

## Quality of life after oesophagectomy: the patients' perspective\*

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There have been formal publications which address the quality of life after oesophagectomy for oesophageal cancer,<sup>1–5</sup> but what follows is an account of my own experience as a patient and of the experiences of the many fellow patients and their carers whom I have met during my 14 years as Chairman of the Oesophageal Patients' Association (UK). The Association works closely with clinicians and paramedical professionals and enables former patients to support new patients who have oesophageal problems. Because the incidence of adenocarcinoma is increasing rapidly in the Western world,<sup>6</sup> the need for this type of support will be ever more pressing. I was invited to give the talk on which this article is based at the ISDE Congress in Montreal, Canada, in 1998. My hope is that dissemination of the experiences of others and myself will be of use to the wider clinical world involved in the treatment of this aggressive disease.

In 1980, when only in my 40s, I developed an adenocarcinoma of the lower third of my oesophagus. An oesophageal resection, including 30% of my stomach and a pyloromyotomy, was performed. The remaining stomach was brought through my chest and joined to the oesophageal remnant in my neck. There was no nodal involvement.

Three years later, I met, for the first time, other patients who had had the same treatment and there was an immediate affinity between us, with a feeling of mutual reassurance. This made me realize that others could be similarly helped by such contacts and, with the help of my surgeon, I founded the Oesophageal Patients' Association (OPA), which has been formally in existence since 1985.

Since then, contact with over 4000 patients and work alongside the medical teams has given me some insight into quality-of-life aspects. I am quite clear that exchange of experience between new and former patients has a major influence on patients' quality of life. Written information about these experiences and why they occur is enormously helpful.

I left hospital 9 days after my operation with no information about recovery, what to do or not to do, what to eat or not to eat. In retrospect, that experience has in fact helped my wife and me to develop the guidance leaflets that OPA now issues. The main problems I experienced were continued weight loss, extreme tiredness, eating very little, dramatic diarrhoea and nausea and milk intolerance. It is during this immediate post-operative period that many patients in the UK feel the isolation of their situation.

After the operation, I lost a further 6.5 kg over 8 weeks, having lost 9.5 kg beforehand. I became extremely worried and was reluctant to let my doctor weigh me. My weight then levelled out and slowly increased over the next 9 months until I reached my present weight, i.e. about 6.5 kg lighter than I used to be. A hard way to lose weight! I have never felt so tired in my life as when I got home from hospital. Minor activity caused over-tiredness, and sleeping at night was disturbed (because of some pain). I did not feel that I was getting better. I found the answer was to go to bed (properly) for 2 h in the afternoon during the first 5 or 6 recovery weeks. I have learned that men in particular can find this difficult; they want to be back to normal habits soon after leaving hospital, but the body needs time and respect.

Eating little can be more of a problem for the carer than the patient. The carer understandably wants the patient to start eating again after the months of not being able to eat well and of losing weight. It is very frustrating when the patients' favourite foods are prepared and then not really wanted. If you do try and then eat too much, the after-effects are difficult

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and painful for half an hour or so, but hopefully the lesson is learned. While 'little and often' is the eating guideline, little does become bigger over the months, although generally one's capacity is not as much as it was before surgery.

I found intermittent diarrhoea distressing, particularly with its very sudden onset and because it did not relate to what I had eaten. I understand now that it is more to do with the messages not getting through to the gut because of the severed nerves. I find that most patients experience such diarrhoea with reducing frequency, sometimes with the aid of drugs that slow the motility of the gut.

I also suffered from a good deal of nausea during the early months of recovery, retching first thing in the morning but not regurgitating food. I felt very uncomfortable after eating, with a great need to belch but finding it difficult to do so. I also realized that I felt worse after anything with milk in it, even tea or coffee. However, on ceasing to take any milk, I began to feel better. I think about 20% of patients experience this milk intolerance. After about 3 months, I was able to take milk again. During the early recovery period, carers probably wish to serve nutritious milky drinks and desserts but in the process may make the patient feel very much worse. Some time later, I realized that nausea can also be caused by gastric retention in many patients; even now, I carry metoclopramide with me, just in case.

My life now, 19 years on, is very different. I returned to work as a management consultant after 4 months. My weight is stable. I am physically active, with regular swimming, some jogging, and walking holidays. I travel to many meetings around the UK. I enjoy an aperitif and wine in moderation with meals. I still do not eat large meals, unless very slowly. There is some discomfort if I eat too much at one time and I occasionally get some reflux during the night, but I am not on any regular medication.

I suggest that some key elements of a good quality life after oesophagectomy are:

- to be able to eat adequately and enjoy it;
- to be able to drink as desired, with moderate alcohol consumption;
- to be able to do both of the above socially;
- to have weight stability;
- to be able to sleep comfortably in a normal position;
- to be free of pain;
- to be able to earn one's living;
- to be able to participate in sports or hobbies;
- to have unimpaired libido.

I would like to discuss a few specific influences on some of these aspects. There is no universally recommended diet for those having had an oesophagectomy. Certainly, for the first 6 weeks or so, it makes sense to avoid swallowing a hard or large

bolus of food, but generally one should pursue a healthy balanced diet, not striving unduly for weight gain. There is much scope, however, for dietetic advice as to what constitutes a healthy balanced diet for recovering patients. The general rule is eat 'little and often', and it is surprising how many patients (particularly men) find this difficult to follow. It is wise to indicate to patients that alcohol absorption can be quicker after such surgery.

Some hospital guidance notes for post-oesophagectomy patients say that they will never sleep lying flat again because of reflux. I do sleep lying flat using just two pillows, and not to be able to do so would seriously affect my quality of life. An influence on this ability is the fact that I have a high anastomosis (I had a neck wound). Some of the literature would agree with me.<sup>5,7</sup> Another advantage of the high anastomosis may be better surgical clearance above the tumour, increasing the likelihood of complete surgical removal of the tumour and of survival.<sup>8,9</sup> Patients are increasingly aware of the literature and the effects of the surgical approach on their quality of life.

Although not generally disabling, there is no doubt that some patients do have significant residual pain after surgery, affecting quality of life. I cannot comment on the causes of this pain, but it would appear that alleviation is not easy and it is an area perhaps deserving closer attention. If it persists, it can clearly affect the ability to work, and as there are more younger people developing oesophageal cancer in the West this is an important consideration. Manual workers, in any event, do find it more difficult to return to the same work if bending, lifting, crouching, etc. are involved. Such workers may also find it less convenient to eat little and often.

One member of the OPA committee took up marathon running a few years after his operation (now 15 years ago): at the age of 60, he shows no sign of stopping! Also in the Association, we have a boxer (who has since given up boxing to take up hang-gliding), golfers, tennis and squash players, swimmers, climbers, skiers and flyers. Thus, oesophagectomy does not preclude participation in sports. However, I do think that there is a case for those who are older or more used to a sedentary life to be offered a short course of physiotherapy, say 6 weeks or so after surgery, in order to encourage greater activity and particularly to assist in overcoming breathing difficulties. Many patients are not disciplined enough to continue doing the exercises given by the physiotherapists in hospital, and 'shortage of breath' is a common after-effect of surgery.

I would now like to mention some other (less tangible) influences on quality of life. First, confidence in the expertise and experience of those administering the treatment will lead to a positive attitude in the patient, who will be encouraged to feel

that he can achieve a good long-term quality of life. In the UK, as more information becomes available to patients and carers, they are increasingly asking questions, such as 'how often is this operation carried out at this hospital and by whom?' 'What are the results?' 'What are the effects on my quality of life likely to be?' Clinicians and support groups, such as the OPA and CancerBACUP, are being asked to supply the answers. I have been pleased to be invited to join various senior national committees debating and developing standards for the treatment of upper gastrointestinal cancers. The consensus is that oesophageal cancer should be treated in units where significant numbers are received and by specialists dealing with these cases very regularly. Research has shown that better results are obtained at such units.<sup>10-13</sup> The input from multidisciplinary teams planning the treatments is also valuable. Such units are more likely to know the answers to questions and may have former patients available who are willing to be involved with new patients and who are willing to form a support group based on the OPA style.

It is the example of former patients that can perhaps convince a new patient that he or she can have a good quality life. They can answer better than any doctor the question I just mentioned: 'what are the effects on my life likely to be?' This is one of the key elements of our work in the OPA; to give long-term reliable information about all the factors described above. Our aims are to help new patients with oesophageal cancer, and their carers/families, to cope with the fact of the disease and to help them with the problems of treatment by providing clinically supported information. We establish links with former patients to encourage a good recovery.

There are some negative influences that can affect the patient's attitude:

- the survival statistics;
- negative or conflicting statements by medical staff;
- the inability to do the same job as before;
- negative attitudes of social contacts;
- inappropriate dietary advice;
- the need for dilatations;
- fear of recurrence of disease.

Unfortunately, as patients and carers increasingly ask questions and are encouraged to do so, the survival statistics become known. I had a bad night when I learned the 5-year survival rate, and that was 3 years after my operation: patients may now know the figure before surgery. We do not highlight survival rates within the OPA. 'I am a statistic, why not you?' Doctors today do have to be more open when questioned directly, but do they have to volunteer negative information? Predictions as to how long a patient has to live are often so wrong. Why give them? Let the patient have the best quality of life possible for as long as

possible. The OPA wants to influence public awareness of the symptoms of oesophageal cancer and what to do about them and also to encourage the family doctor to consider the possibility of the disease at an earlier stage than many do presently. Patients may see many different doctors during the cancer pathway, and the same question can sometimes elicit contradictory answers. Junior doctors may not like to admit to not knowing the answer and may guess, but if it conflicts with something said previously or later the patient loses confidence. We, as clinicians or supporters, should never guess an answer. If one does not know, say so, find out, and gain much respect in doing so.

In the social world, cancer can be very difficult for a patient because friends, carers and colleagues cannot handle it or speak about it. The OPA has helped many with this dilemma. I also believe that clinical nurse specialists inside and outside hospitals and hospices have a developing role in providing a focal point, enabling all concerned to speak more freely to a familiar face.

Too often, I hear of patients told to eat at set frequencies, to eat rich foods, never to drink during a meal, never to eat after 7 p.m., etc. Dietitians attend our patient and carer meetings, and all groups learn from each other. As stated earlier, eating is a vital part of a good quality of life and dietary advice has to be right. There is perhaps some logic in not following a soft diet for very long after the operation because the anastomosis is naturally exercised by swallowing a bolus of food. I have not needed a dilatation, but many do, and I would certainly never suggest that eating solid food is the answer to this problem.

The most frequent problems that patients encounter after oesophagectomy appear to be:

- nausea and gastric retention;
- continued weight loss;
- dumping syndrome;
- diarrhoea;
- the need for dilatations.

I have already referred to some of these aspects. Patients find them easier to manage if they know that they may occur and why. Gastric retention with resultant nausea and retching can often develop as the intake of food increases, although the retching and regurgitation of saliva often occur from early days. For some patients, metoclopramide and cisapride may be helpful, but studies have shown that patterns of gastric emptying are complex and quite individual.<sup>14</sup> Nearly all patients seem to experience dumping at some stage, and in a few cases it is very severe. Reducing the sugar content of food may help, as may the immediate ingestion of a small sugar source, such as a glucose tablet, to counteract the overproduction of insulin (diabetics may need specific advice). Certainly, sitting quietly for 20 min after

eating is essential. Intermittent diarrhoea is also very commonly experienced and is often assumed to be due to what has been eaten. This is generally not true, and drugs that slow the motility of the gut usually bring the persistent cases under control.

All the above influences on the quality of life of patients after surgery can be affected by the provision of good-quality information. Booklets on all aspects of oesophageal cancer are available from OPA and from CancerBACUP (web site: [www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)). As I have indicated, I strongly believe that personal contact with former patients can play a very significant role in helping new patients to achieve a good quality of life. However, it can only happen if the patient group, like the OPA, works alongside the clinical team. We have to be responsible and knowledgeable, not guessing answers but communicating with nursing staff, dietitians, physiotherapists and doctors.

## CONCLUSIONS

- Recovery from oesophagectomy is not easy or quick.
- The long-term quality of life for those getting over the first 6–12 months and not suffering recurrence can be very good.
- Patients and carers need to be involved in the treatment plan and they need quality information to manage the illness.
- The surgical expertise has an effect on the subsequent quality of life.
- Former patients can have a key role in the encouragement of patients to achieve a good quality of life.

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