THE DEVELOPMENT OF
PALLIATIVE CARE SERVICES
IN ST ALBANS CITY AND DISTRICT

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Mary would like to pay tribute to Mrs Mary Kirk who played a major leading part in the early stages and had the wisdom to retain some of the early documents

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PATIENT NEEDS IN THE EARLY 80s

Early in the 1980’s a deep concern was developing in St Albans about the inadequate provision required to meet the needs of the terminally ill in our City and District. These needs were particularly felt and expressed by:

• A a senior social worker, Mary Kirk whose vision was very much instrumental in starting the service. At that time, she had recently retired from working in St. Albans City Hospital.

• The Consultant Chest Physician, Dr Kathy Greenacre who was looking after many patients with lung cancer many of whom had to spend their final days in a busy ward in a general hospital - not in the best environment and with much of the medical and nursing staff not trained to respond to the special needs of the terminally ill.

• Concern was also strongly expressed by a teacher and a nurse.

• Four general practitioners

  Dr Gerard Panting

  Dr Jean Roberton whose concern was particularly poignant in that her only daughter, Kirsty, had developed a horrible embryonic cancer which in due course proved fatal

  Dr Michael Jameson

  And myself, Dr. Mary Groves whose concern arose particularly because as a new GP in St Albans I had a patient with terminal bowel cancer with whom I identified very deeply. She was the same age as myself, had children similar in age to mine and she died on Christmas morning in 1979. I had tried to care for her as best I could but I was deeply aware that to meet all the varying needs of herself and her family I was woefully inadequate.

We were also aware of the feelings of isolation expressed by many patients suffering from cancer and other life threatening illnesses...

“Is there anyone else who shares some of the feelings, the questions that trouble me?”...“Where can I find information?”
Thus two services began to develop more or less in parallel:
The St Albans City and District Hospice Care Team (HCT)
The Cancer Support Group

**ST ALBANS CITY AND DISTRICT HOSPICE CARE TEAM BEGINNINGS**

This group first met in October 1982 with:

- Dr. Kathy Greenacre, Consultant Chest Physician who gave the lead and was the first Chairman
- Four GPs (listed previous page)
- Mary Kirk, an energetic retired senior social worker
- Hilda Thornton, a retired teacher who took the role of secretary
- Carol Komarovy, a nurse

To this group was soon added:

- Jo Jenkins, former Mayoress of Harpenden, a vitally energetic fundraiser who for many years raised a great deal of money, particularly on an annual basis organising the “Voices for Hospices” event in the Abbey.
- And Cathy Overall, the District Nursing Officer who heard of our activities and wished to be involved

All of us, for various reasons were motivated to provide additional care and support for those families nursing a terminally ill person at home and to enable more families, if they so wished, rather than having to arrange for their loved one to be admitted to the necessarily more impersonal surroundings of the hospital to be cared for at home as long as was possible and ideally to the point of death

So the St Albans City and District Hospice Care Team was set up with the immediate creation of a Home Care Volunteer Group and with the aim of providing specialist Macmillan Nurses as soon as this could be implemented.
The ‘Office’

The beginnings were small and informal and initially, Mark Kirk’s home was the ‘office’ for over a year. The volunteer group quickly grew to about twelve and from the start the monthly meetings in one another’s homes proved vital. Hilda Thornton, the first energetic secretary to the team was one of the group and progress on the negotiations for the appointment of a Macmillan Nurse was relayed to the volunteers at the meetings. Everyone was involved in discussion about the future; about how and where we should operate from and about the philosophy, content and application of ‘Hospice Care’.

The first volunteers came mainly from recommendation and after an informal interview with Mary Kirk were invited to join the team. Very soon a training course was developed, using the professional team members and this evolved as the team progressed.

The value of using the volunteers was soon recognised by many of the district nursing team. Mary Kirk remembered one occasion when a very enthusiastic nurse presented the details of twelve families who she felt could benefit from a volunteer visitor! At that time only the four most needy could be helped since volunteer numbers were small!

1984 was an important year for the HCT. After negotiations with the District Health Authority and the National Society for Cancer relief the first Macmillan Nurse was appointed, funded for three years by Macmillan and also helped by money raised through the effort of Jo Jenkins, the fund raiser. After three years it was agreed by the District Health Authority that they would take over the funding. Elizabeth Nesbit, the nurse, was introduced at the official launch of the Care Team in January 1985 when a party was held at the Kimberley Rehabilitation Unit. Guests included the MP and his wife, members of the Health Authority, members of the Hospital Staff, members of the Primary Care team and also of course the Hospice team – indeed all who had supported the busy first year of planning and negotiation.
Also in that year the HCT was able to have a small ‘office’ – one desk and a telephone in a room shared with the physiotherapists and occupational therapists. The phone was manned by Pat Haywood, a willing volunteer. I must point out that my involvement at that time was minimal since I was a full time GP. Dr Hans Horton, a retired GP supported the evolving team. However I had reason to be very grateful not as a doctor but as a person in need. Early in 1985 my husband was diagnosed with a very aggressive lymphoma. Initially he responded to chemotherapy and went into remission but in the autumn of that year there was evidence of recurrence. Early in 1986 he was clearly terminally ill and I was extremely grateful for the skilled help of Elspeth, the Macmillan Nurse who supported us until his death at home on 26th April.

Around that time the top floor of Waverley Lodge became available and the team was delighted to move into there.

**Changes of Personnel**

Dr Kathy Greenacre, the highly committed chest Physician moved to the USA and for a time Geoff Sagor was chairman then President. Hilda Thornton moved to the West of England while Jill Kenner became the secretary and later the dynamic chairman.

An additional Macmillan Nurse time was needed. For a short time Eileen Neal came then Ann Golton took over from her and was an enormous help for many years. As the years went by further Macmillan Nurses joined the team and they became a wonderful recourse for patients, families and also as advisors to the primary care teams.

Dr Gerard Panting joined the army and Dr Jean Roberton gave more time and skill to the Cancer Support Group.

**Cancer Support Group**

During Kirsty’s (Jean’s daughter) terminal illness she had her own support system from the Royal Marsden’s specialist nurses. She and others who were trying to adjust to a diagnosis of terminal illness said, “I do wish I could talk to others coping with the same type of situation.”
From this expressed need the ‘Cancer Support Group’ came into being. As Jean had to try to cope with the awfulness of her daughter’s illness and death she developed an interest in holistic medicine and alternative therapies. She took a leading role in the Cancer Support Group. One of the first people to help was Sheila Walton, recovering from Chronic Fatigue Syndrome and the small group began to meet once a month in Sheila’s house. Slowly the group grew in size, took on charitable status and they began to use publicity and had a dedicated phone number, wonderfully manned by a retired Health Visitor severely disabled by multiple sclerosis.

As time went on about fifteen interested people with some counselling training took on the role of ‘Befrienders’, visiting people in their own homes. Also the value of a ‘holistic’ approach and alternative therapies became increasingly explored.

I shared a little of what was happening and attended meetings when I could while, simultaneously, the hospice care team was moving on.

Mary Kirk who took such a major lead in the early days was recruiting, interviewing and training some wonderful volunteers to support people in their own homes. She set up monthly support meetings and worked closely with district nurses and, as they became appointed, with the Macmillan Nurses too. One of the volunteers who stands out in ones memory was Rachel King who acted as counsellor.

In 1987 the service had grown so much that the work was divided between two part time staff - Hilary Hatherill as Volunteer Organiser and Gilliam Burland as social worker. In the same year, a bereavement care service was opened led by Mary Kirk with the help of Rachel King. Help was offered to anyone in the community regardless whether they had been cared for by the HCT.

Around the same time one of the volunteers, Mrs Jill Wood, appreciating the need for social support to people with cancer, led volunteers trained by the volunteer organiser, to set up a Day Care Group initially at Trinity United Reformed Church, later moving to Homewood Road and meeting
on a Tuesday. As time passed it was felt that a professional nurse was needed as leader and Biddy Turner was appointed. She continued as leader and became one of the Day Care nurses at Grove House working there until she moved out of the area. A little later volunteers in Hemel Hempstead started a similar group meeting in the Centre for the Blind, visited by the Macmillan Nurses and from time to time by a local GP.

When Gillian Burland retired in 1988 Rhoda Brutey acted as the temporary social worker until Pam Firth was appointed in 1991. Christine Mills became Volunteer Organiser in January 1990.

I would wish to pay particular tribute to the long term dedicated work of Mary in particular and to Pam and Christine whose creative work carried on well into Grove House.

Someone else who became administrator in 1990 who had experience of working in the health service and had much skill to bring to the role was Jane Waller. Her work was not only exceedingly helpful but immensely so as the move to Grove house was planned and executed. Her financial skill was also valued during her many years in the finance department at Grove House.

**THE WAY FORWARD**

Where would all this lead, what was the way forward?

As early as 1989 the Chairman of the hospice care team Frank Kilvington was asking this question. To quote from his speech at the HCT AGM. “Obviously we would like a place of our own where we could concentrate not only our administration but the activities of the Day Centre, Bereavement Support Group and extend the services.” Nevertheless the vision of a small bedded hospice was a hope in many people’s minds. However as Frank pointed out “a residential Hospice of about ten beds would cost at that time about £440,000 a year to maintain” whereas a day hospice would:

- Be more cost effective
• Could help more people to be cared for at home
• If sited near the city hospital some of the hospital’s facilities could maybe be shared and the hospice staff’s expertise could be available to the hospital staff.

Still the vision of a small bedded hospice was uppermost in people’s minds. By this time, since I had become the Medical Director of HCT, I was offered a month’s scholarship by ‘Help the Hospices’ in order to visit and work with other hospices throughout the country. The money was to be given to the practice to recompense for my absence. That month, divided into weeks or days away from the practice was so helpful giving insights into the best way to serve the whole community. From this, the vision grew.

THE VISION

The vision that developed at this time was about providing:
• Skilled day care for patients with cancer and other life threatening illnesses in an informal environment but run by trained nursing staff, volunteers and with access to a doctor qualified in palliative care.
• A ‘team approach’ so that the Macmillan Nurses should be based in the building
• Help and support from the time of diagnosis
• Part time physiotherapy and occupational therapy
• Appropriate complementary therapies
• Spiritual support
• Counselling if required both for patients and families and also for the bereaved
• Social worker skilled help
• Education on ‘How to communicate and care for the dying’ for health
care professionals, clergy, residential home staff and teachers both ‘on site’ and by offering these skills to the hospital and community staff. In this area of work tribute should be made to Pam Firth, an excellent teacher.

- In due course, to offer home care volunteer visitors (those already working in this area were absorbed into the day care staff) and long term either 24hr nursing home care or/and a small number of terminal care beds (we looked at this possibility at the Red House in Harpenden)

They were very ambitious plans! But we realised it could only happen step by step.

THE DAY HOSPICE IS BORN

It took a long time, lots and lots of meetings in order to obtain a site, planning position, meetings with the health authorities, policy documents, job descriptions and so on. Eventually, led by the late Lord Robert Runcie (an outstanding saintly man) the Macmillan Runcie appeal aimed at raising £1,000,000 was launched late in 1992 with an official launch at Verulam House by the kind invitation of Lord Verulam and enhanced by the presence of Terry Waite, just released from captivity! Fundraising was ably led by Marie Daley as professional fundraiser and the target was met within a year. Incredible!

Since the Hospice Work was taking up so much of my time, I could not manage to continue my work as a GP and felt I had to make one of the most difficult choices in my life and that was to retire early from the practice in order to devote my time to the hospice work. It was clear that the service could not move forward without medical leadership. The building began, furnishings and equipment were ordered, and in November 1993 the Day Hospice was opened.

Since all the previous services run by the HCT and Cancer Support Group were being offered within the Hospice, these groups folded.
From the beginning of 1994 patients began to use the Macmillan Day Hospice. Of course, since then, the work has expanded enormously so that the initial ambitious vision has now been achieved and more!

After a few years the trustees felt that the name should be changed from being known as a hospice which for many conjures up a place of death to ‘Grove House’. However, I would emphasise that I was only one of an amazing group of people who helped make it happen. Most people involved were volunteers who gave their considerable expertise and time. It is still true today that the fabulous volunteers as well as a wonderful group of professionals make it a great place of care, celebrating life as well as sharing pain.

The wonderful work that is being done now is very well known. For full details of the services go to www.grove-house.org.uk.

*Mary CP Groves (now married name Rowe)*

November 2012
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*Joint President*

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