

# LANCASTER AND KENDAL CANCER SERVICES – BACKGROUND, CURRENT STATUS AND FUTURE

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Cancer services in the Lancaster and South Cumbria health districts have developed since the appointment of a cancer physician in 1978.<sup>1</sup> Previously the only non surgical specialist service was a fortnightly visit from a consultant radiotherapist from the Christie Hospital, Manchester. There was limited provision for patients requiring terminal care and supportive care was not available. There were no specialist nurses. Patients requiring chemotherapy were often asked to travel to Manchester for treatment and sometimes for assessment or monitoring of the blood count.

The cancer services have been developed in three ways:-

- 1 Hospital-based services at the Royal Lancaster Infirmary (RLI) and Westmorland County Hospital (WCH)
- 2 Supportive care organisation (CancerCare)
- 3 Palliative and terminal care unit (St John's Hospice)

## HOSPITAL-BASED SERVICES

An outpatient cancer clinic was established at the RLI in 1978. It is held weekly in the Day Investigation Unit (DIU). At the WCH, cancer patients are seen in the weekly general medical clinic. Patients are referred for assessment, nonsurgical cancer treatments and for palliative care. Those with rare or potentially curable cancers may be sent to the Christie Hospital for inclusion in the Manchester protocols. Treatment in these cases is often given locally and follow-up is shared between the two centres. Patients requiring radiotherapy are referred to the clinics held in Lancaster, Morecambe and Kendal by the visiting radiotherapists. The number of new patients referred in 1990 and the main diagnostic types are shown in Fig 1.

| Tumour type | Lancaster | Kendal |
|-------------|-----------|--------|
| Breast      | 17        | 5      |
| Ovary       | 15        | 2      |
| Leukaemia*  | 9         | –      |
| Lymphoma HL | 3         | 6      |
| NHL         | 13 (4*)   | 5      |
| Myeloma*    | 8         | –      |
| GU tract    | 17        | 4      |
| Lung        | 12        | 5      |
| GI tract    | 8         | 5      |
| Misc        | 19        | 5      |
| TOTAL       | 121       | 37     |

Fig 1 – New patient referrals in 1990  
\*patients referred to haematology clinic

Cancer patients and their families are frightened and distressed at various times during the course of the illness. Emotional upset may be particularly profound and prolonged during radiation treatment and chemotherapy and at the four "key moments" which we recognise; namely when the diagnosis is made; the time of first relapse; when treatments to control the cancer are withdrawn; and when the patient first realises that he is dying. Problems of communication can arise especially if information is misunderstood, misinterpreted or forgotten, and this often happens after the clinic visit. In the early days, patients suffered because of these problems and also from physical symptoms which could have been readily relieved but which were only discovered at the next clinic visit. In 1981 a health visitor was appointed to the RLI cancer clinic to deal with these wider psychological and practical issues. This was probably the first cancer support nurse post in the UK. Four other posts (two in South Cumbria) have since been created through the priming support of the MacMillan Fund. The two most recent posts were filled this year. Their role, which is to liaise between the hospital, hospice and community, provide counselling, information and support, advise the primary team on symptom control and develop educational programmes for other health care workers has been described elsewhere.<sup>2</sup> Other posts have been created – a nurse counsellor in the breast screening unit and a social worker designated to cancer families in the community. All the specialist nurse posts in the Lancaster Health District, including the Marie Curie nurses, are directed and supervised by the cancer support nurse appointed in 1981 (Pippa Holdcroft).

Safety regulations state that cytotoxic drugs must be prepared and administered in a designated unit and it was important to centralise chemotherapy as far as possible. At the RLI, outpatient treatments were given in the DIU and patients were admitted to the medical wards for prolonged infusion treatments or an overnight stay. This was unsatisfactory for several reasons. The DIU is small, vacant beds were not always available and junior medical staff attachments were short and their cannulation skills were variable. The situation was resolved when in 1986, the private patients ward at the RLI was reopened as a combined haematology/oncology unit. This provides five designated beds (including a single room converted with voluntary funds into a high-dependency isolation suite) and a day treatment facility. All chemotherapy is administered in this unit (Ward 3 annexe) and the ward sister, whose post is part-funded from the RLI Cancer Fund, is accredited to perform intravenous cannulation and treatment. This has the great advantages that treatments can be arranged to suit the patients and with minimal delay and are given by the same person on each occasion. Treatments in Kendal have always been given on the wards at WCH. Our experience of the chemotherapy sister in Lancaster led to a sister in Kendal being similarly

accredited and junior medical staff are no longer involved in the administration of these treatments. The number of patients treated in 1990 and the cost of cytotoxic drugs are shown in Fig 2.

|                                  | Lancaster | Kendal  |
|----------------------------------|-----------|---------|
| No. treated with IV chemotherapy | 72        | 30      |
| Cost of IV cytotoxic drugs:      |           |         |
| total                            | £56,317   | £11,268 |
| adriamycin                       | £4,774    | £3,492  |
| mitozantrone                     | £7,947    | £3,231  |
| carboplatin                      | £18,209   | £579    |

Fig 2. - Chemotherapy - usage and cost in 1990

Ward rounds on Ward 3 annexe take place twice weekly and are held jointly with the cancer physician, haematologist, bacteriologist, cancer support nurses, pharmacist, dietician, social worker and junior staff. Only a small delegation visits the bedside. Patients undergoing intensive outpatient treatments are encouraged to attend the ward without delay for any unexpected symptoms, notably fever, or any symptoms suggesting an infection.

## SUPPORTIVE CARE ORGANISATION (CANCERCARE)

In 1981, soon after her appointment, the cancer support nurse arranged for relatives and later patients to meet her, the clinic sister and the cancer physician in a hired room in Ryelands House, Lancaster for one evening each month. These meetings provided an opportunity for people to share their experiences and talk to the health workers involved in their care. Anxiety was common and relaxation therapy was made available during the meeting. This was the beginning of CancerCare (North Lancs and South Lakes), a support organisation granted charitable status in 1984. An office was provided for CancerCare in the RLI and a telephone answering service was established, the number being advertised in the local press, hospital wards and clinics and GPs surgeries. The frequency and range of therapies increased and CancerCare undertook to pay the fees of professional therapists who were employed on a sessional basis. Similar developments took place in Kendal, the weekly meeting coinciding with the hospital outpatient clinic on a Thursday morning. When St John's Hospice opened in December 1985, CancerCare transferred its office and activities from the RLI and Ryelands House into the hospice, whilst retaining its separate identity. In July 1989 CancerCare bought the large Victorian house, Slynedales, adjacent to the hospice. The extensive renovations were completed last year and CancerCare moved to its final home in October 1990. For three years from 1984 CancerCare employed workers from the community service programme to staff the office. In 1988 a full-time services manager was appointed and in 1990 a part-time administrative assistant. A caretaker was appointed in 1990 and lives in the flat on the top floor of Slynedales.

Access to CancerCare is by referral from the primary health care team, cancer support nurses, consultant staff or self-referral by telephone. There are four main categories of activity:-

- 1 information, education and counselling
- 2 relaxation therapies
- 3 creative work and practical skills
- 4 social activities

## Information, Education and Counselling

There is a telephone service whose number is widely advertised. This may be the first point of patient contact. It is manned during normal working hours, mainly by volunteer workers. The needs of patients and families are assessed by the cancer support nurses. They may be directed to the GP, consultant, dietician, social worker or any of the services available through CancerCare. A number of volunteer workers, many of them health professionals, are available as befrienders or counsellors and may be allocated to families at the discretion of the cancer support nurses. Some have been on a self-awareness training course run by CancerCare. BACUP literature is provided if factual information is requested.

Monthly evening meetings are held in Lancaster and Kendal when a short talk, usually on a cancer-related topic, is followed by light refreshments. These are attended by patients, families, bereaved, staff, therapists and volunteers. They provide a focus of interest and an opportunity for social intercourse.

Educational activities include an annual public lecture, a biannual national conference for health care workers, workshops and seminars for in-service training, and talks in schools and the community. CancerCare and the hospice receive nurses on the Christie hospital oncology course and the ENB 931 course in terminal care. Three doctors from Spain have been here on a residential training programme organised by CancerCare and the hospice.

A magazine, *Rapport*, is published three times a year. It contains general information, items on cancer, personal accounts and correspondence and is circulated widely. Other CancerCare publications include "Eat Yourself Well" produced with the district dietician, and "Chemotherapy - An Information Booklet".

## Relaxation Therapies

Therapies are provided for the relief of anxiety. The choice of therapy is determined by the skills available locally, the individual needs, and an assessment of both by the cancer support nurses. Patients, relatives, bereaved, staff and volunteer workers are eligible. Therapy is arranged individually or in groups either in Slynedales or in the home, hospice or hospital. The duration and number of sessions vary according to continual assessments made by the cancer support nurses and therapists and courses may be repeated during the illness. The therapies currently available are massage, the Alexander technique, hypnosis and meditation, yoga and a breathing control method of relaxation. The numbers attending in 1990 are shown in Fig 3. No claims are made for an effect of any therapy on the natural history of cancer.

## Creative Work and Practical Skills

Two local artists supervise artwork by patients for two sessions each week in Lancaster and Kendal. Jewellery-making takes place and other activities such as weaving and pottery are set up according to demand. There are swimming sessions in Lancaster and Kendal each week.

| CancerCare in 1990                     |            |
|--|------------|
| Facility                               | Number     |
| telephone calls to answering service   | 1757       |
| attendance monthly meeting (Lancaster) | 40 (22-55) |
| Kendal drop in (weekly)                | c60        |
| Windermere drop in (weekly)            | c30        |
| Morecambe drop in (weekly)             | c50        |
| people attending:-                     |            |
| massage                                | 167        |
| hypnosis/meditation                    | 65         |
| Alexander technique                    | 65         |
| relaxation                             | 30         |
| yoga                                   | 8          |

Fig 3 – Usage of some CancerCare services in 1990

## Social Activities

Social functions take place at various times in the year and there is a social element to many of the regular CancerCare activities. A “splinter” group of young people has its own social programme and there is a mastectomy group which is affiliated to CancerCare. Drop-in centres are available in Kendal, Lancaster, Morecambe and Windermere and day care twice each week is held at St John’s Hospice.

A huge volunteer workforce has enabled CancerCare to flourish: – drivers who use their own cars or the CancerCare minibus to take patients to therapy sessions, clinic appointments etc; supervisors for the drop-in centres and daycare; administrative assistants who man the telephone, Slynedales reception and help in the office; editors of the *Rapport* magazine; visitors, befrienders, counsellors to patients, bereaved or families with particular problems; decorators and gardeners for Slynedales; and those involved in fundraising, including the Slynedales’ appeal and running the charity shops in Lancaster and Morecambe.

## PALLIATIVE AND TERMINAL CARE (ST JOHN’S HOSPICE)

The first discussions concerning the possibility of a hospice for Lancaster and Kendal took place in the early 1970s but were shelved because it was thought it would not be financially viable. A conversation between the cancer physician and the group medical social worker (Lucy Parker) in 1978 led to the resumption of these discussions and the matter was taken up with the district administrator (the late Harry Carr). Meanwhile the Health and Safety Executive issued a report on the St John of God hospital, Silverdale as a result of which large sums of money would have to be spent on the building for it to continue to provide a service for the Lancashire Area Health Authority (LAHA, now disbanded).

Two agreements triggered the launch of the North Lancashire and South Lakeland Continuing Care Trust appeal in 1980. Firstly, the LAHA agreed to transfer the contractual arrangements which existed between the authority and the Order of Our Lady of the Apostles which owned St John of God hospital, to a proposed purpose-built unit for palliative care in Lancaster; and secondly the Provincial of the Order agreed that the sisters of Our Lady of the Apostles would administer the new unit for an initial five year period with an annual review and a three-year period of notice if they should withdraw at any time. St John of God Hospital ceased to function as a hospital in December 1985 when St John’s Hospice opened in Lancaster. The building was sold and is now a nursing home. The orthopaedic and longterm geriatric beds were largely reprovided elsewhere and the palliative care beds transferred to St John’s Hospice. The sisters of the Order moved to their new premises on Slyne road in Lancaster.

St John’s Hospice contains 28 beds and offers short-term relief, palliative and terminal care for patients with cancer, and chronic disabling disorders such as multiple sclerosis and motor neurone disease. It is owned and administered by the Trust and receives a substantial part of the running costs from the Lancaster Health Authority (Fig 4). There is a management committee comprised of representatives of the district health authority and the trustees. Day-to-day medical care is provided by two part-time medical officers, one a family doctor with special training in palliative care (Dr M Warren), whose partners also provide out-of-hours cover; the other a retired gynaecologist and member of the religious Order (Dr K Caffrey). The cancer physician has one clinical session during which the weekly multi-disciplinary ward meeting is held. The matron, assistant matron and some senior nursing staff (currently two) are from the religious Order and all other nursing, domestic and administrative staff are drawn from the local community. A physiotherapist is employed. Drugs are provided by the hospital pharmaceutical stock. There is a large volunteer workforce and a lively association of friends.

| Costs of hospice and CancerCare                        |                  |
|--|------------------|
|  | Amount in pounds |
| building of St John’s hospice                          | c2000,000        |
| purchase/renovation of Slynedales and education centre | 400,000          |
| budget for hospice 1990/91                             | 531,000          |
| – contribution from LHA                                | 385,950          |
| budget for CancerCare 1990/91                          | 73,000           |

Fig 4 – Capital and revenue for hospice and CancerCare

Patients are admitted free of charge. Admissions are usually planned in advance to arrive in the mornings and to avoid weekends. Admission arrangements are made with the medical staff or matron by telephone or following receipt of an admission application form. Admission details for 1990 are shown in Fig 5. A continuous audit is made of outcome for the main symptoms on admission in patients with cancer, namely pain, vomiting and constipation. Results of the first year have been published.<sup>3</sup> There have been innovative schemes in sculpture and writing which have resulted in publications,<sup>4,5</sup> one, a poetry book,<sup>6</sup> available from most bookshops. A newsletter “In Touch” is published three times each year and is prepared, edited and produced by volunteers.

| St John's Hospice in 1990     |           |           |       |
|-------------------------------|-----------|-----------|-------|
| HEALTH DISTRICTS              |           |           |       |
|                               | Lancaster | S Cumbria | Other |
| No. of admissions             | 300       | 75        | 6     |
| No. discharged                | 106       | 26        | 2     |
| No. deaths                    | 193       | 47        | 4     |
| Average length of stay (days) | 21        | 28        | 36    |

Fig 5 - Hospice patients in 1990

## THE FUTURE

District cancer services in the UK are patchy. Recommendations to create more cancer physician posts have been largely ignored.<sup>7</sup> Arguments between those who favour centralising services<sup>8</sup> and those who favour a combined approach have not been resolved. Yet there is a groundswell of opinion supporting the holistic, coordinated and integrated type of care illustrated by the Lancaster and Kendal cancer services. Increasingly they are being seen as a model for other districts to follow and service definitions are being circulated to purchasing and providing authorities which contain elements of these services in an attempt to encourage change. Lancaster expects to remain at the leading edge of developments in this field and will strive to raise the standards of cancer care in districts in the UK through publicity and education. The education centre at Slynedales will be opening shortly. It will be run jointly by CancerCare and St John's Hospice. Courses, seminars and workshops in cancer, communication skills and palliative care will be organised for health workers in this and other districts. A service for the special problems of children with cancer (and children with a parent with cancer) is being developed with money received from the Sir John Fisher Trust. The recent appointment of two additional cancer support nurses should enable the links between hospital, hospice and community to be firmly and widely established. It should also allow a hospital palliative care team to be formed which would offer an advisory service to all wards in the acute sector.

Finally the case for Lancaster being the site of the proposed "Christie hospital of the North" has been presented to the Christie Hospital Trust and their decision is awaited. Clearly if this is successful a new era would begin.

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