



Patient Information for patients living with Head & Neck Cancer

Report for the BAHNON Committee meeting on 29 April 2004.

Findings from the national questionnaire circulated to BAHNON members.

This report has been split into 5 sections:

1. Introduction and background
2. Summary of findings
3. Conclusions
4. Recommended next steps
5. Detailed breakdown of findings

1. Introduction and background

The NHS Plan and The NHS Cancer Plan both recognise that to provide high quality patient centred care, the information provided to patients as part of that care must also be of high quality, accessible, given at the right time and in the right place.

The Improving Outcomes Guidance for Head & Neck Cancers highlights that:

- Treatment is often complex and difficult for patients
- Skilled assessment, care and rehabilitation are crucial to quality of life outcomes
- Many are disciplines involved in treatment, support and rehabilitation
- Specialist rather than generic expertise is required
- Effective MDTs are crucial to high quality, co-ordinated patient care
- Support and rehabilitation need to be well managed – often sustained over long periods of time

and makes a number of recommendations for improving patient care – including concentrating services within cancer centres, streamlining referral methods and providing better co-ordination for local rehabilitation and support services.

BAHNON recognise how difficult it is for each clinical team within this complex service to identify the wealth of information that is currently available throughout the country and to decide if, when and how it should be provided to their patients. As one of its core objectives, the BAHNON Committee is committed to developing an Action Plan for providing its members with more accessible and consistent high quality patient information that their patients and carers want to be offered by the clinical teams caring for them.

In January 2004, the BAHNON Committee, with the help of the Cancer Services Collaborative 'Improvement Partnership' (CSC 'IP'), circulated a questionnaire to all its members. The aim of this questionnaire was to identify:

- What information resources are currently being used by clinical teams
- What other information is available nationally but not being used at the moment
- The information gaps clinical teams have already identified
- The evidence needed for developing and implementing the Action Plan

2. Summary of findings

Returns rate:

- 59 responses were received by 29 February 2004
- Although there was only a 17% returns rate, returns were received from MDTs working in 25 cancer networks
- 2 separate responses were received from each of 6 of these MDTs

Providing patient information:

- 88% (52) MDTs offer written information to their patients
- 85% (50) MDTs offer patient information produced by national organisations
- 58% (30) MDTs fund patient information through their Trust's budget
- 42% (22) MDTs fund patient information through charitable funds

Offering nationally produced information to patients:

- The national information most commonly offered to patients is produced by:
 - BACUP
 - National Association of Laryngectomy Clubs (NALC)
 - Macmillan Cancer Relief
- 54% (32) MDTs offer patients information provided by commercial companies – Platon, Medical, Kapitex and Forth Medical being the most popular
- Where national information is not available to MDTs free of charge, 32 MDTs ask patients to contact national organisations direct

Offering locally produced information to patients

- 58% (34) MDTs offer patients locally produced information
- All of these MDTs are happy to share the information they produce with other MDTs
- Most locally produced information is offered to patients:
 - At diagnosis (unit clinic) – 28%
 - When discussing treatment plan (MDT Clinic) – 23%
- MDTs offer the least amount of locally produced information to patients during supportive & palliative care – 8%
- Only a handful of locally produced leaflets are available online
- Different MDTs offer similar local information at different times in the patient journey
- Some MDTs offer palliative care information at pre-diagnosis. Others offer surgery information and information about chemotherapy and radiotherapy at pre-diagnosis
- Much locally produced patient information covers similar topics and themes

Perceived gaps in current information:

MDTs highlighted where they thought the gaps were.

- A number of MDTs wanted to offer more nationally produced information
- Others were keen to offer patients more comprehensive information on:
 - Tests, scans and biopsies
 - Treatment options
 - Care and recovery after treatment
 - Appliance care
 - Emotional and psychological support
 - Information about MDT and contact details
 - Local and national support groups

Reasons why patients do not receive information

Some MDTs highlighted why they felt unable to offer their patients written information:

- 14 said they don't have the budget or access to locally produced information
- 5 said work was done at other centres
- 4 said local patient information was under review

3. Conclusions

A number of key themes have emerged from these results:

- Head & Neck Cancer is complex involving specialist treatment, rehabilitation and emotional support
- Nationally produced information is offered to patients by over 80% MDTs
- Local information is produced by over 50% MDTs
- It is difficult from the findings to identify the proportion of local to national information offered to patients by MDTs
- All MDTs are happy to share the local information they have produced
- A number of MDTs would like to provide their patients with more information
- MDTs have spent a considerable amount of time, effort and resources to design, produce and circulate local information. Even more effort is needed to ensure locally produced information is regularly updated and stocks maintained.
- Most local information offered falls into a number of core topics and themes. However different MDTs offer patients similar information at different times.
- MDTs provide the least amount of local information at pre diagnosis and as part of supportive & palliative care

4. Recommended next steps

To meet BAHNON's key objective of providing more accessible and consistent high quality patient information to its members, a number of actions should be considered as a result of these findings:

- Identify the common topics and themes
- Identify the common gaps in the information currently being provided
- Design and create a common core template for information protocols – the guidelines that indicate what information should be given at various stages in the patient pathway
- Identify core national information and decide how a central resource should be developed to house this
- Work more closely with national organisations producing patient information
- Decide how to share the local information currently being produced to reduce unnecessary duplication of time, effort and funding

5. Detailed breakdown of findings

Questionnaires circulated	350
Questionnaires returned	59
• Scotland	6
• Wales	2
• Ireland	3
• England	48
Cancer Networks returning questionnaires	25
Cancer Networks – no returns	9
MDTs where 2 completed questionnaires were returned	6

Question	Number of teams
Question 1 We offer patients written information about head & neck cancer	52
Question 2 We offer patients information that is produced by national organisations	50
Question 3 NHS Trusts are charged for some national leaflets. We offer the following national leaflets to our patients:	
BACUP Understanding Mouth & Throat Cancer	32
BACUP Understanding Cancer of the Larynx	36
BACUP Understanding Cancer of the Thyroid	29
BACUP Understanding Head & Neck Cancer	10
BACUP Understanding Radiotherapy	4
BACUP Understanding Radioactive Thyroid Therapy	1
BACUP Understanding Chemotherapy	1
BACUP What now? Adjusting to life with cancer	1
BACUP Dying with Cancer – coping with advanced cancer – what do I tell the children?	5
Laryngectomy – Your Questions Answered (Royal Marsden Series)	13
Question 4 These leaflets are funded by:	
Hospital budgets	30
Charitable funds – Trust Endowment Funds, Patient Support Groups, Drugs Companies	22
Question 5 We ask patients to send for these leaflets themselves	32
Questions 6 & 7 We offer patients other national information that is available to us free of charge.	
National Association of Laryngectomy Clubs (NALC)	
Handbook for Laryngectomy Patients	39
Stoma Care and Information Pamphlets	34
Living with Laryngectomy Pack	40
Living with a Pharyngo-laryngo-oesophagectomy	4
Self Help Benefits Guide	28
Video Talking it Through	32
Emergency Card, Sticker	35

Question	Number of teams
Changing Faces	
Making the change – facing the future	4
When cancer affects the way you look	3
Everybody is staring at me	3
Facial paralysis – what happened to your eye?	1
British Thyroid Association	
Thyroid Cancer & Treatment	4
The Thyroid Gland and Thyroid	4
Thyroid Surgery	4
Understanding chemotherapy	4
Wessex Cancer Trust	
Squamous Cell Carcinoma	1
Basal Cell Carcinoma	1
Fact card – sun know how – skin cancer	1
Melanoma & related cancers of the skin	1
Macmillan Cancer Relief	
The Cancer Guide	35
Other assorted pamphlets	25
Benefits advice line details	20
General help-line number	23
Assorted	
The Teamwork file – National Cancer Alliance	1
Information for Patients – The Pain Society	1
Cancer & the answers to your questions – Imp Cancer Research Fund	1
Tenovus Cancer Help-line	1
Gastrostomy – Freserius Kabio	1
Smoking cessation pamphlets - NHS	26
What can I claim – Benefits Agency	27
Question 8 We offer patients product brochures produced by a number of commercial companies	
Kapitex	29
MedicAlert	9
Platon Medical	32
TVM Healthcare	14
Forth Medical	22
Merck	3
Atos	2
Countrywide supplies	2
Pharma	3

Question	Number of teams
Question 9	
Locally produced information we offer to patients grouped by topic	
At pre-diagnosis	
The Head & Neck Clinic and Team	5
The rapid access neck lump clinic	1
Cancer, Diagnosis & Palliative Care Information	2
Pathway of Care – Oral Tumours, laryngeal cancers	3
Smoking cessation	1
CT and MRI Scan information – what to expect	5
Investigative procedures – laryngoscopy, biopsy, Pharyngoscopy, tonsillectomy	4
	1
Surgery for removal of neck glands	1
Thyroid surgery	1
Neck dissection, parotidectomy, tracheostomy care, speech valve record	1
Radiotherapy and chemotherapy for head & neck patients	2
At diagnosis – in the unit clinic	
Cancer and palliative care information	3
Cancer services information booklet	5
Head & Neck Team information and contact details	12
Support Group Information	7
Patient diary	1
Pathway of care for parotid tumours	1
Pathway of care for thyroid tumours	2
Face to face leaflet	1
A guide to head & neck cancer	7
I have mouth cancer	1
Face facts about oral cancer	1
A patient's guide to surgery to the head & neck	2
Neck dissection – unknown primary, skin cancer	3
Chemotherapy	2
Radiotherapy	1
What is radiotherapy of the head & neck?	7
Eating better booklet	3
Thinking about your drinking	2
When discussing treatment plan (MDT clinic)	
Planning treatment, head & neck team information & contact details	5
Pathways of care for the various tumours	4
CT planning	1
A patient's guide to surgery to the head & neck	11
A patient's guide to preparation for surgery to the head & neck	2
Squamous cell carcinoma of the middle ear	1
Surgery for removal of neck glands, neck dissection, partial glossectomy	3
Laryngeal, hypopharyngeal surgery	3

Question	Number of teams
Parotidectomy	2
Nasal cavity, paranasal sinus surgery	1
A guide to anaesthetic	1
Chemotherapy	2
Radiotherapy to the head & neck	9
Guide to planning mould room	2
Photodynamil therapy	1
Fitting and obturator as part of your maxillectomy	1
Help the speech and language therapist can give after surgery to the mouth and jaw	1
During treatment	
Information about the cancer centre	3
About radiotherapy – both generic and tumour specific – head & neck, mouth, thyroid, skin, mould room	17
A patient's guide to surgery to the head & neck	2
Thyroid Gland – various booklets	1
About your laryngectomy	2
Nasal douching	1
Skin care	2
Using gel caps	1
Changing your prothesis	1
Swallowing difficulties – how to look after your mouth	6
Blended or soft diet sheets	1
Discharge home	1
After treatment - rehabilitation	
Information for patients finishing a course of radiotherapy – reactions and, after effects, mouth care	7
Care of blorn singer voice prothesis, using blorn singer gel cal loader	4
Nursing and aftercare guidance and follow up support	5
Support Groups	2
Home enteral feeding booklet	2
Laryngectomy care	3
Gastro-oesophageal reflux	1
Head & Neck Lymphoedema	1
A patient with atracheostomy	1
Management of xerostomia & mucositis	1
Guide to holiday insurance	1
As part of supportive & palliative care	
How do you feel, understanding and dealing with emotions, counselling, details of other information and follow up available	6
Palliative care teams, hospices and contact details	7
Support Groups	4
Talking to children when adult has cancer	1
Complementary therapy	1

Question	Number of teams
Question 10 Our MDT is willing to share their locally produced information	34
Question 11 We feel there are a number of reasons why patients do not receive written information about head & neck cancer	
No budget to buy the information needed	10
No access to locally produced or free information	4
No-one to co-ordinate patient information	2
We do not know where to obtain information	1
Patients are treated at other units and centres	5
Information is under review	4
Question 12 We feel more information should be given to patients	
At pre-diagnosis	
Biopsy, CT, MRI scan information	2
Information about what happens next – tests and investigations -	4
Contact details for MDT	3
Information about how cells change	1
Oral screening information	1
Alcohol and diet information – health promotion advice	2
Possible financial help organisations	1
At diagnosis – in the unit clinic	
Contact details for MDT	4
What happens next	1
Details of local and national support groups	4
Information about disease and the treatment available	5
The different specific treatments in separate leaflets	4
BACUP booklets	3
When discussing treatment plan (MDT clinic)	
Specific pre operative literature explaining procedures and outcomes	7
Better communication between units and centres	2
Contact details for MDT	2
Details of local and national support groups	3
Radiotherapy and chemotherapy leaflets	4
During treatment	
Individual leaflets on specific treatments, side effects and after care	12
BACUP booklets	4

Question	Number of teams
After treatment - rehabilitation	
Side effects, symptoms, what happens next, follow up support	8
After care, how to cope, dealing with looking different, dealing with sounding different, body image, expectations, eating socially	5
How look after prosthesis, tube care etc	3
Support Groups	4
As part of supportive & palliative care	
Contact details for palliative care team	7
Information about palliative care	4
Support Groups	2

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