Scottish Partnership Agency
for Palliative and Cancer Care

Care in the Community for Cancer Patients

Second Briefing Paper

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CARE IN THE COMMUNITY FOR CANCER PATIENTS

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Briefing Paper II

Introduction

In the first Briefing Paper (in January 1992) the Scottish Partnership Agency showed how cancer impacts on a significant group in the population, affecting one in three people and being the cause of death of one in four of the Scottish population.

Although the 27,000 diagnosed each year with cancer in Scotland will suffer from a range of different cancers and cancer sites, nevertheless the problems experienced by patient and carer alike will often be profound physical pain and distressing physical symptoms, emotional anxiety and mental confusion, social isolation and spiritual fear.

It is largely in the home setting that people will encounter such experiences and learn how to cope with appropriate support, or find themselves increasingly disabled. Our case is that here is a client group of significant size and with special characteristics whose care in the community will be shared among Social Work Departments and health services as from April 1993.

This Second Briefing Paper is designed principally for those whose tasks will include the assessment of need and the management of care. The Paper sets out a statistical outline of prevalence and incidence within health board areas, and provides a check list of the special characteristics of the needs/resources equation for this client group. A supplement to the Briefing Paper comprises four short case studies illustrating care of cancer patients in the community from different professional perspectives.

Following the distribution of this Briefing Paper it is the Agency's intention to mount a series of seminars bringing together in different areas of Scotland people with experience in cancer care and those who will be involved in assessment of need and management of care. Setting up such exchanges of experience and information should be the first step in that multi-disciplinary approach which is essential for the effective care of cancer patients in the community.

Living with Cancer - the statistical picture

1. Incidence (numbers of newly diagnosed cancer patients)

   One person in three in the Scottish population will develop cancer in their lifetime.

   About 27,000 people are diagnosed each year in Scotland as having cancer. Table I below breaks down the 1990 registrations into age groups and according to Health Board.

TABLE I

Number of registrations of malignant neoplasms (ICD 140-208) by age at diagnosis and health board of residence, Scotland 1990.

	Age at diagnosis			
Health Board	**under 15**	**15-64**	**65+**	**All ages**
Argyll & Clyde	10	852	1403	2265
Ayrshire & Arran	15	716	1287	2018
Borders	2	222	463	687
Dumfries & Galloway	4	285	535	824
Fife	11	566	1171	1748
Forth Valley	6	468	867	1341
Grampian	18	876	1453	2347
Greater Glasgow	23	1936	3362	5321
Highland	7	397	703	1107
Lanarkshire	17	1045	1461	2523
Lothian	20	1582	2723	4325
Orkney	1	24	45	70
Shetland	1	35	56	92
Tayside	6	787	1471	2264
Western Isles	0	68	105	173
Scotland	**141** **(0.5%)**	**9859** **(36.4%)**	**17105** **(63%)**	**27105**

2. Prevalence (numbers of people with cancer at any one time)

The increased incidence of cancer together with some improvement in life expectancy in certain cancers is resulting in a greater number of cancer sufferers in the community at any one time.

TABLE II

Percentage five year relative survival rates in Scotland 1968-82 (All Malignant Neoplasms)

	Years of Registration		
	1968-72	1973-77	1978-82
Males	31.8	34.6	37.9
Females	43.6	46.2	48.1

TABLE III

Number of registrations of cancer 1981-91 by Health Board and patients alive at 31.12.90.

Health Board	Total Registrations 1981-91	Patients Alive at 31.12.90
Argyll & Clyde	20524	6646
Ayrshire & Arran	17074	5584
Borders	5781	2231
Dumfries & Galloway	7315	2616
Fife	16645	6296
Forth Valley	12384	4247
Grampian	23771	9451
Greater Glasgow	51921	15965
Highland	9296	3788
Lanarkshire	22008	7293
Lothian	39492	15211
Orkney	868	338
Shetland	854	341
Tayside	21018	7650
Western Isles	1497	625
Scotland	**250548**	**88272**

3. Age Range

Cancer rates increase progressively with age, and more than 70% of cases occur in people aged 60 and above.

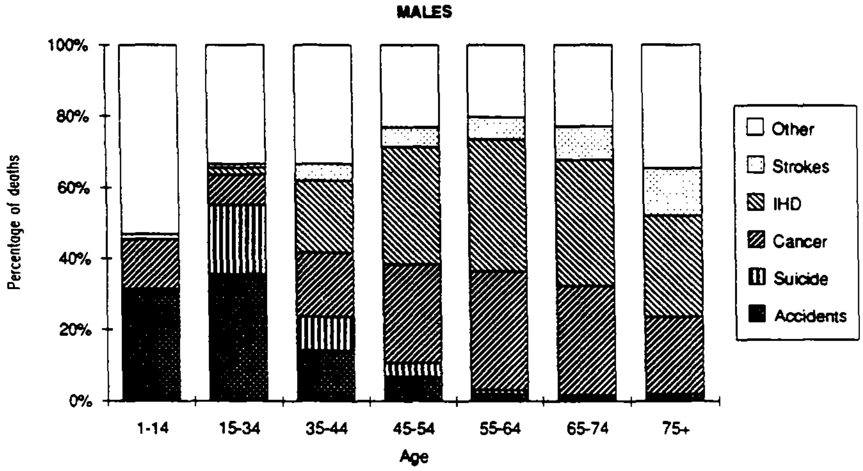
Whilst the numbers of cancer registrations in lower age groups are much smaller they remain significant and may cause proportionately greater problems particularly where young families are involved. (See Case History/Appendix)

9879 (36% total registrations) people aged 15-64 were diagnosed with cancer in Scotland in 1990 and 141 children aged under 15.

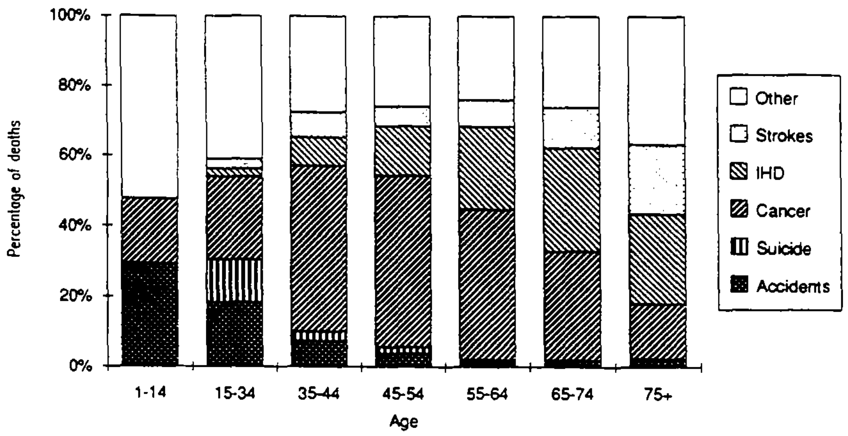
4. Mortality

One in four people in Scotland will die from cancer.

Figure 3 : Deaths by cause and age group, Scotland 1990



Deaths by cause in each age group, females, Scotland, 1990



"Cancer is one of the main causes of death at all ages. In children, cancer accounts for 18% of deaths. Between the ages of 15 and 44 cancer is now the single most important cause of death - more common than accidents or heart disease. From 45-64 cancer accounts for over a third of deaths and from the age of 65 it remains a major cause of death, although its relative importance is reduced as stroke and heart disease becomes more common causes" ("Management of Non-Surgical Cancer Services in Scotland" CRAG/SCOTMEG 1992)

5. Place of Death

Only 30% cancer patients die at home although studies have shown that the great majority would prefer to do so. A study at Northwick Park Hospital, Harrow (BMJ 1990) showed 58% patients wished to die at home given existing circumstances and had circumstances been more favourable 67% patients would have preferred to die at home. The authors concluded that "with a limited increase in community care 50% more patients with cancer could be supported at home, as they and their carers would prefer."(1)

Table IV: Place of death of cancer patients 1989

Health Board	**Deaths all places**	**Deaths at home**	**%**
Argyll & Clyde	1,333	385	28.8
Ayrshire & Arran	1,090	337	30.9
Borders	338	86	25.4
Dumfries & Galloway	437	142	32.4
Fife	985	325	32.9
Forth Valley	721	227	31.4
Grampian	1,325	384	28.9
Greater Glasgow	3,214	829	25.7
Highland	575	192	33.3
Lanarkshire	1,398	403	28.8
Lothian	2,082	503	24.1
Tayside	1,239	267	21.5
Western Isles	95	48	50.5
Total for Scotland	**14,917**	**4,162**	**27.9**

(Figures collated by C.S. McGilvray, Co-ordinator for Community Nursing, Marie Curie Cancer Care, Scotland)

Assessment of Need and Management of Care:

The statistical tables above indicate the population size of cancer patients who are "in the community" at any one time. The statistic which sharpens the focus even more shows that cancer patients are likely to spend up to 90% of their last year of life in the community setting.

Social Work Departments will therefore be sharing responsibility along with community health services for a numerically significant client group. However, it is not just the numerical aspect that is significant, but also the characteristics of the cancer patients' needs which often demand specialist, speedy, and flexible responses. The assessment of needs and the management of care required to facilitate cancer patients remaining at home and to enable their key carers to continue their support are complex. The Partnership Agency offers the following check-list as an initial guideline for further clarification and discussion:

1. Preference of setting:

There is now considerable evidence which shows clearly that the majority of cancer patients prefer returning home, remaining at home, and to die at home.(1)

2. Level of awareness:

With the increase in public awareness of cancer and its consequences it is reasonable to assume that in many cases people will have a better understanding of their diagnosis and prognosis. This means that issues and options for treatment and care management may be discussed more frequently than in the past, and, ideally, are decided openly between patients and professionals. This requires all involved in assessment, care planning and delivery to be well-informed about the disease process and its consequences, and to be capable of responding honestly and sensitively to the person with the disease and his/her family.

3. Process of treatment, rehabilitation, palliative care:

Most people with cancer will experience a series of clinical contacts from the point of diagnosis, through a range of treatments, either to cure, or to the point where anti-cancer treatment is stopped and palliative care is dominant. These points of clinical contact occur both in the community and in hospital, and rarely on a continuous basis. So most people with cancer will be away from home sporadically. The speed of this process will vary, but however quick or slow, the changes in physical, emotional, and social patterns can be rapid and far-reaching. This means that speed and flexibility are essential requirements if the delivery of care and services are to maintain quality of life. A well coordinated primary care service can provide that speed and flexibility. Families and key carers are often in need of continuous support.

4. Continuity of care and teamwork:

Continuity of care which facilitates the cancer patient's journey through the points of clinical contact is vital if the personal resources of the patient and family are to be strengthened and used. This is dependant on a teamwork approach by all the professionals involved, working together to achieve a "seamless service". It is recognised that the General Practitioner plays a major role as 'gatekeeper' to many of the services required.

Clearly the key professionals to be involved in the physical care will be health care professionals. They will also be involved in emotional and psycho-social support in co-operation with others eg social workers, counsellors, home helps, care attendants, and volunteers in support groups. It will be important for the team to agree who will act as coordinator - ensuring that each member of the team is updated when not immediately involved, or brought into active involvement when needed.

5. Day Centres:

Day centres established to provide palliative care for people with cancer can be a major source of support to the patient, and provide respite to the carers. Visiting clinicians with enhanced competency in pain and symptom control together with nurses trained and experienced in palliative care can provide a back-up resource to the GP and District Nurse. Physio and occupational therapists can achieve remarkable degrees of rehabilitation and quality of life from early stages of the illness right through to the final stages. Involvement of such skilled and specialist staff in a Day Centre is an effective use of time.

Volunteers play an invaluable part in Day Centres acting as drivers, working in the activities of the centre itself and providing useful links with home, family and community. Volunteers require careful selection, appropriate training, and support.

6. Care of the dying and bereavement support:

With the increased levels of awareness and openness people with cancer and their families may anticipate a person's death and so begin to grieve. Those professionals and volunteers giving support need to know and understand something of the process of grieving and be able to respond to expressions of grief appropriately. Sensitive support at this time may alleviate suffering, restore dignity, and prevent undue suffering in subsequent bereavement.(2)

7. Cancer and the Younger Patient

Although most cancer patients are diagnosed and treated after 60, there is a significant group of younger patients often with children. The needs of these families are often compounded by the age factor. This is particularly true of the support required for children and spouses facing a profound loss. Considerable time may be required from skilled counsellors to help families identify and use their own coping mechanisms as they work through the range of emotional responses. Studies have shown that such an input of skilled help is extremely valuable in terms of preventing future morbidity in the family at the time of bereavement and afterwards.(2)

8. Support Services:

Those most frequently used for cancer patients at home include:

- home helps
- day and/or night sitting service
- "aids to daily living"
- meals on wheels
- laundry services
- community alarm systems.

Availability of such services needs to be rapid and flexible if they are to be effective. Co-ordination of the services is vital with the co-ordinator recognising that intensity of service delivery may be greater at the very end of a person's life. However, such intensity can be anticipated and the planning of service delivery measured rather than responding to crisis intervention.

9. Specialist Services:

A range of services and personnel exist to facilitate the community care of cancer patients. These include:

Macmillan Home Care Nursing Teams

- complement the district nurse's function by providing specialist support to patient and family

Marie Curie Day and Night Sitters

- provide a nursing service to allow the family rest and respite.

Hospice Units

- respond to critical needs and seek through rehabilitation to enable people to return home. Also respite and terminal care.

Cancer Support Groups

- offer information sharing, mutual support, befriending and practical help eg car driving to clinics etc.

Day Care facilities

- provide specialist services and social support for people able to continue to live at home.

All these organisations/personnel have expertise in their field and can provide advice/resource to other professionals, patients and carers.

References/Bibliography

Ref 1 "Terminal cancer care and patients' preference for place of death: a prospective study". Townsend and others. British Medical Journal Volume 301 Sep 1990.

Ref 2 "Bereavement as a psycho-social transition". Colin Murray Parkes. The Journal of Social Issues Vol.44 No.3 1988.

Background reading:

1. "Care in the Community for Cancer Patients" Briefing Paper No.1. Scottish Partnership Agency for Palliative and Cancer Care 1992.

2. "Management of Non-Surgical Cancer Services in Scotland" CRAG/SCOTMEG 1992.

3. "The Care of the Dying and the Bereaved in Scotland". A Review and Recommendations by a Working Group of the Scottish Health Service Advisory Council. HMSO 1991.

4. 1992 Directory of Hospice Services in the UK and the Republic of Ireland. The Hospice Information Service.

5. The Patients Charter.

6. Cancerlink Charter (copy enclosed).

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CASE STUDIES

CASE STUDY 1 - The Social Worker's Perspective

Mr and Mrs Smith, aged 44 and 35 respectively. Living in a tied house (Mr Smith employed as a farm worker).
Family - Michael 14, Peter 9, Karl 7, Mrs Smith pregnant with fourth child.

Mr Smith diagnosed as having secondaries of the brain. Prognosis poor. Family referred to the Social Worker by the District Nurse for practical and emotional support.

First visit to Mr and Mrs Smith - emotional, 3 hour visit. Both were distraught about the diagnosis and prognosis. Also very concerned about the financial situation. Discussed all the relevant benefits and arranged a further visit.

Over the next 6 months visited Mr and Mrs Smith and the boys on a regular weekly basis, with extra visits as necessary. Built up a good relationship with the whole family and introduced other helping agencies to them.

Mrs Smith had previously lost a baby son. Mr Smith very concerned that his wife would overdo things and lose this baby, which they both desperately wanted. With GP and District Nurse persuaded Mr and Mrs Smith to accept Home Help to assist with the heavier chores in the house.

Situation remained stable for several weeks, Attendance Allowance awarded to Mr Smith and Mobility Allowance. Cancer Relief and Cancer First Aid grants applied for and received. Despite their father's illness and obvious deterioration, boys coped well at this time. A lot of time was given to helping Mr Smith come to terms with his dying and to preparing the boys for their father's death.

Mrs Smith became depressed and after discussion between Mr and Mrs Smith, the GP and myself she agreed to admission to the maternity hospital for respite care and psychiatric treatment. Home Help now also took on the role of Childminder, as Mr Smith unable to cope alone. This arrangement undoubtedly played an important part in keeping the family together.

Arrangements were made through the hospital Social Worker for Mr Smith to visit his wife. Mrs Smith returned home after 10 days and psychiatric help was made available at home. To give Mr Smith some respite from home he began to attend the 'woodwork group' at a local centre for the disabled. Mr Smith's health continued to deteriorate; the Occupational Therapist supplied various aids; the District Nurse, GP and myself met regularly and 'teamwork' good.

Mr Smith was admitted to the local hospice for pain control. Liaison between staff and myself meant they were aware of the family situation and knew of his fears of admission.

Mr Smith returned home with pain controlled. Family situation stable for 3 to 4 weeks with all support continuing.

Mrs Smith was found by the GP to be in danger of miscarrying unless she had total rest. After discussion with Mr and Mrs Smith it was decided that Mrs Smith should stay in the maternity unit until the baby's birth (to the parents' delight, tests had shown that the baby was a girl!). Separation meant a very emotional, stressful, anxious and heart-breaking time for the couple and added strain for the boys.

Mr Smith's employer very supportive and involved in working out how to improve the family finances. Application for alternative housing submitted. Community Alarm installed.

Volunteer drivers regularly took Mr Smith and the boys to visit Mrs Smith.

Baby daughter born prematurely in May, complications set in and both mother and baby nearly died. When mother and baby out of danger, arrangements made for Mr Smith and the boys to visit Mrs Smith and baby and a very special photograph taken of a very proud father holding his baby daughter. Early in June, with Mrs Smith and baby still in hospital, Mr Smith was admitted to the hospice for pain control and, again through good communication between hospice and hospital and with staff in the community, arrangements were made for Mrs Smith, baby and the boys to visit on a regular basis.

Mr Smith died in the hospice six months after his cancer was diagnosed. Social work support continued to the family after Mr Smith's death.

Professionals Involved

GP
District Nurse
Social Worker
Home Help Supervisor
Home Help/Childminder
Medical and Social Work Staff at the Hospice
Medical and Social Work Staff at the Maternity Hospital
Medical staff in the Intensive Care Unit, District General Hospital
Occupational Therapist
Community Alarm
Disablement Centre
Psychiatrist
Mr Smith's employer
Department of Social Security
Minister
Housing
Cancer Relief
Cancer First Aid

CASE STUDY 2 - The Hospice Home Care Nurse's Perspective

This patient was referred to the hospice home care team by the hospital consultant suffering from bilateral breast cancer with bone metastases.

She was 33 years of age, married, with 1 son aged 2 who had spina bifida.

1. On first couple of visits applied for Attendance and Mobility Allowance.
2. Also applied for Independent Living Fund grant to enable her husband to have time out at night and enabling patient to pay for help on a regular basis.
3. Applied to Cancer Relief for money for holiday to Morecambe for 1 week.
4. District Nurses contacted to request general nursing assessment as patient quite weak and debilitated.
5. GP contacted regularly as each problem arose re chest infections and pain and symptom control.
6. Hospital consultant contacted regularly re chemotherapy treatment.
7. Occupational Therapist and Physiotherapist contacted regarding son's progress.
8. Health Visitor and GP contacted re subsequent care of son.
9. Psychiatrist contacted for husband (through his work), after consultation with GP, as he was not coping with his wife's deteriorating condition (also previous abuse of alcohol).
10. Ward staff at General Hospital contacted on a daily basis when patient receiving treatment.
11. (Home help offered but refused).

12. Health Board Community Appliances Department contacted to arrange loan of commode.

13. Social Worker contacted re son's care. Each time patient was admitted and discharged from hospital it was home care sister who arranged and contacted community staff.

14. Patient became suicidal. Lots of time spent with her - in depth counselling provided.

15. GP contacted and made aware of the situation.

16. Advised patient's parents to take legal advice over care of grandson - husband had disappeared as he could not cope with the situation (on patient's discharge from hospital husband denied her entry to her home).

17. Priest contacted to give emotional support to husband.

18. Patient died at parents' home with her mum, dad, and close members of her family. Pain free and peaceful. Husband not present.

19. <u>Professionals involved:</u>

District Nurses
GP
Hospital Consultant
Psychiatrist
Occupational Therapist
Physiotherapist
Nursing Sister and ward staff
Community Appliances Department
Social Worker
Hospice Staff: Consultants, Ward Sister, Staff Nurse, Matron and Assistant Matron, Enrolled Nurses and Ancillary Staff
Priest
Solicitor

CASE STUDY 3 - The District Nurse's Perspective

Miss D was a 75 year old lady diagnosed as having cancer of the oesophagus. She was referred to me (District Nursing Sister) on her return home from hospital by the General Practitioner. Miss D was a very fine brave strong lady and was aware of her diagnosis and implications of poor prognosis. Although she lived alone she had many good friends and neighbours who formed a reliable support network. On discharge from hospital Miss D was told that a referral had been sent to the Home Help department. After one week at home there had been no contact. Two weeks later despite telephone calls from GP and myself still no contact. Eventually an assessment was made by the supervisor, cover two days a week for two hours each was given. In the interim time Miss D's circumstances changed as did her general condition. She was becoming more frail and dependent on carers formal and informal. Unfortunately at this time her support network broke down. She had a difference of opinion with one friend and the other had a crisis within her own life which meant that although would still be in contact for a temporary period she would be unable to give the same input. Miss D was now spending more time in bed due to general debility. She was unable to travel to and from the kitchen to make drinks or liquidise lunch etc. Her diet was mainly nutritional drinks or liquidised food as this was easier to swallow because of original problem. Two issues of concern arose here

(i) would she receive adequate hydration/nutrition.
(ii) she was very much at risk of falling, injuring herself if attempts to go to kitchen were made. It was not possible or practical to move equipment to bedroom.

Miss D very much wished to be at home. She knew she was going to die and did not mind being alone in between the nursing visits she was receiving through day, evening and nightsitter. Attention to care and fluid intake was given at all visits.

I contacted the Home Help department again with Miss D's permission. The change of circumstances and situation was explained to the supervisor. I was told that this was a busy time for the department as it was the trades holiday period. This meant there was a staff shortage. I stated that I understood and appreciated the staffing difficulties (having experienced them many times within my own service). I also explained the circumstances again and the fact that we did not have time to play with. We could not wait for the holiday period to finish as it was possible that Miss D may not be alive then. It was stressed that it was only a short term but very important input that was required. The supervisor gave it some consideration and returned my call, asking if the following input would make me happy! It was not me that had to be made happy but 75 year old lady whose only wish was to die at home. Eventually the input was increased to daily but it was felt to be under sufferance.

Miss D was admitted to hospital at a later date.

Afterwards the District Nurse commented: "I shall never forget this time as it was hard to believe that I had such difficulty in obtaining help for a lady who really wanted very little from what was left of her life.

None of this is a criticism of people involved. I fully appreciate that they were working within the constraints of a very over stretched service. I can only hope that this will highlight the need for priority to be given to clients at home who had limited time with us."

Professionals and carers involved

District Nursing Sister and Auxiliary Nurse
General Practitioner
Home Help Supervisor
Friends & neighbours
Home Help

CASE STUDY 4 - The Cancer Support Group Perspective

Peter: aged 28
Community Education Worker
Active - keen on individual sports: canoeing, skiing and hill walking
At the turn of the year a painless lump developed on his right leg. In April the lump was removed. It proved malignant.

TREATMENT

June: Radiotherapy treatment. Thereafter regular follow-up, until December the following year (Peter's 30th Birthday). Chest X-Ray revealed lung secondaries. Chemotherapy suggested. This was delayed until semen gathered for sperm bank; Peter was engaged to be married. Peter's mother talked to friend who had had cancer and discussed possible alternatives to chemotherapy. Peter's father not keen on the idea but mother suggested it to Peter, who was interested. Contacts made with practitioners in England, Mexico and, via the local homeopathic consultant, the USA. Local experts were contacted re diet in relation to chemotherapy. Peter's mother spoke to the Cancer Support Group, Macmillan Social Worker and Bristol Cancer Help Centre.

Jan 4th - Telephone calls from Peter and his mother.
Jan 5th - Peter came to see me (Support Group Organiser & Counsellor) at home and there was discussion of the back-up support we could provide. Thereafter, during the whole of the year, there were frequent telephone contacts/visits to and from Peter, his fiancee and his parents. Peter and Susan spent a week at the Bristol Cancer Help Centre and found this very helpful. Peter attended the relaxation meditation classes at the Support Centre; went to the National Conference of Cancer Self Help Groups and joined the Committee. Group members all offered informal support apart from my more formal role as counsellor. Peter was in regular contact with, and regularly monitored by the consultant oncologist with his ward staff. He also had a particularly supportive GP in relation to the prescriptions for alternative medicines. Peter did his own injections of Iscador and, at the later stages managed his own pain control with the syringe at home. He had the option of attending the local hospice, but this was never necessary.

By the Autumn, with episodes of sickness, generalised pain and discomfort necessitating more frequent admissions, Peter was back to receiving chemotherapy and some localised radiotherapy, while continuing a complementary regime. He and Susan planned to be married when his hair had grown in again: a good number of his support group friends attended a very happy wedding on 15th December. Peter was so thin he had to wear several thick jumpers under his suit, which also ensured he was warm. He had acquired a full head of curly hair by then.