22 (18-28)
3 EARLY/LARYNGEAL/SURGERY ONLY	149	88 (3)	92	25 (20-31)
4 EARLY/OTHER/SURGERY ONLY	7	86 (13)	4	26 (na)
5 EARLY/ORAL/SURGERY+RT	119	65 (4)	69	23 (20-29)
6 EARLY/PHARYNGEAL/SURGERY+RT	47	93 (4)	36	23 (18-29)
7 EARLY/LARYNGEAL/SURGERY+RT	31	87 (6)	17	26 (21-33)
8 EARLY/OTHER/SURGERY+RT	7	100 (-)	5	30 (na)
9 EARLY/ORAL/RT-CRT	35	40 (8)	6	36 (na)
10 EARLY/PHARYNGEAL/RT-CRT	38	63 (8)	15	21 (17-32)
11 EARLY/LARYNGEAL/RT-CRT	115	88 (3)	58	28 (20-43)
12 EARLY/OTHER/RT-CRT	11	73 (13)	6	41 (na)
13 LATE/ORAL/SURGERY ONLY	205	61 (3)	111	24 (19-28)
14 LATE/PHARYNGEAL/SURGERY ONLY	72	73 (6)	40	21 (17-24)
15 LATE/LARYNGEAL/SURGERY ONLY	34	76 (7)	18	27 (19-45)
16 LATE/OTHER/SURGERY ONLY	39	50 (8)	12	26 (16-53)
17 LATE/ORAL/SURGERY+RT	334	61 (3)	182	24 (19-28)
18 LATE/PHARYNGEAL/SURGERY+RT	197	86 (3)	145	23 (19-28)
19 LATE/LARYNGEAL/SURGERY+RT	68	73 (5)	27	25 (21-32)
20 LATE/OTHER/SURGERY+RT	72	76 (5)	45	25 (21-31)
21 LATE/ORAL/RT-CRT	68	21 (5)	5	25 (na)
22 LATE/PHARYNGEAL/RT-CRT	184	62 (4)	87	24 (20-29)
23 LATE/LARYNGEAL/RT-CRT	42	46 (8)	13	21 (14-25)
24 LATE/OTHER/RT-CRT	41	57 (8)	21	25 (18-30)
Total	2624	74 (1)	1511	24 (20-29)
25 Trans Oral Laser Resection (TOLR)	132	89 (3)	93	24 (19-32)
26 Laryngectomy	176	72 (3)	74	32 (25-59)

* at least 9 months into follow-up and if multiple records exist then UW-QOL record closest to 24 months

**na: insufficient cases for computing an interquartile range