



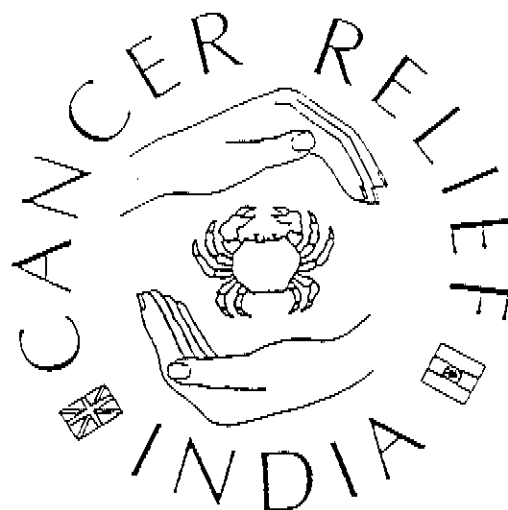
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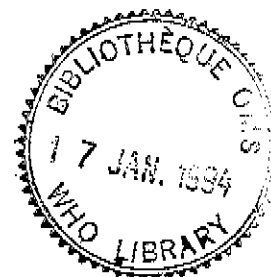
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**REPORT ON THE FOURTH LECTURE TOUR TO CANCER
PATIENT SETTINGS IN INDIA OF MISS GILLIAN BURN,
PERIPATETIC NURSE TUTOR, MARIE CURIE CANCER CARE**

JANUARY - MARCH 1992



**"DON'T JUST CRY,
SUPPORT C.R.I."**

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and

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B. Braun Medical for their very generous donation of two syringe pumps and financial support to C.R.I.

Dr Niak, Indo Medic U.K. for the donation of a Graseby syringe pump to the "Joy Burn Pain Clinic".

I would also like to acknowledge all those who have helped so generously with their time and efforts to support fund-raising in order that the aims of C.R.I. can be met; and also all those friends and family in India and the United Kingdom who have supported me by their enthusiasm, encouragement and prayers. Last but by no means least sincere thanks to Corinna for all her help with unending paperwork and to Emma Vine who, with her great artistic talent has produced such professional information which has helped to publicise C.R.I.

INTRODUCTION

This describes the fourth teaching visit to India by Gillian Burn - the first visit being sponsored by the Cancer Unit of the World Health Organisation. This venture was undertaken under the auspices of "Cancer Relief India", a UK based charity, the main aims of which are to:-

1. Educate doctors and nurses in the principles of palliative care and cancer pain relief.
2. Provide relevant equipment which will relieve suffering and enhance the quality of life for cancer patients.

The 1992 tour this year included observations, discussions, workshops, and lecturing at conferences in the following places:-

Bangalore

Bombay

Delhi

Manipal

Trichur

Trivandrum

Udaipur

Lahore (Pakistan)

A World Health Organisation Workshop on Cancer Control in India was also attended in Trivandrum.

January 1992 - March 1992

Gilly Burn presented papers on various aspects of palliative care at the following conferences:-

January 31st - 2nd February: Bangalore, Karnataka

VIII Annual Conference of the Indian Society for the study of Pain

Paper: Bringing Hospice into Hospital: The Role of the Terminal Care Support Team.

February 13th - 16th: Manipal, Karnataka

XIII Annual Conference of the Association of Radiation Oncologists of India

Paper: Radiation and Palliation: Working Together for Optimum Care.

February 17th - 19th: Trivandrum, Kerala

Attended W.H.O. Workshop on the Cancer Control Programme for India.

February 20th - 22nd: Bombay

Tata Memorial Hospital Golden Jubilee Conference

Paper: The Role of the Nurse in Palliative Cancer Care

February 23rd - 25th: Bombay

Tata Memorial Hospital Golden Jubilee Conference

Paper: The Challenge of Education in Palliative Cancer Care

February 27th - March 1st: Lahore, Pakistan

1st International Congress on Environment Geocancerology and Cancer Control

Paper: Putting Research into Practice - From Cancer Control to Cancer Care

March 3rd: Udaipur, Rajasthan

Workshops on Palliative Care - attended by 350 health care professionals from Rajasthan.

March 5th - 6th: Trivandrum, Kerala

Four Workshops on Palliative Care in Nursing.

Lectures to groups of doctors and nurses within hospitals were also delivered in Udaipur, Trichur, Bangalore and Trivandrum.

VENUE ALL INDIA INSTITUTE OF MEDICAL SCIENCES

DATE 8 JANUARY 1992

Dr Abba Saxena, an anaesthetist with an interest in Oncology working in the Oncology Department, informs me that oral morphine has been available on a limited basis, but there are problems getting a regular and adequate supply.

Contact was also made with W.H.O. Delhi office and Mrs Nagpal, Trained Nurses Association of India. I requested 100 copies of W.H.O. Cancer Pain Relief in Hindi - this has still not gone to press, despite the fact it was ready for printing nearly 14 months ago. An offer of 10,000 Indian Rupees (approx: two hundred and fifty pounds) has been made by Cancer Relief India to expedite this much needed publication.

(N.B. 1st April 1992. This offer has now been accepted and the first 1,000 copies have gone to press in Gujerat, and will be freely distributed to the doctors)

VENUE GENERAL HOSPITAL UDAIPUR, RAJASTHAN

DATE 10 JANUARY 1992

A lecture was given to approximately 150 doctors and nurses including medical students. A lively discussion ensued, which was very encouraging. There has been much progress at this hospital since my first visit in 1989. Dr Rakesh Gupta, is an extremely keen surgeon with a strong interest in Oncology having completed two years at Tata Memorial Hospital, Bombay. He is very interested in the philosophy of palliative care, but has been very much a lone voice. He has started a Cancer Research Society in Udaipur which now has over 500 members and puts out regular newsletters and information about Cancer, in Hindi.

There has been strong opposition to Dr Gupta, until recently when the wife of an eminent doctor contracted cancer. I was asked to visit her. She had many symptoms including pain, insomnia and anorexia. There was a great fear of using morphine, despite the extreme pain. Oral morphine is not legally available in Rajasthan - however a supply had been obtained from West Coast Pharmaceuticals and after pain assessment and education about the drugs, morphine was taken. It has provided complete pain relief. The starting dose was 10mg 4 hourly.

The patient was seen again seven weeks later - the dose had been increased to 20mg 4 hourly and the patient remains pain free. This episode has persuaded the doctor of the importance and need for Palliative Care in Udaipur and Dr Gupta's efforts are now being supported.

Post Script

14 April 1992

The patient died on 19 March 1992. Correspondence from her husband confirmed that she was able to continue with oral morphine and that she died pain free, at home, with the support of her husband and family.

VENUE AMALA CANCER HOSPITAL, TRICHUR

DATE 24 - 29 JANUARY 1992

This was perhaps the highlight of the tour - to see the work over the last three years come to fruition and to inaugurate the first major project of Cancer Relief India - the "Joy Burn Pain Clinic". Dr C.D. Joseph, Chief Radiation Oncologist of the Amala Cancer Hospital was the first doctor in Kerala to obtain oral morphine tablets. It took nine months of legal bureaucracy to do so. However, since the supply ran out it has been exceedingly difficult to obtain further supplies. He had been told by the Regional Cancer Centre in Trivandrum that once he had a registered pain clinic, then supplies would be forthcoming. It was on that premise that C.R.I. has agreed to fund the project for an initial period of 5 years. This includes paying for an anaesthetist and a nurse/masseuse for 3 sessions a week. Mr R. Cambata, of Greaves Travel London is also sponsoring this particular project and a room where the pain clinic also functions has been named in his honour.

Supplies of oral morphine have still not yet been secured and there seem to be problems with the legalities. I have written to the State drug controller asking for his assistance in this matter. Frequently, Dr Joseph sees over on hundred patients per day, the majority of whom come from long distances, are in the advanced stages of their disease and who are suffering considerably. Many such patients were seen on this particular visit. These problems are compounded by the fact that many patients cannot afford to pay for their treatment. Free palliative care is given for those who cannot pay.

N.P. Lectures on palliative care were given to doctors and nurses in the hospital and also a public lecture was given to approximately 60 people at a centre 70 miles away. Dr C. D. Joseph is very keen for a social worker to join the team to support cancer patients. This is in line with the philosophy of C.R.I. who are happy to fund such a post. However, at the moment, the hospital authorities are not wanting to have such a person in the team at the moment. Dr Joseph informs me that a priest with a special interest in the pastoral care of cancer patients will soon be joining the hospital team.

A syringe pump has been donated to Amala Cancer Hospital from Indo-Medic U.K. Amala Cancer Hospital will provide quarterly reports to C.R.I. regarding the finances and functioning of the pain clinic.

VENUE GENERAL HOSPITAL UDAIPUR

DATE 3 MARCH 1992

A whole day "Workshop on Palliative Care" (programme in Appendix) including an evening lecture to the general public and the Maharani of Udaipur, was organised by Dr Rakesh Gupta.

This was a most enlightening educational event for over 350 doctors and nurses. Lectures were given on different aspects of Palliative Care. One of the most productive outcomes was a panel discussion for approximately 2 hours concluding with an "Action Plan" and recommendations for the future of palliative care in Udaipur.

Cancer Relief India has pledged to pay for a Palliative Care Clinic, to include drugs and staff provided that oral morphine can be obtained. Plans are under way to achieve this goal.

A syringe pump (B.Braun) was presented to Dr Rakesh Gupta. C.R.I. has also agreed to fund the annual subscription to "Palliative Medicine" for the Cancer Relief and Research Society.

VENUE BANGALORE

DATE JANUARY 31ST - FEBRUARY 2ND

VIII Annual Conference of the Indian Society for the Study of Pain

Presentation "Bringing Hospice into Hospital" - "The Role of the Terminal Care Support Team"

This conference was attended by over 100 anaesthetists. One social worker, one nurse and one pharmacist attended from Kidwai Memorial Institute of Oncology. Different aspects of pain were discussed - mostly benign pain although there was a section on Chronic Malignant Pain. A good deal of interest was expressed about the palliative care concept although the anaesthetists in general were not keen to have a Palliative Care Association of India. It was envisaged that this would be multidisciplinary. However, Dr Vidya Sagar, Neurosurgeon has expressed an interest in trying to start a Palliative Care Society in the hope this would foster better communication between members of the multidisciplinary caring team and thus improve patient care.

VENUE BANGALORE

DATE FEBRUARY 26TH - 27TH

The social work team requested a talk about issues in palliative care. This was followed by a discussion which focussed on some of the family problems in the Indian setting. A lecture on palliative care was also requested at one of the private hospitals in Bangalore. This was attended by approximately 25 doctors and nurses and was arranged by Dr Vidyasagar.

A second syringe pump was donated from B. Braun to Kidwai Memorial Institute of Oncology.

VENUE KASTURBA MEDICAL CENTRE, MANIPAL

DATE 12TH - 16TH FEBRUARY

XIII Annual Conference of Radiation Oncologists of India -

Presentation - "Radiation and Palliation - Working Together for Optimum Care

This conference was attended by more than 230 Radiotherapists from all over India. My lecture had the privilege of being presented during the first session of a four day conference. It was the only paper on Palliative Care. I have noticed a great deal of change in the attitude of the medical profession and radiotherapists in particular, who are now realising the importance of palliative care in India - especially since 80% of the patients first present when this is the only option. This conference was very well organised, with good time keeping on the whole and plenty of time for discussion and exchange of ideas. Many doctors expressed sincere interest in the concept of palliative care and many books were given on symptom control and on the use of oral morphine. Many doctors were unaware of how to obtain oral morphine. Dr Jan Stjernsward, WHO was able to offer advice in this respect. The idea of a Palliative Care Society for India was also suggested and interest was shown. It is essential that members of the profession realize the importance of a multidisciplinary approach.

Oral Morphine is available at Kasturba Medical College and Hospital and the pain clinic is working well although there seems little interaction between anaesthetists and radiotherapists which is unfortunate. Dr Akhileshwaram, Assistant Professor in Radiotherapy is extremely keen on Palliative Care. He needs support and encouragement to continue his enthusiasm. C.R.I. will be happy to support him to undertake training in the United Kingdom which has been organised by Dr Robert Twycross.

A positive outcome of this conference was the generous donation of a syringe pump from Dr Niak, Indo-Medic U.K. to Cancer Relief India. The pump worth £500.00 will be donated to the Pain Clinic, Amala Cancer Hospital, Trichur.

The response from the radiotherapists regarding Palliative Care has been very positive - in fact, Dr Harish Kulkarni, President of All India Association of Radiation Oncologists asked me to arrange visits to Palliative Care Settings in the U.K. A four day programme has been organised with the help of Professor Geoffrey Hanks of St Thomas's Hospital Palliative Care Team and Dr Adrian Tookman, Edenhall Marie Curie Centre.

VENUE TRIVANDRUM

DATE 17TH - 19TH FEBRUARY

W.H.O. Workshop on Cancer Control Programme in India - attended by 70 doctors from various states in India.

Convenor:- Dr Jan Stjernsward W.H.O. Geneva

This was a most stimulating 3 day meeting, discussing cancer from prevention to palliation, the Anti-Tobacco Campaign, the role of industrial pollution as a cause of cancer, and also looking at rehabilitation issues. Palliative Care was also discussed and the following recommendations have been made:

A review of nurses and doctors training programme should be done with a view to include cancer pain relief and palliative care.

Oral Morphine availability should be ensured and the search for a centralised government production be done.

Home Care programmes for the terminally ill should be established. Hospices should only be encouraged in this context and they should serve as teaching and training centres in which case their role will be important.

So as to achieve a meaningful coverage, a search for family guidelines and family support in palliative care should be done.

Co-ordination of the several initiatives emerging in palliative care should be supported.

Allocation of resources to palliative care during the 8th Plan is essential.

(N.B. The complete proceedings of this meeting can be obtained from Gilly Burn).

VENUE TATA MEMORIAL HOSPITAL BOMBAY

DATE FEBRUARY 19TH - 24TH

Cancer Nursing Workshop

Presentation - "The Role of the Nurse in Palliative Cancer Care"

The Nursing Conference was attended by approx: 150 nurses from all over India. Dr D'Souza, a surgeon with an interest in Palliative Care presented a paper looking at the medical aspects of Palliative Care and this was followed by the Nursing Care. Again, this is a new concept to most nurses and yet is vital in the Indian setting. Doctors outnumber nurses 3:1 and many times there are only two or three nurses per 50-60 patients. It is thus vital that nurses are able to educate relatives in palliative care as they are the main caregivers. The status of the nurse is very low in India and it may be many years before doctor and nurse work comfortably together. Education of nurses needs to be changed to enable them to understand the rationale behind care and to become more assertive. This conference allowed for good interaction between the nurses and the sharing of ideas.

Cancer Education Workshop

Presentation - "The Challenge of Education in Palliative Cancer Care"

This workshop focussed mainly on prevention, education in schools, cancer control treatment and anti tobacco campaigns. There was no paper on education regarding palliative care in the original programme. Thus, at the eleventh hour and with the help of the photographic department who kindly made new slides, I presented a paper entitled "The Challenge of Education in Palliative Cancer Care". The hypothesis put forward was in fact that good palliative medicine is also good prevention. One of the main reasons for late referral is fear of the diagnosis of cancer - because cancer is synonymous with pain and suffering in the dying process. By educating the medical profession and the public that something can be done to relieve the suffering, some of the fears of cancer may be reduced and people may refer earlier for treatment. Also the severe trauma to the relatives and friends who observe someone dying a painful death from cancer, may also be alleviated. The response from this paper was very positive with many doctors expressing that they had not viewed palliative care in such a positive light before. There were many requests for further information, especially on the formation of Hospital Palliative Care Support Teams. Recommendations discussed at the W.H.O. meeting in Trivandrum regarding the inclusion of palliative care in the training of medical and nursing staff and post basic courses in palliative care were also discussed in the paper. As public education is important in Cancer Control, doctors were left with the challenge -

"Patients fear cancer because they believe nothing more can be done"

"What are YOU doing about those beliefs - endorsing them or changing them by offering good palliative care"?

VENUE LAHORE, PAKISTAN

DATE FEBRUARY 27TH - MARCH 2ND

First International Conference on Environment, Geo-Cancerology and Cancer Control

Presentation:- Putting Research into Practice - From Cancer Control to Cancer Care

There were approximately 250 delegates, mostly from Pakistan, and some from Kuwait, Turkey, Poland, Lithuania, France, Germany, Italy and China though none from India due to visa restrictions. Most of the papers related to basic biological research, but there were also papers on Cancer Prevention and Control. Late stage presentation of aggressive breast cancer was reported to be a major problem in Pakistan. Palliative Care Services are virtually non-existent despite education from Dr Pamela Sutton of the W.H.O. My paper from "Cancer Research to Cancer Care" was presented during the first session of the conference and thus allowed for considerable time for discussion of the issues raised. Codeine and morphine are not available in Pakistan and there is a great fear of drug addiction which is a major problem here. The delegates from Kuwait and Turkey have both requested further information and the possibility of undertaking some education programmes in oncology in their own country.

VENUE REGIONAL CANCER CENTRE TRIVANDRUM

DATE MARCH 5TH & 6TH

Two days of workshops with different groups of trained nurses had been organised.

Many of the nurses had in fact been taught by me last year and it was very encouraging to assess how much they had learned and retained. As the groups were quite small - approximately 12 - good discussion was facilitated. These nurses are the most forthcoming that I have come across in India. The doctors in this hospital and Dr M Krishnan Nair, Director, in particular, are keen to educate the nurses and improve their status.

Cancer Relief India has offered to fund the post of one specialist nurse, for one year, to help set up a Palliative Care Unit/Hospital Support Team within the Regional Cancer Centre. The nurse in question has a Masters degree in Nursing and completed her thesis on Pain Assessment, having done her research at the Regional Cancer Centre. She is well respected by the doctors. If the team is formed it will be the first of its kind in India. This will be a pilot project for other centres.

Cancer Relief India has also presented a second syringe driver from B. Braun Medical which is functioning well.

CONCLUSION

During the 1992 lecture tour of India it has been most encouraging to record the development of positive attitudes towards palliative care over the last three years. Many doctors and nurses are becoming more interested and aware of its importance. It is to be hoped that this trend continues and that Cancer Relief India will be able to fund further projects in India aimed at relieving the considerable suffering of Indian patients with cancer, and, by continuing to work in conjunction with the World Health Organisation, achieve the goal of Cancer Pain Relief for ALL by the year 2000.

