THE MASTECTOMY ADVISORY SERVICE

JOHN F. O'SULLIVAN, F.R.C.S., F.R.C.O.G.

The Ulster Cancer Foundation
40-42 Eglantine Avenue, Belfast BT9 6DX

THE Ulster Cancer Foundation was established in 1970 with the threefold aims of: supporting research in Northern Ireland, the establishment of a cancer education programme, and helping to fund the Chair of Oncology at Queen's University of Belfast.

At education meetings, many questions were asked about the management of women who had a mastectomy performed. It was obvious that little or no information had been given to these women about prostheses, clothes, etc., nor had any psychological support been offered in dealing with husband and family. As nearly five hundred women undergo mastectomy each year in the province, it was obvious that there was a great need for support and help in this field.

In 1975, the constitution of the Foundation was changed to include the provision of cancer care. An article on the problems that these women faced was published in the local press and on appeal was made for volunteers to help. The response was dramatic. Thirty women who had undergone mastectomy at least 2½ years previously were selected to train as our first volunteers. A training programme was drawn up and has since been modified as required. The potential volunteer is interviewed and selected by our officers. The training consists of six lectures given by a surgeon, a radiotherapist, a psychiatrist, a sister from a female surgical ward, a volunteer and a member of our staff.

The surgeons in all the hospitals were informed of this new service. Many already used former patients selected personally to advise their new patients. After an initial slow start, our volunteers are now invited into all hospitals in the province. Nursing officers and ward sisters from all hospitals were invited to attend symposia held in headquarters. Lectures were given by a surgeon, a radiotherapist, a volunteer and member of staff. Visits to Belvoir Park Hospital were arranged.

In 1977, a “mastectomy centre” was established. It contains a permanent display of bras, prostheses, aids, swimwear, etc. There is an extensive selection of literature available to patients, relatives and nurses. Our own booklet “Reaching to Recovery after Breast Surgery” was favourably reviewed in the British Medical Journal (1980): the reviewer concluded by stating that any surgeon who undertakes a mastectomy should have a copy and base his advice on it.

The organisation has developed rapidly. The volunteers meet at headquarters four times per year. Now, many of the clients come as well. The aim is to provide something positive. A speaker talks on a topic which will be helpful to many of the audience. These meetings have become so popular that they are now also held twice a year in several provincial towns. An annual dinner is held in many towns. A social weekend is held annually in Castlewellan Castle.

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All advice given is non-medical. Originally, when a patient was about to undergo breast surgery the ward sister requested that a volunteer visit the patient. The visits are arranged through the co-ordinator at headquarters. Experience has shown that it is much better to visit the patient three or four days after the operation. A number of patients had been counselled and biopsy proved negative so mastectomy was not performed.

The volunteer brings a soft temporary prosthesis to the hospital when she visits the patient. This expense is borne by the Ulster Cancer Foundation. This boosts the patient’s morale and preserves her self image. One of our booklets is given to the patient. A follow-up visit is arranged when the patient goes home from hospital.

There is a wide variety of extremely sophisticated breast forms available for patients. Many are available under the National Health Service and the others may be purchased privately. Each hospital has its own arrangements for fitting patients with prostheses and brassieres. A list of shops in Belfast providing these facilities is included in the booklet.

The co-ordinator regularly gives talks to student nurses in hospital at Royal College of Nursing refresher courses, to health visitors and to groups of selected medical students.

A meeting of mastectomy associations in Europe was held in Copenhagen in May 1980. One of our volunteers and a Belfast surgeon were invited to read papers. It was obvious from reaction at the meeting that the service provided in Northern Ireland is the best in Europe.

DISCUSSION

It is now obvious that this is the most valuable of all the services offered by the Ulster Cancer Foundation. When the author was collecting data to present to Council for consideration to establish this service he was amazed at the lack of follow-up care these patients received.

One startling discovery was that the majority of ward sisters in female surgical wards outside Belfast had not trained in one of the City hospitals. Therefore, many were unable to advise patients about the location of Belvoir Park Hospital, visiting facilities, etc. Many did not know what treatment in that hospital entailed. The surgeon usually left all this work to the ward sister!

One lady wrote to say that she had had a mastectomy performed in 1950 and that for 25 years she used a bag of birdseed to fill her bra! She is now an enthusiastic supporter of this organisation. Another lady wrote to describe her first treatment in the radiotherapy ncentre. She was in a 'strange' hospital. Many of the patients in her 'home' hospital were neighbours and friends. She became quite terrified when she found herself alone in the treatment room despite all the reassurances that she had been given by the staff in the department. Another lady had been distressed when she had been told never to sunbathe as the treated area would be damaged by sunlight! A continental holiday planned to aid convalescence had to be cancelled.
The psychological aspect of the mastectomy operation had also been largely ignored. Some women wrote to say that they felt to be only half a woman. They wondered what would be their husband's feeling for them. They did not know how to talk to their children, especially their daughters. The modern mastectomy operation is not physically incapacitating but often it is mentally incapacitating. If a woman is going to regain her confidence she must come out of hospital feeling and looking as normal as possible.

Many women have reported that the 'fitters' of bras and prostheses carry a poor selection of sizes and cups and that the actual fitting of the garments leaves a lot to be desired. The 'fitters' appear to hurry away from them. Is this a genuine complaint or is it a fear on the part of the fitter that she may get the disease? This is a major problem for our clients. It is gradually being overcome by inviting fitters to attend some of our meetings. Indeed, everyone, fitters, surgeons, doctors and nurses who have attended the meetings of volunteers have assured me that they learned from the volunteers instead of teaching them!

Unfortunately, some of the volunteers developed carcinoma in the remaining breast. They have not been asked to advise anyone until 2½ years have elapsed and are only asked to see other women who are having the second breast removed. A few have died. Because of the attitude of positive living instilled into all our staff, these deaths did not have a long lasting effect on the other women. We have restricted the number of volunteers to approximately thirty so that they can be well trained and later acquire a wide experience in visiting clients. Too many volunteers would reduce the amount of experience available to each.

Since 1975 over seven hundred requests have been received for help — over two hundred of these being in the present year. Recently one has been heartened by the number of requests from health visitors, social workers, psychiatrists, family doctors and community nurses. We had concentrated all our efforts in the hospital service. This new development is welcome. Much work has yet to be done in advising doctors, nurses, families and, indeed, the women who develop this all too common disease.

**SUMMARY**

The need for an advice service to patients who have a mastectomy is noted. The non-medical problems that they encounter have been discussed. A group of women who have had the operation have been trained to advise these patients in hospital and at home. A "Mastectomy Centre" has been established to coordinate the service and to organise displays of prostheses, clothes etc., and to supply appropriate literature. The demand for this service is increasing annually.

**ACKNOWLEDGMENTS**

The outstanding success of this organisation is entirely due to its first co-ordinator, Miss Betty McCrum, to whom I am deeply grateful. I also wish to
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REFERENCES

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