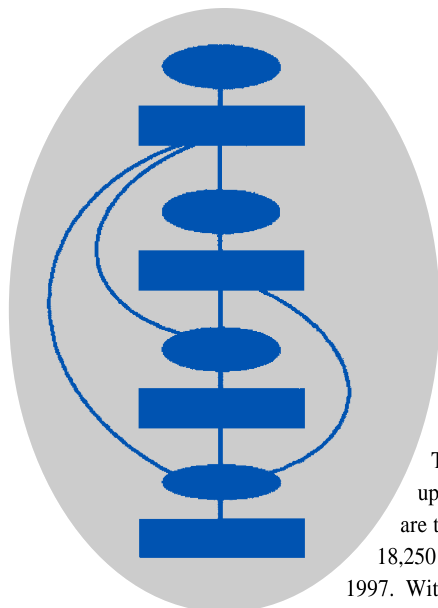
Guidance for General Practitioners and Primary Care Teams

Improving Outcomes in Upper Gastro-intestinal Cancers



This document deals with cancers of the oesophagus, stomach and pancreas. These cancers (described collectively as upper GI cancers) are not common, but nor are they especially rare; they accounted for 18,250 deaths, or 13.5% of all cancer deaths, in 1997. With an annual incidence rate of about 1 in 2,500, an average GP is likely to see a patient with one of these cancers each year, and a group practice with a list of 10,000 can expect to deal with four such patients. However, incidence varies widely, with higher rates in northern and less affluent regions.

Although the incidence of upper GI cancer as a whole is fairly stable, the rates for specific cancers are changing. Gastric cancer has been declining for more than half a century, but the numbers of cases of cancer of the oesophagus or oesophago-gastric junction are increasing quite rapidly. The nature of these cancers is also changing; whereas squamous tumours of the upper and mid-oesophagus used to predominate, adenocarcinomas of the distal oesophagus are now more common. The reasons for these changes are not known.

Survival rates are poor, at just over 20% after one year. This is mainly due to the late stage at which the disease becomes apparent, but international comparisons suggest that it may also be linked with poor management in the NHS. For example, the European average 5-year survival rate after diagnosis of gastric (stomach) cancer is 21%, compared with 12% in England.

In many parts of the country, care has been fragmented and the level of expertise required for optimum treatment of these challenging cancers has not been available. Implementation of the Guidance on which this document is based will involve radical organisational changes designed to give patients access to treatment by appropriate specialists. This will affect provision at all levels.

It is difficult for GPs to identify patients who might be suffering from upper GI cancer, so that they can refer them promptly and appropriately. It is rarely possible to discriminate between patients with early cancers and those with benign conditions on the basis of symptoms alone; further investigations are required. It is possible, however, to identify patients who are more likely to have cancer, and clinical features on which such selection may be based are listed in Topic 1, overleaf.

Older age and an unhealthy lifestyle are associated with a greater probability of upper GI cancer. 92% of patients are 55 years old or more. Oesophageal and pancreatic cancer are more common among smokers; heavy smoking and drinking together dramatically increase the risk of oesophageal cancer. All three cancers have been linked with low fruit and vegetable intake. Taking action against smoking and promoting consumption of fruit and vegetables might prevent some of these cancers.

Surgery is usually used to treat early disease. Chemotherapy and radiotherapy can play important roles both in primary treatment and palliation, especially when the tumour is too far advanced for surgical excision. Most patients have advanced disease at diagnosis and may require palliative interventions to allow them to eat, and for pain control.

The pattern of service provision recommended in the Guidance involves interlinked clinical teams working in different hospitals. Together, these teams are intended to form a Network which can provide appropriate levels of expertise for optimum management of individual patients. Initial investigations will be carried out by Upper GI Diagnostic Teams working in local District General Hospitals which serve populations of 200,000 or more. Patients with oesophageal or gastric cancer will then be referred to Specialist Oesophago-gastric Cancer Teams in large Cancer Units or Centres, whilst those who are likely to have pancreatic cancer will be referred to Specialist Pancreatic Cancer Teams in major Cancer Centres. These specialist teams will be responsible for decisions about patient management and the provision of cancer treatment.

This document has been produced by the National Cancer Guidance Steering Group. It summarises guidance for commissioners of upper GI cancer services given in *Improving Outcomes in Upper Gastro-intestinal Cancers: The Manual*, which draws on systematic reviews of the research evidence described in *Improving Outcomes in Upper Gastro-intestinal Cancers: The Research Evidence.* This follows similar publications on breast, colorectal, lung and gynaecological cancers. All can be obtained free of charge by calling the NHS Response Line on 0541 555 455.

Key recommendations

- Hospitals which provide services for upper GI cancer should work together in an integrated Cancer Network. Each region should ensure that proposals for local services reflect the Guidance accurately.
- There should be documented local referral policies for diagnosis of upper GI cancer, jointly agreed between all levels of service including primary care.
- Specialist Oesophago-gastric Cancer Teams and Pancreatic Cancer Teams, serving populations of over one million and two to four million, respectively, should be established at appropriate Cancer Centres and Units.
- There should be clear policies for referral of patients between hospitals.
- Co-ordinated palliative support and specialist care should be available to all who need it.
- Systems should be established to audit key processes and outcomes of treatment.

1 Primary Care Referral and Diagnosis

The symptom pattern produced by early tumours is not distinctive. Oesophageal and gastric cancers usually present with common symptoms such as indigestion, heartburn, reflux, and pain in the chest or upper abdomen, for which the generic term "dyspepsia" is used, but fewer than 2% of patients with dyspepsia have cancer. Other symptoms include persistent nausea and/or vomiting, recurrent reflux or regurgitation of food or fluid, and an inappropriate sensation of fullness in the stomach. Cancer of the oesophagus or oesophago-gastric junction may also cause dysphagia, or food sticking when swallowed; pancreatic cancer may cause jaundice and/or pain. The incidence of upper GI cancer is 1 per 100,000 in people under the age of 40, rising to 155 per 100,000 in people over 55 years old; the majority of patients are over 70.

Recommendations

- Patients over the age of 55 with symptoms that could be due to upper GI cancer should be directly referred for endoscopy.
- Fast-track endoscopy services should be available. These should be provided by the Upper Gastro-intestinal Diagnostic Team at a local District General Hospital, but may also be provided within primary care by suitably trained endoscopists.
- Patients with any of the following symptoms should be referred for investigation within two weeks by a designated Upper GI Diagnostic Team at a local hospital:[1]
  - Dysphagia at any age; this may be an emergency.
  - Dyspepsia at any age combined with one or more of the following "alarm" symptoms: weight loss; proven anaemia; vomiting.
  - Dyspepsia in a patient aged 55 years[2] or more with at least one of the following "high risk" features: onset less than one year ago; continuous symptoms since onset.
  - Dyspepsia combined with at least one of the following known risk factors: Family history of upper GI cancer in more than two first-degree relatives; Barrett's oesophagus; pernicious anaemia; peptic ulcer surgery over 20 years ago; known dysplasia, atrophic gastritis, intestinal metaplasia.
  - Jaundice.
  - Upper abdominal mass.
- Symptoms of uncomplicated dyspepsia in patients under the age of 55 should be managed empirically.

2 Patient-centred Care

There are few research studies dealing specifically with patient-centred care in upper GI cancer, but the information available suggests that these patients should be treated with the same degree of openness as patients with other types of cancer. Good communication and adequate information for both patients and carers can reduce anxiety and depression. Communication systems need to be quick and effective because time is often short. These patients have specific needs for dietary advice and nutritional support; this information can be important to their quality of life.

Recommendations

- Patients and their relatives should be offered as much information as they want. GPs should ask what they would like to know, and give unambiguous answers to their questions.
- Information should be clear, full, and prompt, and should be available in both verbal and written forms. It should include information about the disease, diagnostic procedures, the aims and anticipated benefits of treatment, and realistic estimates both of the probability of success and potential adverse effects.
- Specialist guidance should be available for patients from a dietitian, to advise on nutrition and minimising problems with eating, and to help those who have undergone resection to cope with post-surgical syndromes.
- Many patients and carers will require both practical and social support. They should be given information about sources of help, such as local and national support groups and disability and benefits helplines.
- Psychological interventions such as counselling should be offered to patients who are anxious, depressed, or who have particular difficulty coping.

3 Multiprofessional Teams and Specialist Centres

Services for upper GI cancer will be reorganised to create an integrated Cancer Network offering efficient and consistent delivery of high standards of care. Upper GI Diagnostic Teams will be established in local hospitals (DGHs) to provide rapid diagnostic services. Patients will be then be managed by Specialist Oesophago-gastric or Pancreatic Cancer Teams serving appropriate populations, as specified in The Manual.

The establishment of specialist teams is fundamental to the strategy to improve outcomes. Treating these cancers is particularly challenging and surgery is currently associated with unacceptably high peri-operative death rates in many places. When patients are managed by specialised clinicians in hospitals which deal with large numbers of these cancers, surgical mortality rates can be less than one third of the level that prevailed in many NHS hospitals in the 1990s.

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[1] Department of Health. Referral Guidelines for Suspected Cancer. (Available on http://www.doh.gov.uk/cancer)
[2] 55 years is considered to be the maximum age threshold. Local Cancer Networks may elect to set a lower threshold (e.g. 45 or 50 years).

Recommendations

- Specialist Upper GI Diagnostic Teams, working in one-stop diagnostic clinics in local DGHs, should be responsible for diagnosis of oesophageal or gastric cancer. These teams should aim to achieve histological confirmation of cancer by endoscopic biopsy.
- Diagnosis of probable pancreatic cancer will also be the responsibility of Upper GI Diagnostic Teams, but histological confirmation should not normally be sought.
- Patients with oesophageal or gastric cancer should be referred for assessment and treatment to specialist Oesophago-gastric Cancer Teams. These teams will work in large Cancer Units or Cancer Centres which serve populations of one to two million.
- When results of diagnostic investigations suggest pancreatic cancer, patients should be referred for further assessment and treatment to specialist Pancreatic Cancer Teams. These teams will be based in Cancer Centres which serve populations of two to four million.
- Specialist teams may manage smaller numbers of patients in sparsely populated areas. Minimum acceptable population sizes are 500,000 for Oesophago-gastric Cancer Teams and one million for Pancreatic Cancer Teams.
- Referral to a Cancer Centre may be inappropriate for patients who are very frail, or who have metastatic disease or other serious illness. Palliative care will be provided locally for such patients by Local Upper GI Cancer Care Teams, working closely with the specialist teams to which patients are normally referred.

4 Oesophageal and Gastric Cancers: Diagnosis and Assessment

Biopsy to discover the nature of a tumour can be achieved by endoscopy. Further assessment and tumour staging require imaging, followed by laparoscopy if radical surgery is being considered.

Recommendations

- Each Network (local DGHs and the hospital where the specialist Oesophago-gastric Cancer Team is based) should produce agreed assessment and referral guidelines which specify procedures to be used throughout the network.
- CT or MR scanning can reveal when tumours are inoperable, but further assessment is required when imaging does not show metastatic spread.
- Endoscopic ultrasound is an effective way of assessing tumour depth.
- Laparoscopy is often worthwhile to assess whether surgery is appropriate.

5 Pancreatic Cancer: Diagnosis and Assessment

It is often possible to diagnose pancreatic cancer using abdominal ultrasound. When patients have jaundice and dilated bile ducts, but no evidence of gallstones, the cause may be pancreatic cancer. It is not appropriate to treat jaundice or to seek histological confirmation of cancer if it is possible that the patient will be offered radical surgery.

Recommendations

- Each Network (local DGHs and the Cancer Centre where the specialist Pancreatic Cancer Team is based) should produce agreed assessment and referral guidelines which specify procedures to be used throughout the network.
- Abdominal ultrasound is usually sufficient to reveal tumours.
- Further assessment may involve CT scanning, endoscopic ultrasound, endoscopic retrograde cholangiopancreatography (ERCP), or other specialist procedures. Such investigations would be carried out by the Pancreatic Cancer Team.
- If radical surgery seems appropriate, tumour stage and spread should be assessed by laparoscopy.

6 Treatment for Oesophageal Cancer

Treatment will be the responsibility of specialist Oesophago-gastric Cancer Teams, working in large Cancer Units or Cancer Centres. All the major modalities of cancer treatment - surgery, chemotherapy and radiotherapy - may be used.

Recommendations

- Surgery (sometimes after neo-adjuvant treatment) offers the chance of long-term survival for patients with early cancers but complications are common and 5-year survival rates in the UK are below 20%.
- Survival rates are higher when patients are managed by surgeons who work in hospitals which treat large numbers of patients with oesophageal cancer.
- Combined treatment with chemotherapy and radiotherapy may be offered as an alternative to surgery. Surgery may be appropriate when there is evidence of residual tumour after chemo-radiotherapy.
- Most patients have advanced disease at diagnosis, and many are not sufficiently fit to tolerate radical treatment.
- Palliative chemotherapy and/or intra-luminal radiotherapy (brachytherapy) can help to control symptoms.
- Many patients require stents to keep the oesophagus open and relieve problems with swallowing. Stents should normally be fitted after, not before, treatment which may reduce tumour bulk.

7 Treatment for Gastric Cancer

As with oesophageal cancer, treatment will be the responsibility of specialist Oesophago-gastric Cancer Teams, working in large Cancer Units or Cancer Centres. Surgery is the most important form of treatment, although palliative chemotherapy may also be beneficial.

Recommendations

- Surgical resection offers the chance of long-term survival for patients with localised tumours. Palliative surgery may be appropriate to relieve symptoms in selected patients with more advanced cancer.
- Surgeons who treat larger numbers of patients with gastric cancer achieve better survival rates.
- Patients may be offered chemotherapy after radical surgery.
- Palliative chemotherapy is usually based on 5-fluorouracil (5-FU). In patients with advanced gastric cancer, chemotherapy can improve quality of life and may increase survival time by about six months, compared with best supportive care.

8 Treatment for Pancreatic Cancer

Pancreatic cancer generally has a very poor prognosis. Pancreatic resection is appropriate for 10-15% of patients and can lead to long-term survival, but surgery is technically difficult and life-threatening complications are common. Palliative measures to relieve pain and bile duct obstruction are necessary for most patients.

Recommendations

- Surgery for pancreatic cancer should be carried out only by specialised hepato-pancreato-biliary (HPB) surgeons working in large Cancer Centres where patients can be closely monitored.
- Chemotherapy may help to relieve symptoms and may increase the probability of survival after surgery. It is appropriate for patients who are sufficiently fit to tolerate it.
- Radiotherapy is not likely to be beneficial.
- Jaundice due to bile duct obstruction can be relieved by stents.

9 Palliative Interventions and Care

The majority of people with upper GI cancer have advanced disease at the time of diagnosis, and few survive for more than a few months. Quality of life is therefore of paramount importance. Palliative care should be an integral part of patient management and the GP can play a crucial role in ensuring that patients receive the care that they require. A substantial minority of patients are likely to require specialist interventions such as stenting to control their symptoms.

Recommendations

- GPs should have access to a member of a specialist palliative care team who can offer advice and guidance on dealing with patients with upper GI cancer.
- Continuity of care, good co-ordination, and rapid communication between all those involved in caring for patients, are important to maintain optimum quality of life for patients.
- Carers are likely to need support from the primary health care team, especially when patients are treated at home.
- Nausea, vomiting and problems with eating, which can lead to poor nutrition and dehydration, are common with all types of upper GI cancer.
- Pain may be a problem with all these cancers. It can usually be controlled with oral or parenteral analgesics, used in accordance with the WHO 3-step method for control of cancer pain.
- Pain should be re-assessed regularly, and doses of analgesics should be titrated to match the severity of the pain.
- Specialist interventions such as nerve blocks may be necessary to control pain, which can be particularly severe in patients with pancreatic cancer.
- Most symptoms of gastric cancer can usually be managed medically, but some patients will require specialist interventions.

Guidance on Commissioning Cancer Services: Improving Outcomes in Upper Gastro-intestinal Cancer was produced by the National Cancer Guidance Steering Group, chaired by Professor Bob Haward of the University of Leeds. This document was written by Dr Arabella Melville and Alison Eastwood of the NHS Centre for Reviews and Dissemination, University of York. The contributions of Dr Arthur Hibble, Dr Nick Summerton and Professor Mike Richards are acknowledged.

Copies of The Manual and The Research Evidence can be obtained through the NHS Response Line on 0541 555 455.

- National Cancer Guidance Steering Group. Improving Outcomes in Upper Gastro-intestinal Cancer: The Manual. NHS Executive, Department of Health, 2001.
- National Cancer Guidance Steering Group. Improving Outcomes in Upper Gastro-intestinal Cancer: The Research Evidence. NHS Executive, Department of Health, 2001.