DOROTHY HOUSE Hospice Care

REVIEW OF THE LAST 10 YEARS AT DOROTHY HOUSE

Introduction

The Chief Executive for Dorothy House, Sarah Whitfield, celebrated ten years in post on 1st April 2007. The Board of Trustees asked her to do a review of the last ten years at Dorothy House and this is described below.

Patient Services

Within five years of the founding of Dorothy House, patient services had developed into the core services which we still have today – a community nursing service supported by Day Care and a small inpatient unit at the hospice, with bereavement support for families and an educational role with health and social service colleagues. Ten years ago the community nursing service had developed into a nurse specialist service giving expert and experienced support and advice, and a hands on nursing auxiliary service, known as the family carer service, which provided night sitters to allow families to get a good night's rest.

In 1997 the community nurse specialist nurses were called Macmillan nurses, because, historically the Macmillan charity pump primed two posts for two or three years back in the late 1970s. The majority of them were employed by the NHS, with three funded by Dorothy House, and all were based at the hospice and managed by the Director of Nursing. When the NHS Bath and West Community Trust dissolved in 2001, Dorothy House was asked to take on their direct employment. After some negotiation we did so, on the understanding that their costs would be fully funded. Today, their employment costs are now part of our overall service level agreement with the PCTs. During the late 1990s there was increasing confusion in the public's mind with the name 'Macmillan'. Community groups were raising funds for their 'local Macmillan branch' thinking that the money was going to the local hospice. Misleading information was being given to one or two local people about legacies. Therefore the decision was taken in January 2000 to change their name to Dorothy House Nurse Specialists.

Over the last ten years the nurse specialist role has increasingly become focussed on meeting the specialist palliative care needs of patients as opposed to general palliative care, which is the remit of the Primary Care Teams (GPs, district nurses etc). In 1997/98 the nurse specialists had 870 new referrals and in 2006/7this had risen to 1,207.

In 1997/98 the family carer service delivered 11,115 hours of care to patients at night. In 2000, the then Kennet and North Wiltshire Primary Care Group received designated NHS money to develop up to 24 hour Hospice at Home with Dorothy House. This service was very positively evaluated by district nurses, as well as patients and families. As a result, when additional NHS money for specialist palliative care became available in 2003/4, the other three PCTs agreed to spend some of the money on up to 24 hour Hospice at Home care. Today, the majority of requests are for night care, but we average 2 – 3 patients at any one time who are receiving care during the day. In 2006/7 we delivered 16,874 hours of care.

Day Care has remained at 11 patients each day, from Tuesday to Friday, as this number works well for the style of service delivery which is mutually supportive but allows for individual support and a choice of activities. However, what has changed is the range of creative and diversional activities with the appointment of our first creative therapist several years ago. This has widened the activities that are offered and often results in some tangible items for patients to take home and for families to keep after the patient dies. With the additional specialist palliative care money in 2004 we were able to offer two extra sessions on Mondays – one

for patients earlier in their non-curative diagnosis, and a discharge group from Day Care. The other innovation was a short holiday at Centre Parcs, first held in1999 for three patients, by our then Day Care leader, now our Director of Nursing, Alison Stevens. This was so successful that it is now an annual event, taking place this year from18th June to 22nd June with 13 patients.

A completely new service for Dorothy House was the introduction of complementary therapies in 1996. This service, up until this year, has been completely delivered by qualified volunteers with co-ordination by one of our staff nurses. The first services were aromatherapy and reflexology and we now offer reiki as well and Indian head massage to carers. 19 volunteers currently deliver the service. We have many positive comments from patients. Most patients are treated on an outpatient basis but the therapists also offer their services to inpatients. Up to four sessions per patient are given.

Although the hospice had moved to Winsley in 1995 with more capacity for inpatient beds it remained at six until 1998. The decision to open two more beds was made by the Board of Trustees because we were frequently having to refuse admissions. Dorothy House has always been a short stay inpatient unit with the emphasis on getting symptoms under control and discharging patients back home.

Ten years ago we had one full time experienced social worker who had a special interest in children although much of her work was with our adult patients. The bereavement service was co-ordinated by a nurse specialist manager and nurse specialists did bereavement care as well as patient support and advice. The social worker had a vision to develop a specific service for children and this materialised in 2001 when The Wessex Cancer Trust pump primed a half time post for two years. Sadly the social worker never saw this development as she died of cancer, but her brother remains in touch with us and knows about our children's service. It soon became clear that a part time post with children was not meeting the need and therefore in 2003/4 the PCTs agreed that the post could be funded to full time by the specialist palliative care money. The children's service is currently being reviewed as it has been going for 5 ½ years now.

With increasing numbers of patients, there were an increasing number of families needing bereavement support. The nurse specialist manager had retired and the nurse specialists were struggling to meet the bereavement needs of families alongside the needs of terminally ill patients. The Director of Nursing was also struggling with her span of management responsibilities. Therefore the decision was made in 2003 to appoint a new senior management post of Head of Family Support and Bereavement Services. This post brought together the adult social worker, the children's worker, the chaplain and the administrator into one team – the Family Support Team. The person appointed to this new post was very experienced in bereavement and over the last years has developed our bereavement service through well-trained and supported volunteers, currently numbering 19, and his own professional skills. Last year the post was reviewed and the decision made to separate the roles of Head of Family Support and Bereavement Service Co-ordinator.

The majority of Dorothy House services are delivered on an individual, one to one basis. In 1997 there were no groups, but in 1998 the first group for bereaved adolescents was formed for a limited period, ending with a weekend away. The Group was jointly facilitated by the chaplain, the social worker and a nurse specialist. Today, there is an adolescents group run jointly between Dorothy House and Cruse for six weeks of two hour sessions. The first widowers group, again run jointly with Cruse, started in 2005. The third type of group was initiated by the nurse specialists for carers. It offers weekly two-hour sessions for five weeks and covers a range of topics from nutrition and manual handling to looking after themselves. The first group was held in 2003, and run twice a year. This year it will be run three times.

Our lymphoedema service has also evolved over the last ten years. Lymphoedema is a swelling of an arm or leg as a side effect of cancer or cancer treatment. For a number of years Dorothy House was the only provider of a lymphoedema service apart from an outpatient sister at RUH who delivered the service as part of her general role. In 1997 we had a part time nurse and saw172 patients. In 1999, the service became overwhelmed with referrals, partly because the outpatient sister had left and also because an increasing number of patients were surviving cancer but living with lymphoedema as a chronic illness. We had to restrict our service within specific guidelines. We worked with RUH to help them obtain NHS funding for a lymphoedema nurse at RUH.

In 2000, Kennet and North Wiltshire Primary Care Group obtained NHS funding to pilot a lymphoedema service in the community and asked Dorothy House to set it up. Again, this service was very positively evaluated, and therefore when the additional specialist palliative care money became available in 2003/4, the other 3 PCTs asked us to set up a similar lymphoedema service. The original intention of the funding was to treat palliative care patients with lymphoedema. However, this has evolved so that we are currently offering a lymphoedema service to a number of patients who do not have life threatening illness.

Last, but by no means least, our medical service. Since we appointed our first consultant we have provided all the palliative care consultancy service for RUH and our geographical area. In 1997, our medical director spent one day a week at RUH. A few years ago the head and neck cancer service asked for consultant input at a weekly outpatient clinic and this was provided after funding had been secured. We have had weekly consultant sessions at St Martin's and Chippenham hospitals for some years, but in1998, the Friends of Paulton Hospital, funded a weekly session there. This was taken over by the NHS two years later. With the move of elderly patients from St Martin's to RUH there was a need for an extra consultant session there. This was funded from the additional specialist palliative care money. Up and down the country, there is a national shortage of palliative care consultants. We currently do not have this problem, as, to date, we have 'grown our own' with Dr Patricia Needham who transferred from the NHS payroll to Dorothy House in 1997 and Dr Marina Malthouse who was a part time medical officer in 1995 and is now a fully qualified consultant.

Education

Education of others is part of our charitable objectives. Prue Dufour was appointed as a Macmillan lecturer within a few years of founding Dorothy House and Macmillan Cancer Relief funded our education service for nine years. In 1997 the Education Department consisted of an education manager and an administrative assistant. The main focus was on delivering external education study days and workshops to health and social service staff. Clinical staff across Dorothy House were involved in these teaching programmes. There was no clear lead for internal education and this was rather ad hoc apart from fire training and manual handling. The two main education facilities were the lecture room and the library. In 2002 the Education Manager left and a new manager was appointed with the remit for internal as well as external education and a place in the senior management team. Although she was only with us for three years, she put us on a firm footing with our internal training programme, she developed an induction and ongoing education programme for volunteers and she began the marketing of the Bloomfield Suite. She also initiated the joint education facilitator post with UWE, with our 50% of the cost funded by the additional specialist palliative care money in 2004. The department now has three full time teachers and 1.84 admin staff plus the Bloomfield Suite staff (40 hours between 2 staff).

Because of our education programmes, most of the GPs and district nurses in our area are well informed about palliative care. Over the last few years we have been jointly commissioned with St. Peter's Hospice by the NHS to deliver palliative care education programmes for district nurses and more recently for nursing homes.

Our education strategy is to actively facilitate the application of learning to practice and our courses are invariably well evaluated.

Income Generation

One of the key changes over the last ten years at Dorothy House has been our approach to income generation. Our patient services have always been highly professional in their delivery but our fundraising and retail services developed more slowly. Until the need for a capital appeal for the hospice's move from Bloomfield Road in Bath to Winsley, donations came in and were acknowledged and dealt with by the then General Manager. For the Winsley appeal two fundraising consultants were used – one for major donors and one for local community groups. Two weeks after Sarah Whitfield started at Dorothy House in April 1997 she attended a service of thanksgiving at Bath Abbey for the formal closure of the Appeal, i.e. nearly two years after the move was completed. At that time there were two part time staff in fundraising, mainly liaising with local groups and acknowledging donations. The Board commissioned a consultant to develop a fundraising strategy. His report recommended the appointment of a permanent fundraising manager and another full time member of the fundraising team. These appointments were made in 1998 and led to initiatives such as our first 'cold door drop' which was more successful than the average response, an improved use of our fundraising database, Raiser's Edge, and a more co-ordinated approach to charitable trusts. Since then, the fundraising team has developed into the strong, highly professional team that it is today.

When the first fundraising manager left in 2000 the Senior Management Team recognised that fundraising had become fundamental to the survival of Dorothy House and the new post was advertised at a Senior Management level. The appointment of a Director of Fundraising in 2001 took fundraising up to another level. She brought a professional approach not only to fundraising itself, but also the way we communicate with the general public and patients. She appointed a deputy, Katrina Sudbury, now Director of Fundraising, who took the lead for public relations and communications. One of the first changes was the change in logo from a cross and hands to a pink tulip. This was not without controversy, and there were a few objections. However, the tulip is now well established as our logo and is being used proactively with individual Tulip funds in memory of patients who have died. A number of other changes have happened in relation to communications – we changed our newsletter format from a newspaper to a 4 page A4 publication in November 2001, (it is now up to 8 pages) saving money as well as being more professional and easier to put in envelopes. A radical change was made in 1998 to the format of our annual report – from an A5 format with sections written by each head of department to a full colour A4 style with key messages and interesting photographs. We developed a number of leaflets about Dorothy House services to bring a consistent approach instead of photographs in different formats. Our name evolved from Dorothy House to Dorothy House Hospice to Dorothy House Hospice Care to describe more clearly what we do (hospice) and how we do it (care).

Professionalising our approach to fundraising has been essential to ensure that we have a reliable stream of income from voluntary donations and legacies. In 1997/98 our income was just over £1 million and this has risen to just over £2 million in 2006/7. Even so, our percentage of expenditure on fundraising remains low, currently 6% of total expenditure, which compares very favourably with other charities.

Our other main income stream, apart from fundraising and the NHS, is the profit from our charity shops. It was a trustee, Muriel Lacey, who had the inspiration and commitment to open our first shop in 1988 at Moorland Road in Bath. By 1997 we had 13 shops making a profit of £300,000 Shop managers were all part time. Then, as now, there was heavy reliance on volunteers, but their recruitment, induction and knowledge of the actual work of Dorothy House was very different from the hospice based volunteers. In early 2000 the

retail manager decided to take early retirement. This gave us the opportunity to recruit a high-calibre senior manager in the form of Stewart Hoare in September 2000. Since then we have seen an increasingly professional approach to the management of our shops. Shop managers are now all full time with a part time deputy when weekly sales get to £2,000. Since 2001 there has been a planned schedule to refurbish all our shops with a resulting increase in sales and therefore profits. Weekly figures from all the shops are produced and we know the breakdown into different categories of goods. We have opened more shops, closed two due to lack of profitability (Shepton Mallet and Radstock), moved to larger premises in three towns and strengthened management support with area managers in 2001. All these changes have resulted in an increase in our profits to £600,000 in 2006/07 and a more professional image in our shops. This is important as we know from public surveys carried out in 1998 and 2004 that the highest percentage of people who know about Dorothy House are those who recognise the name in association with our shops. Our retail business remains second hand clothes and furniture, in one shop, although we have explored and continue to explore an appropriate commercial retail outlet.

Ten years ago the shops were seen as a recognised part of our income but were not really integrated into the organisation of Dorothy House. The administrative office for the shops was at Moorland Road, but in 2000 this was moved into the hospice. The shop managers rarely got together, so in 2000 Sarah Whitfield started regular meetings with them at the hospice. This had the advantage of bringing them into the hospice as well as meeting together. Now they stay on for a buffet lunch to network with each other. Many shop volunteers had never been to Dorothy House, so during 2001 we arranged a series of visits with coaches laid on when necessary to bring them to the hospice, tell them about patient services and give them a tour of the building. These visits were positively received. We also brought the recruitment process for volunteers in line with the hospices, and opened up the volunteers' induction programme, now joint induction with staff, to shop as well as hospice volunteers. The natural progression of this integration of shop volunteers led to Stewart Hoare becoming the senior manager responsible for all volunteers almost as soon as he joined the Senior Management Team in 2004.

The third main stream of income is funding from the NHS. The original NHS money came from the then Bath Health District. Ten years ago we dealt with three health authorities – Avon, Somerset and Wiltshire. The NHS has gone through several reorganisations since, and we have always met with them together, a strategy adopted by Sarah Whitfield's predecessor, and continued over the last ten years. We currently have three Primary Care Trusts – Bath and North East Somerset, Wiltshire and Somerset. NHS funding has been uplifted each year by 'NHS inflation' (not the same as general inflation!) and twice we have had a major increase – in 2001 when we transferred ten nurse specialists from the NHS community trust and in 2003/4 when we received £400,000 of additional specialist palliative care funding. Relations with the NHS have remained good over the years, despite reorganisations and changes in the NHS staff we deal with.

In 1997 our total budget was £1.6 million. In 2007 it is £4.4 million.

Infrastructure

To support all the developments in patient services and enable us to work as efficiently and effectively as possible, there has been investment in our support systems over the last ten years. In 1997 our computer systems were limited and only the finance, fundraising and admin staff used computers. There were no paid IT staff. Today, nearly all our clinical staff input on to our patient data base meaning that the inpatient unit have up to date information to support advice line calls about patients. Our nurse specialists were provided with laptops in 2004 as part of the additional specialist palliative care money. We now have 90 desktop machines and 25 laptops and 1.8 wte IT staff.

We have also invested in more admin support staff for clinical staff including Hospice at Home, the nurse specialists and physiotherapy and lymphoedema. This frees the clinical staff from administration to concentrate on patient care.

Facilities management has had to grow to reflect the support needs of a 24-hour clinical service and a larger building. In 1997 we had a full time caretaker living on the hospice site. He could not deal with all the out of hours emergencies. When he resigned we decided to outsource facilities. Part of the agreement includes having our own maintenance engineer based at Winsley but also available to do some work in the shops. There is an out of hours number for nursing staff to call in an emergency, e.g. a lighting problem, and we get full time cover for holidays and sick leave.

Growth in overall staff numbers from 120 in 1997 to 200 today has involved the employment of a part time personnel adviser via a local PCT. The result is more proactive management of potential or actual personnel problems, regular updating of policies to reflect employment legislation and a management/staff side forum.

Governance

In 1997 much of senior management time had been invested in the move to the new premises in Winsley and the associated settling down problems. With a new Chief Executive and Chairman it was decided to review the constitution of the charity. With the help of a local solicitor expert in charity law, the Memorandum and Articles of Association were revised in 1999. The main changes included limiting a trustee's term of office to a maximum of nine years, changing the number of members from 50 plus to 15 trustees and including the ability of trustees to take out indemnity insurance and use electronic means of communication in certain circumstances. The main concern at the AGM when these changes were put to the membership was around how previous members would keep up to date with the activities of the charity. A commitment was therefore made to retain some form of open annual meeting and keep a mailing list of previous members who would be sent the annual report. The formula for the open annual meeting has evolved over the last few years from meetings with one or two presentations on services, to display boards and tours of the building, as last year.

The Board of Trustees has remained at 15 (the maximum) although the constitution allows a minimum of five. In 1997 there were some very long-standing trustees who had known Dorothy House from its foundation. With the introduction of fiscal terms of office for trustees, came the need to look at skill mix of trustees and succession planning. Trustees are no longer appointed because of their previous association with Dorothy House or because another trustee knows them, but on the grounds of the expertise they will bring to the Board. Some principles remain, with having clinical and financial trustees but new skills have been introduced from business management, social work and risk management. For the first time we advertised for a new trustee with a financial background last year. Another continuing requirement for trustees is the Christian basis of faith, which is integral to the constitution and cannot be altered, according to the legal advice we have received.

One unchanging characteristic of the Board has been their faithful support and wholehearted commitment to the work of Dorothy House. Trustees do not 'rubber stamp' papers from senior management but critically appraise and challenge. The introduction of trustee provider visits in 2003, as a result of the national care standards legislation, was taken on as an opportunity for trustees to understand our services better and to meet individual staff and volunteers. After initial apprehension by staff, the actual experience is a positive one and actively welcomed. Another initiative which has been well received by staff was the trustees' barbecue which was first introduced in 2002 as a thank you to the staff.

The chairman's term of office is usually three years so that over the last ten years we have had four chairmen. Each one has brought different skills and experience to the Board and charity at a time when those particular talents were required. Thomas Sheppard, a local solicitor, appointed Sarah Whitfield as chief executive and took Dorothy House through changes in key policies and updating the constitution. Helen Chalmers, an experienced nurse and educator, became chairman in 2001, our silver anniversary year, during which she hosted several events. During her three years we obtained the additional funding for specialist palliative care and her clinical experience proved most helpful. Paddy Stewart-Morgan became chairman in 2004 and, as we all know, used his surveyor and fundraising skills to really good effect with the new build and the capital appeal. Now we have Sheila Reiter at a time of further service developments and the ongoing challenge of keeping our income up to meet our expenditure.

Management

Shortly before Sarah Whitfield was appointed as Chief Executive, there had been a management review. Changes were made to reduce the number of staff directly accountable to the then general manager, and to change from a tripartite management system where responsibility was shared between the general manager, medical director and director of nursing to a chief executive with overall ultimate responsibility to the Board of Trustees. When Sarah Whitfield started there were four senior managers – herself, the Medical Director, Director of Nursing and Director of Finance. Over the ten years this has expanded to eight as follows:- Director of Fundraising (2001), Head of Education (2002), Head of Family Support (2003) and Head of Retail (2004). The expansion reflects the increase in staff now employed by Dorothy House and the need to have all aspects of the charity represented at senior management level. Over the ten years there have been three changes of Directors of Nursing, one change of Finance Director, Fundraising Director and Head of Family Support and two changes of Head of Education. The one SMT member to have served longer than Sarah Whitfield is the Medical Director, Dr Chris Higgs. It is good to note that over the last ten years we have been able to 'grow our own senior managers' in Alison and Katrina and brought fresh perspectives to SMT and the rest of the organisation with the senior managers appointed externally.

One of the challenges of a larger organisation with more staff is how to communicate with them all. The staff news sheet, Graffiti, is a key way and has evolved into its current format. Minutes of meetings are now posted on the public drive and there is a weekly staff coffee time for informal interaction and communication. All senior managers walk around the building to see staff rather than email or telephone and they have an 'open door' policy.

Staff and Volunteers

The delivery, efficiency and effectiveness of any organisation is dependent on its staff, and also, in our case, on its volunteers. From the earliest days of Dorothy House, and today, the vast majority of our staff are highly committed, hard working and 'go the extra mile' for patients and in the support services. Our sickness levels are very low and often staff have to be persuaded to go home when they are clearly not well. Many staff stay and retire from Dorothy House, and almost all the others who leave do so for promotion or because of a change of circumstances. Due to the development of patient services and the strengthening of support services, we have grown in staff numbers from 120 in 1997 to 200 in 2007. Two thirds are part time and the majority are women, although we do have a few more men than ten years ago – 2 more nurse specialists, the Head of Retail, a cleaner, an education facilitator, and a facilities manager – all posts held by women in 1997 or did not exist in the case of the latter two. Over the ten years we have developed more structured systems for internal training and development to reflect the larger numbers and the mandatory and professional requirements. We

have various staff support systems in place, including an independent counselling service, Occupational Health and Personnel Advice. Our staff continue to be a great credit to Dorothy House and often return on the bank or as a volunteer when they do retire.

Volunteers are the other real strength of Dorothy House. Their numbers have not changed significantly over the ten years as we have always been dependent on them to help us deliver services and they are the backbone of the shops. What has changed is the range of roles they fulfil and the education and support we give them. New roles that volunteers do today include pastoral care working with the chaplain, looking after the physiotherapy aids we lend out to patients, teaching on diversity issues, information governance support to the Chief Executive and hairdressing for inpatients. Some volunteer duties are shared with paid staff such as Reception, Day Patient Unit and admin support, while others are delivered only by volunteers – driving patients, collecting drugs from RUH, making and serving teas and suppers. 10 years ago we had a two-day induction programme just for hospice based volunteers. This evolved through including shop volunteers on the first day, to what we have today, a joint induction day for all staff and volunteers. Education and training for volunteers after induction was rather ad hoc until about three years ago when the then Head of Education developed a matrix with the voluntary co-ordinators and the managers to identify what training volunteers should receive, depending on their roles. Today, volunteers have to attend mandatory training on fire and manual handling and all other workshops and study days organised as part of our internal or external education programmes are open to them to attend. There is also quite an intensive course for our bereavement volunteers. More recently we have drawn up job outlines for each role and developed a comprehensive volunteers' handbook. Because of all these various developments with our volunteers we applied for the chartermark, Investing in Volunteers, which we were awarded last year. In July this year we will be sharing our experience with other hospices and voluntary organisations about IiV through a workshop here at Dorothy House.

Our volunteers make our services what they are today, not only through their hard work and time commitment, but through the 'added value' they bring because they are giving their time and talents free.

The Buildings

The main building we own is the hospice at Winsley, but we also own the three houses on site, half of the Moorland Road Shop and the Bradford on Avon shop, which is currently let. When Dorothy House moved to Winsley in 1995 it was spacious and seemed to meet all the hospice needs. As we know, this has changed over the last 12 years. The first addition was the entrance to the Bloomfield Suite with lavatories and a kitchen. This was made possible through a donation of £51,000 from WG Edwards Charitable Trust in 1998. Before we could only access what was the original school gym through the main hospice reception area and lavatories were up on the first floor. Although we did use it for larger teaching events, it created a lot of noise and disturbance through reception. The separate entrance meant we could use the Bloomfield Hall much more, not only for education but fundraising events and let it out to generate income. It could be used out-of-hours without disturbing the Inpatient Unit. Over the ten years, before the new build, a lot of moves took place internally. Then, four years ago, recognising we were outgrowing the Winsley building, we started planning for the new build, which was completed last year.

We have had the same tenants in two of the three houses on the hospice site, and used 43A ourselves during the new build. The Bradford on Avon shop was purchased on 5th November 1998. Up until then, we had had two or three short term lets in the town in various shops. Trustees considered it important to have a shop in the town nearest to the hospice, and it brings in one of the highest profits. It is now rented out after we moved to larger premises, which we lease, in 2006. Soon after Stewart Hoare's appointment we began a phased

refurbishment plan for all our shops, refitting and modernising them. This has significantly improved the profits over the years.

Summary

The last ten years have seen the development of an increased range of patient, family and carer services and therefore many more people have benefited from these. Our education programmes have improved the knowledge and skills of many local health professionals and some social service staff. We now have a better infrastructure to support all our services and we have a highly professional approach to income generation. Consistent over the ten years has been and continues to be, high standards of care and support services and the strong commitment of our staff and volunteers to do their best. We remain based in the local community but we continue to develop and to be ‘leading edge’ in many of our services.

Sarah Whitfield
Chief Executive

May 2007