King's Fund

The Work of Volunteers in Home Care Services for Terminally Ill People

Lesley Cullen

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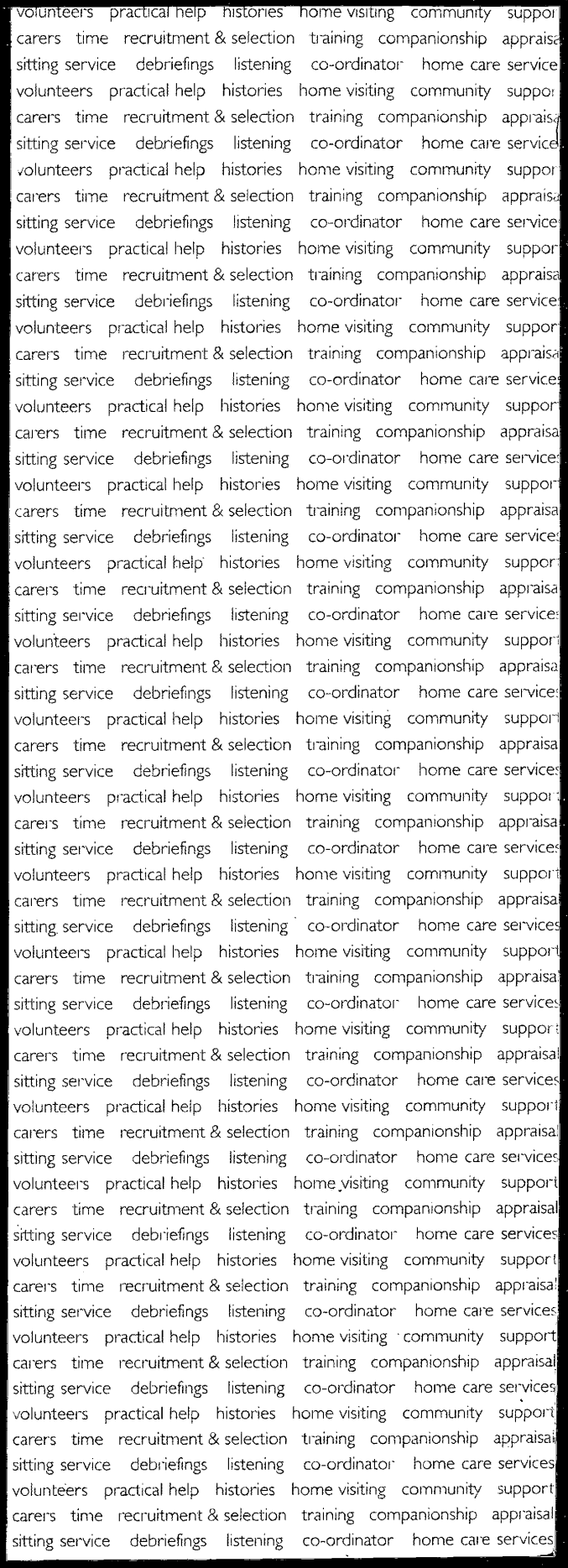

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Foreword

Most people in their last year on earth as people spend most of their time at home. They visit doctors or are visited by them (if they are lucky); they visit hospitals or hospices. But they are looked after at home, usually by their spouses or other close relatives, if they have them, and/or by neighbours and friends. This being so, the first (and by no means the least important) of the functions of the statutory services is to support the army of informal carers. They are not amateurs. Who would dare to call a wife an amateur wife, or even a husband an amateur husband?

But if they are not amateurs, they are not professionals either. This is where volunteers come in. In a different sense they are amateurs, if the definition of an amateur is that they are not paid, and they also have an element of the professional about them insofar as they are trained for the job and may also have had experience caring for someone at home. Yet they are not full professionals. This is also their merit. Volunteers can inspire a special kind of confidence in carers and patients because they are more like them. They are not remote, they are 'our kind of people'.

The volunteers in the home services are carrying on a great tradition, in this case the tradition which has now been established in the hospice movement. The word 'movement' is not misplaced. A powerful push to make the movement *move* was made by Dame Cicely Saunders whose world-wide fame is indissolubly linked with that of the St Christopher's Hospice which she started. There are now hundreds of hospices in Britain, nearly 3000 hospice units in the United States, and hundreds and hundreds more in other countries. The example was not put in place and followed by so many and so far by dint of a dinning propaganda. This forward impetus in health care really was a forward impetus built on practical achievement. It has shown how frequently terminal pain can be brought under control, how care can mean total care for the social, emotional and physical needs of the patient and how vital it is that care embraces the carers as well as the cared for.

All this has been pioneering work of the first order of importance. Now the hospice movement, which has shown the way by offering a proposal to the whole world, is again in the lead by demonstrating how usefully volunteers other than informal carers can contribute to and complement care in the home.

This kind of volunteering is valuable, very valuable, in its own right. But it also has an important added value, a moral value. In a materialist world, where things are too often valued more than people, volunteers are an example the other way round, of people caring for people, not for any shadow of material reward, but out of the goodness of their hearts. They embody the altruism which is so sorely missing from so much of our pushy, everyday life. They are as much unself-regarding as the blood donors in Richard Titmus' famous book on *The Gift Relationship*.

I can say that, as Director of the Institute of Community Studies where much of this research was carried out, I am proud of the path-breaking study of volunteers which Lesley Cullen has done. I hope that readers will be proud in another way, of a book certainly, but also of the people whom the book portrays. We need more of them, more fully recognised for the beyond-price value of the work they do, and the cause is even wider than the cause of the dying.

Michael Young
Director of the Institute of Community Studies

Preface

This report outlines the findings of a study which set out to map services which organise volunteers to visit terminally ill patients and their carers at home throughout the United Kingdom and Ireland[2]. It is intended for all co-ordinators of volunteers who organise home visiting services to terminally ill people, for management and co-ordinators who are considering introducing such services and for those considering organising volunteers to visit people at home generally.

All hospices in the *1995 Directory of Hospices* listed with home care teams and/or day care units and using volunteers were contacted and asked if any of their volunteers visited patients at home. From this initial contact 106 volunteer co-ordinators[3] were identified as running a volunteer home visiting service[4] and they were each sent a questionnaire. Eighty-eight responded, a response rate of 83 per cent. Surveys have their limitations: above all they can only report what people say in response to questions put, which is not necessarily the same as what people do. Another limitation is that not everyone who is contacted participates, and those who do participate do not represent a random selection; for example, a number of inner London services did not participate. The excluded are self-selected, and this may create bias and distort the accuracy of the general picture. Furthermore, postal questionnaires have to limit their size and confine themselves to simple straightforward questions. This means that differences and variety in arrangements will quite possibly not be picked up. Answers given by respondents suggest there is much variety in the work undertaken and the way it is organised. It is hoped that readers will keep this in mind, remembering also there may be other practices in the field which were not picked up by the survey.

The report is in two parts. Part I summarises the information given by volunteer co-ordinators about the services they organise and illustrates the nature and range of services that exist nationally and the kind of support that is given to volunteers when undertaking this work. Part II lists 88 of the 106 agencies which provide volunteer services to the terminally ill in the UK and Ireland, together with details of what volunteers in these services do when they visit patients and carers at home. The service details outlined under each agency are those considered to be 'usually' given during the year 1995. This does not mean that other services were not given or could not have been given if asked for, nor does it mean that such services will necessarily continue. Units identified as offering a service for which we do not have details are listed in Appendix 3.

Acknowledgements

This study would not have been possible without the generous help and co-operation of those co-ordinators and volunteers who made time to talk with me about their work and the work of their services and the many others who made time to complete the questionnaire. I am indebted to them all and thank them.

I wish particularly to thank Michael Young, Director of the Institute of Community Studies, where most of the work was carried out, for his help and encouragement. I would also like to thank Ann Cartwright (formerly Director of the Institute for Social Studies in Medical Care), Carol Cox (The National Centre for Volunteering), Ann Eve (Hospice Information Service), Tony Flower and Wyn Tucker (Assistant Directors of the Institute of Community Studies) for their comments and advice and Ian Cullen for his help and support. The Hospice Information Service based at St Christopher's Hospice, Sydenham, also gave much valuable advice and is a source of help and further information on palliative care services in general.

Finally but not least, I wish to thank the King's Fund for providing a grant to carry out this mapping of services.

Any views expressed in this publication are those of the author and not necessarily those of the King's Fund, which is not responsible for them.

Executive summary

Statutory services are still establishing the range of need for which they should provide care in the community. Wherever the place of death, the major part of a patient's last year of life is spent at home and care is mostly carried out by families. A growing elderly population means a patient's needs in the home and the needs of their carers are likely to increase rather than decrease for the infirm, dependent and chronically ill, as well as for the terminally ill. In 1990 more than 2.5 million elderly people were looking after someone older, more ill and frail than themselves[1]. Schemes to help people save and insure for long term care do not help those who need assistance now or who cannot afford to pay into such schemes.

Crossroads Care is a voluntary organisation which has pioneered support for all carers, and help from Crossroads is often purchased by local authorities. Crossroads carers are paid for their work, and now some schemes are considering introducing nominal charges to those in receipt of this care.

Volunteers also contribute to help patients and carers at home, and one part of this work is for people who are terminally ill. This survey outlines those services which organise volunteers to visit terminally ill patients at home and their carers, the work the volunteers undertake when visiting and the support which is given to them when doing this.

- In 1995, 106 services linked to hospices were identified in the UK and Ireland as running a volunteer home visiting service. Volunteers principally offer companionship and time to patients and carers at home, so helping to relieve isolation and potential loneliness. The companionship given can often be augmented with practical help with light duties in and outside the home.

- Relief for carers was offered by 40 per cent of home volunteer services bringing short term relief in a form that is not usually available from the statutory services. Nearly three-quarters of volunteer services offered help with personal care of the patient which can be given in the absence of the main carer.

- All services offered volunteer help during weekdays but more than half also offered the same help outside normal weekday working hours. This help is managed with most volunteers giving no more than three or four hours of their time on any one occasion.

- More than half the home care volunteer services took referrals from primary team personnel as well as from specialist palliative care services. Establishing home visiting volunteer services to take community referrals can be a slow process for a number of reasons. The involvement of professional nurses in this process on behalf of the volunteer service may facilitate its acceptance among professionals in the community, helping to allay fears about roles and responsibilities. Also the close involvement of volunteers with professional staff may encourage or facilitate the deployment of volunteers in the home.

- A significant proportion of home care volunteers are recruited by word of mouth. Just under half the volunteer co-ordinators thought they had the right number of volunteers for the work available in 1995. Services seeking to broaden the age range and sex ratio among their volunteers might consider using other methods of recruitment in addition to word of mouth.

- Home care volunteer work with terminally ill people can be demanding and needs to be prepared for and supported. The majority of co-ordinators maintain the anonymity of volunteers, issue guidelines on work and length of visits and pre-arrange tasks and visit times, all of which protect volunteers from over-extending themselves. Preparation for the work is mostly provided in training sessions which are specific to home care volunteers, which are likely to be compulsory and which more usually take place before visits commence. Other support given includes debriefing procedures and group meetings for volunteers by 80 per cent of co-ordinators and one-to-one sessions with volunteers by 59 per cent of co-ordinators. General group appraisal of work was undertaken by more than three-quarters of co-ordinators and one-to-one appraisal with volunteers by under half of co-ordinators.

- Home care volunteers generally differ from the national picture of volunteers because of the interviews, training and commitments most are asked to undertake before they begin work.

- Recently established services are more likely to have a stated policy towards volunteers, to have documentation on volunteers' roles and rights, to stipulate rather than suggest guidelines for work and to have any guidelines there are written down. Two-thirds of services had a written policy on the use of home care volunteers; three-quarters had documentation on volunteer responsibilities, health and insurance and training. Smaller numbers had documentation on relationships with staff, equal opportunities and resources for volunteers. Resources are low on the list of items given attention by management.

- The majority of agencies have plans to expand their services; only a few have plans to contract their services. Volunteer services in the community may sometimes feel under pressure to meet needs in the community that are not being adequately covered by statutory services. Volunteer co-ordinators must constantly confirm and clarify the boundaries of what constitutes volunteer work in the home as they strive to complement the statutory services and not supplement them.

Part I

Part

Chapter 1

Introduction

The volunteer

> *You get very close to people very quickly and part of their life quite quickly. Though the sessions may only be a one-off, they somehow stay with you.*

Volunteers who visit terminally ill people[5] at home are in a special category for several reasons. They are part of a minority of volunteers who work directly with the cared for and their carers, they work out in the community in people's homes and the people they care for are dying. This makes their work fairly unique and explains the support that has to be taken into account when making arrangements for them to visit patients and their carers. They are part of a much larger body of volunteers who work in and for hospices[6] and on whom hospices depend, yet there is little written about this service contribution to care in the home and how it is organised.

In 1991, 31 per cent of the United Kingdom population volunteered once a month 'spending time, unpaid, doing something which aims to benefit someone ... other than close relatives, or to benefit the environment'[7]. Studies for the National Centre for Volunteering show social class groups A and B are most likely to participate in voluntary activities and those aged 24-55 have the highest rates of volunteering. Men and women volunteer about equally. There is a decline in volunteer participation after the age of 55 but people who are 65-74 average 5.2 hours a week, which is more than twice that for the 35-44 age group, who average 2.2 hours[8]. Volunteers undertake a variety of tasks; more than half help to raise money and organise events. One quarter of all volunteers are people who give up their time for other people's health and welfare[9] and home visiting volunteers are part of this group.

Replies from 75 co-ordinators showed they had an average of 30 home visiting volunteers for each service. If this figure was extended to all known services using volunteers to visit terminally ill people, it indicates that in 1995 there were 3,180 such volunteers throughout the UK and Ireland. Their profile is different from the national picture. They are older and the majority are women[10], that is more like the age profile found by Hoad in his national postal survey of 401 volunteers in 33 hospices[11] and Field, Ingleton and Clark in their study of the use of volunteer staff in a single hospice[12]. The higher percentage of older women undertaking this kind of work is explained partly by some national trends in volunteering. For example, nationally twice as many women as men volunteers work with an organisation whose interest is health and welfare. This is also the case for volunteers who work with the elderly, though similar percentages of men and women give their time to visiting people[13].

The services

Services, some of which grew through the efforts and persistence of one or two individuals, range from the very small with a handful of volunteers helping on an *ad hoc* basis, to others with several hundred volunteers who can make up to 1,000 or 2,000 visits a year. Only 58 co-ordinators gave details of volunteer visits made and these averaged 301 per service for the year. Some services may visit a patient only a few times late in their illness, while others start visiting

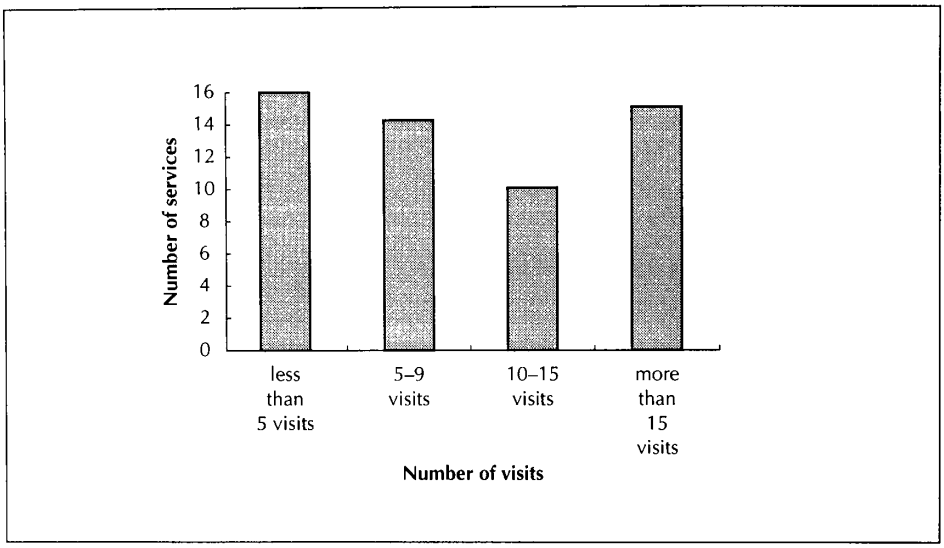

Figure 1 Number of visits per volunteer – for 55 services (62%) in survey

earlier in the terminal illness and make more visits to a fewer number of patients and carers. The number of visits undertaken by a service in part reflects the distribution of volunteers but not entirely so as the ratio of visits per volunteer can vary (Figure 1).

They serve populations ranging from 35,000 to 5 million people. They may be like the Hospice of St Francis in Berkhamsted which covers a five-mile radius or more like the Northern Ireland Hospice which co-ordinates local services over an area of 10,000 square miles. More than two-thirds (69 per cent) describe the area they cover as one of urban and rural mix, 16 per cent as mainly urban and 14 per cent as mainly rural[14]. One service has been operating for as long as 20 years, while some others have been up and running for six months or less (Figure 2).

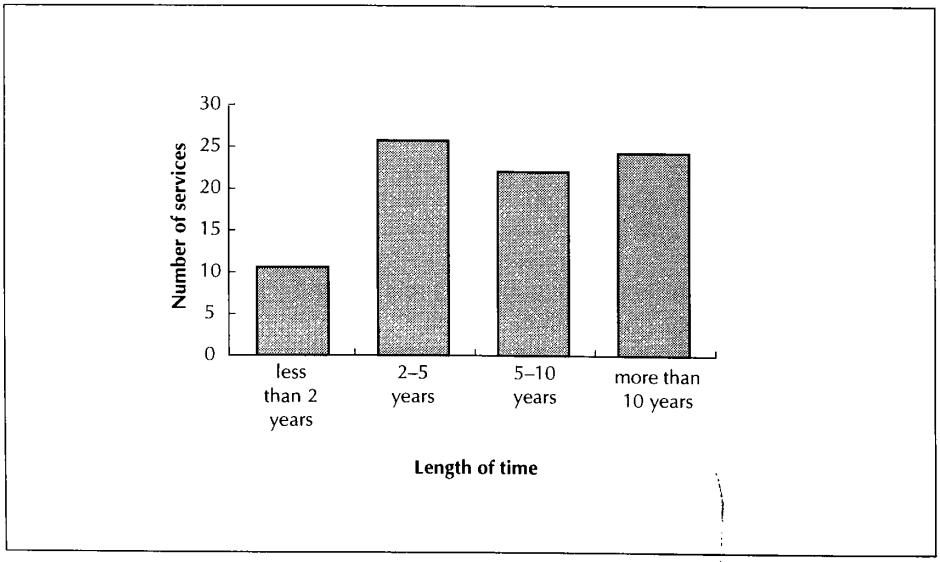

Figure 2 Length of time services have been operating

Base number 83

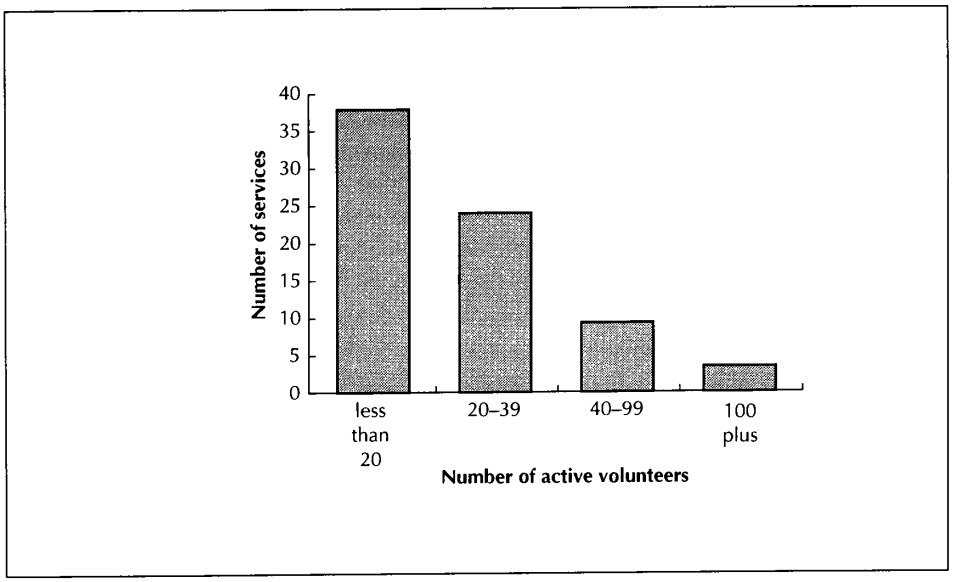

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Figure 3 Number of active volunteers by services

All the services cater for cancer patients and 30 per cent for cancer patients only but a significant number also look after patients with other diseases: 65 per cent for motor neurone disease, 51 per cent Aids patients[15] and 43 per cent other terminal illnesses. The number of volunteers in a service in 1995 ranged from two up to 500, however most respondents relied on the help of a small group of volunteers – 84 per cent had under 40 active volunteers and more than half had fewer than 20 (Figure 3).

The variety in number of volunteers employed, visits made and populations served is mirrored in the kinds of help offered to patients and carers. Volunteers might:

- 'befriend patients and carers'
- give 'practical help in and outside the home' that 'complements the existing statutory service'
- sit with patients to 'give company' and/or so that carers can 'have a break'.

Home visiting by volunteers is usually described as complementing the work of visiting professionals and statutory services with the oft-stated or implied aim of 'enhancing their (patients and carers') lives and its quality'. Many co-ordinators could and some did describe the work as 'a good neighbour' service, though several might have said 'a good family service', volunteers often doing as much if not more than some family members do, even if not as much as the main carer. No two services are quite the same, some giving patients occasional company, maybe during the absence of a carer, others offering company and undertaking light tasks in the home, while yet others organise a more intensive input with the stated aim of helping patients to stay at home to die if that is their wish. Some services are very much based in the community, perhaps run from someone's living room or an office in their home, with volunteers using the local hospice resources for training and back-up as and when required. Others are housed in a hospice, sharing the building's facilities and maybe sharing volunteers with in-house activities[16]; here the volunteers may be in regular if not daily contact with a professional visiting home care team. Whichever it is, volunteers are considered 'part of the whole service of care for patients

and families', and being part of a team is described by several co-ordinators as an important aspect of the volunteer's work.

Ten services identified themselves as independent charities, usually working in close association with a hospice. In some areas, the independent volunteer service preceded the hospice establishment and has continued to operate independently. SHARE, established in 1987 and serving Basingstoke and North Hampshire, is such an example. In others the service has emerged as one of many offered by the hospice to its local community. Hospice Home Support in Camberley is an example, being a separate charity set up by the Phyllis Tuckwell Memorial Hospice[17].

Some histories

We are pioneering the service and seeing what the needs are.

These are words from the co-ordinator of a new service but judging from replies, they may well have been said by co-ordinators of longer-established services who told us they were reviewing how they approach their work, not least because of the introduction of community care and demands being made of them. Four co-ordinators were spoken with to get a feel for the variety and range of work and the different histories behind services. Their services were chosen to illustrate a range of different features, such as the number of years operating, the number of volunteer visits made, whether independent or not and whether they were co-ordinated by a voluntary services manager or a nurse[18]. They cannot be said to be representative of services generally but are described to give a feel for the very different work that is undertaken and the way some of it has come about.

When Cotswold Care Day Hospice opened, volunteers were recruited to help and some of them also went out to patients' homes. The Director of Nursing saw a need for the support that was given to patients in the day hospice to be continued in their homes, should they be unable to attend for any reason. But it wasn't easy.

There was resistance and misunderstanding when the idea was first broached. Mainly there appeared to be a fear that we were setting up a nursing service.

After six months, a report on the work showed that demand was more than had originally been anticipated. The service was being used by a number of outside agencies as well who wanted to refer people who did not attend the day hospice but who fitted the referral criteria. It was evident the service needed to be organised on different lines, so more volunteers were recruited and in June 1995 a nurse was appointed Home Care Sister to co-ordinate and develop the service which is available to patients within the boundaries of South Gloucestershire, excluding Gloucester City. It is now the policy for volunteers to work either in the hospice day-care centre or for Cotswold Care at Home. Because of the different nature of their work, these two groups of volunteers receive quite separate training. Cotswold Care at Home is evolving.

We could well be setting the foundations now for what lies ahead so they must be right and must be secure. We are therefore taking it quite slowly. There is often a feeling that we should be doing more but we mustn't respond too quickly. Things need to be worked through carefully so that we carry other professionals with us.

Liaison with local professional groups at regular intervals remains an important aspect of the Home Care Sister's work to maintain confidence and facilitate the best use of the service. Referrals come from doctors and district nurses, from hospitals, day-care, social services and from families who may ring up on their own behalf. There is a specialist palliative care team at the hospital in Gloucester and two Macmillan nurses are based at the day hospice, each covering a separate area. The Home Care Sister works with these and with other Macmillan nurses in the region. She is responsible for training the volunteers and for visiting and assessing each patient's needs. She considers being a nurse enables her:

> *to make a better assessment of a patient's needs and how they might change in the coming days and weeks; to know why symptoms are the way they are, understand the effects of medication and also to take care of volunteers' needs ... My position involves understanding the needs of the district nurse, understanding the needs of the patient and family and understanding volunteers' needs.*

Also fairly new, but operating now for five years, compared to Cotswold Care at Home's 18 months, is the St Clare Hospice Care Trust which covers the whole of West Essex. St Clare Hospice Care offers day-care on two days of the week with nursing staff going out to three other centres on the remaining three days to run day-care from those locations. The home visiting service is available but not confined to visitors to Day Care and is now run jointly throughout the region by a Voluntary Service Manager and a Family Support Manager. The former said:

> *The service was set up following the Government Circular (HC (87)4) when a local group of social service, district health and voluntary bodies looked at what was needed locally ... A trust, the St Clare Hospice Trust was formed and I was appointed in 1991 as voluntary service manager. At the beginning I worked from my lounge and then later from a small council office. We weren't known then. People are very aware of us now. We are much larger and the next stage of care is an in-patient unit. The cash appeal for an in-patient unit has run parallel with the development of the other services. We have volunteer drivers and sitters and an equipment loan scheme. Equipment was loaned to people from the very earliest stage. It meant that the community which was donating money could see something practical straightaway. The equipment loan scheme is probably unique*[19]*. We are looking after 156 patients/carers at any one time. About 10 of those will just be having information and the other 140 will have one or more items of equipment, some several. Volunteers deliver items to people as they need them, such things as power operated armchairs and beds, and mattress elevators which patients can operate themselves with the press of a button.*

The Voluntary Service Manager recruits and trains volunteers alongside other responsibilities for the hospice, while the Family Support Manager is responsible for family support, including home assessments and is the person who allocates and oversees volunteers when visits are made. Most of the work at the moment is equipment loan with sitters going in to visit four or five times a month. Occasionally there are teams of volunteers going in to help one patient.

The St Francis Hospice Family Support Group in Havering is different again. It concentrates on giving companionship and befriending patients and carers. In 1977 a public meeting in Harold Wood Hospital was addressed by Dr Richard Lamerton from St Joseph's Hospice in Hackney and heard the report of a steering committee headed by a local GP, Dr Peter Kershaw, on whether there was need for a local hospice. From these first steps a commitment was made to fund-raise and establish a local hospice; St Francis Hospice was opened in 1984. Before this however,

Dr Kershaw had expressed concern that the hospice wouldn't have enough beds to meet local needs and in his experience many people wanted to stay at home to die if they could have the support they needed. A second meeting was held in Harold Wood Hospital and two years before the hospice was opened, before there were local Macmillan nurses and before there was a specialist palliative home care team, the Havering Family Support Group was launched. Volunteers, after four weeks' training, visited patients as befrienders and tried to get 'used to the idea that it was all right to speak openly about death and dying'[20]. The current chairman has been involved with the group since it began and was on the original steering committee which saw through the establishment of the hospice.

The Family Support Group is wholly voluntary and run by volunteers from their own homes. When the hospice opened, the group became part of the hospice service operating under the umbrella of St Francis Hospice, as do other local support groups[21]. While not an independent charity, it in most respects acts independently with its own committee to manage business and fund-raising and a separate bank account and audited accounts. It has so far succeeded in staying financially independent of the hospice. The full-time co-ordinator of volunteer visits is herself confined to home because of poor health but is available to organise requests and assist volunteers over the telephone, 24 hours a day if needs be. Recruitment and training are undertaken by members of the voluntary management committee, sometimes with help from the hospice. Referrals come from GPs, district nurses, hospitals, the hospice specialist palliative care team and from patients' friends and relatives. Not all the patients the service helps are known to the hospice and visits can vary. 'As a befriender, we tend to "go with the flow"' depending on what is needed, from patients who are very ill and who need lots of help at the very end of an illness when many volunteers may be sent in rotation for up to two hours at a time, to others, like Henry, who was a patient paralysed from the waist down. The referral, however, was for his wife who was blind and who needed to be taken out once a week to give her a break. It was a long-term befriending.

Fairleigh is a small hospice on the outskirts of Chelmsford with in-patient beds and day-care facilities. It operates as a centre for two other bases in Mid Essex, each of which has day-care. The volunteer home visiting service was set up 12 years ago by a woman in the local community when it was decided to fund-raise for the hospice. She felt the local need was immediate and set about organising day visitors to patients at home to meet that need. These volunteer home-sitters remained separately organised from the in-house hospice volunteers until very recently when they were brought under the supervision of one co-ordinator. The volunteer home-sitters are now a small group recruited from in-house volunteer workers. Referrals come from GPs, district nurses and the specialist palliative home care service which has four Macmillan nurses, about to be expanded to six, each working in the community serving her own area. Although a large number of visits are made, the service is not used as extensively as it used to be. It is not known why; it is thought that services offered by some church groups and the expansion of day-care facilities may have alleviated some patient and carer needs and it is possible that more recently appointed nurses do not know so much about the service that volunteers can give.

Chapter 2

Home visiting volunteer services

When asked what volunteers usually did for patients and carers at home volunteeer co-ordinators indicated the main thrust of services (99 per cent) is in the first instance companionship. Other help may grow from this or be provided with companionship but the main benefit is bringing a sympathetic layman, the friendly neighbour, into the home of patients and carers who, because of their circumstances, may be increasingly isolated. These are commitments to the patient and to the carer saying quite simply 'you are not alone'. More than half the co-ordinators (58 per cent) also referred to providing an opportunity for this companionship to take on a particular form, that is a befriending of the carer which continued into bereavement.

Time

Allan has documented the social isolation of carers[22]. 'Time which is often a problem for paid staff' is what 67 per cent (47) of co-ordinators felt home visiting volunteers brought to patients and carers which professionals were unable to provide. 'We've got time ... the district nurses haven't got time to be with people'[23]. It was 'quality time', 'time to listen without interruption' to give 'undivided attention for longer periods', 'without pressure from other work'. Volunteers have the time to stay with patients and carers. Many co-ordinators also referred to them giving emotional and psychological support to those they visited. When working at St Joseph's Hospice, Dr K. Boyd noted that 'support and counselling are increasingly common referral reasons' to professional visiting home care teams[24]. Volunteers who can listen and empathise and be a comfort with the ordinary everyday things can contribute to the quality of life.

The ordinary touch

When so much that is happening may be tied up with the patient's new state of dying, volunteers bring 'a sense of ordinariness' and give patients 'a chance to be something other than a disease', 'to talk of things other than illness' in an informal non-medical relationship. So said co-ordinators who clarified what they thought was special about the time that could be so helpful to patients. Many co-ordinators (40 per cent) said the 'normality' that volunteers represented was valued. It was social contact, empathy and friendship from 'a listening ear that's not professional' and valued for being just that.

Community

A volunteer can bring a sense of 'community into the home' with 'local news' and 'neighbourly support'. A quarter of co-ordinators (18) spoke of social contact and interaction which keeps people in touch with their local world and helps break the isolation that can come as patient and carer are increasingly confined to the home. The companionship which volunteers bring is symbolic of belonging to a bigger family and of not being alone at a time of great uncertainty and stress.

Practical help in and out of the home

Time and companionship, the two pillars of the services, are augmented with other help which can be practical help about the home or relief for the carer to take a break and emotional support. Practical help was organised by 86 per cent (76) of co-ordinators and covers a wide range of activities. Escorting lone patients out and sometimes carers was the single most important activity. This was followed by help with shopping and with driving[25]. There is then a big drop in the number of co-ordinators who outline offering volunteer help with household tasks like ironing, cooking and gardening.

Table 1 Practical services usually offered in the home by 76 co-ordinators

Number of services		
Escorting	72	95%
Shopping	66	87%
Driving	63	83%
Ironing	39	52%
Cooking	35	46%
Gardening	31	41%
Looking after children	23	30%
Washing	20	26%
Maintenance jobs	10	13%
		Base Number 76

Other: reading, games, walking dog; support/friendship; playwork for siblings; children to/from school; help with forms; outings; light household duties; errands; separate driving service.

Sitting service – relief for the carer

The other main thrust of help offered by volunteers and organised by 98 per cent of co-ordinators is a sitting service. This service is described as companionship for patient and/or carer, silent or not, as the client prefers, allowing the carer to take a break if they wish. Some co-ordinators called it respite care, as the help was intended principally to give carers a break. The Government White Paper defines 'respite care' as 'an arrangement whereby elderly or disabled people, normally cared for at home by relatives, are placed temporarily in alternative accommodation to give their usual carers a break'[26]. A large number of co-ordinators work with units which offer day-care facilities and in-patient beds some of which may be given to respite care. I will call the help which volunteers bring when giving carers a break in the home 'relief care' to distinguish it from out of home respite care, though relief in the home would quite clearly fall into the wider range of respite care that the House of Commons Social Services Committee would like to see implemented for the benefit of carers generally. Co-ordinators indicated when their volunteers offered sitting services.

Table 2 Times in the week when volunteers offered sitting services

	Number of services	
day	82	93%
evening	53	60%
weekends	50	57%
night	11	12.5%
		Base number 84

What stands out is that more than half the respondents said services offered volunteer visits during and outside normal weekday working hours. Evenings and weekends were offered by volunteers in well over half the services. More than two-thirds (65 per cent) offered day and evening sittings, 59 per cent day and weekends and as many as 57 per cent offered day, evening and weekend sittings. This is responding to client and carers' needs. The 'time' that co-ordinators speak of making available to patients and carers is unpressured with space to wait and listen and sometimes, time in the 24 hour clock that is not usually made available to carers, except by family and friends if they are around. This sort of volunteer help means carers can take time off not just for a break from caring but at times when they may possibly want to relax with other family and friends who might not be around during the day.

Respite care offered by the statutory services tends to be longer-term, involving overnight accommodation that often has to be booked well ahead of time. Even when available, it may 'involve such preparation and effort as simply to make it not worthwhile'[27] and 'it is in a sense in the gift of the person being cared for. If your mother won't go to the day centre or your wife won't go into the residential care so that you can go to visit your daughter, then you simply can't go.'[28] Home visiting volunteers are hence meeting a need in the home that is not met by current statutory services and giving carers a break at times and in a form which they feel they can accept. 'Carers demands are notoriously modest: offered the choice of one night's sleep or two weeks off, carers will choose the former'[29]. Such relief sitting was specifically mentioned by 40 per cent of co-ordinators. By so doing the services contribute to patients' and carers' quality of life. That quality may be enhanced by occasionally relieving the dependency patient and carer have on each other. One co-ordinator in fact described the service as 'a bridge to release family tensions by giving patients and carers time apart' and in evidence to the House of Commons Social Services Committee, Dorothy Silberston and Sandra Lawman speaking about carers and cared for, felt that 'at least part of the day should be lived separately from each other. And that applies, I am sure, to the person with the illness'[30]. In this way services are doing what the hospice movement has done before, showing how dying people and their carers can be supported in ways that help them and their families.

Personal care of the patient

We know from other studies that 'the difficulties of the relatives were more often a cause for hospital admission than those of the patients'[31] and that 45 per cent of relatives caring for terminally ill people had health problems of their own[32]. Yet however desperate a carer may feel the need for a break it can be difficult to leave Annie or Harold for a few hours with someone they do not know well or perhaps have not met before. What if Annie asked for them, was hungry or wanted to go to the toilet? Carers may feel more relaxed knowing many volunteers are trained in basic moving and handling skills[33] so they can assist patients while not taking on nursing tasks. Nearly three-quarters (72 per cent) of co-ordinators could usually offer volunteers to help with a patient's personal care if such help was needed. This was most frequently made up of necessary care for a patient in the absence of a carer such as feeding and assistance with toilet. Seventy-one per cent of services offering personal care offered assistance with both feeding and toilet.

Co-ordinators indicated that most of this help could be managed with volunteers giving just a few hours at a time as most visits (96 per cent during the day and 92 per cent in the evening) were thought to have lasted four hours or less and more than two-thirds (70 per cent in the day and 67 per cent in the evening) were thought to have lasted three hours or less (Figure 4). A few co-ordinators indicated that a six-hour service could be and has been provided when

Table 3 Personal services usually offered in the home by 63 co-ordinators

Number of services		
Feeding	51	81%
Lavatory	49	78%
Hairdressing	21	33%
Manicure/pedicure	18	29%
Washing	17	27%
Aromatherapy	17	27%
Reflexology	7	11%
		Base number 63

Other: included walks/transport out; massage; touch massage & nursing; support; giving medication; occasional bathing[34]

needed, by volunteers in rotation. Three services offered night visits which could vary from one to ten hours.[35]

Other help

A few co-ordinators outlined organising volunteer help with care that might normally be covered by statutory services. It is difficult to say where sympathetic listening ends and counselling begins; 35 co-ordinators organised services offering counselling and several indicated their volunteers were trained in listening skills. Thirteen co-ordinators described offering 'some' nursing help and nine described offering physiotherapy. Those services offering nursing and physiotherapy were a minority. Co-ordinators' descriptions did not draw attention to this help and many made a point of using literature to draw potential users' attention to the fact that nursing was not offered by volunteers.

For most co-ordinators, volunteer contributions were described as a good neighbour service with the emphasis on complementing statutory services. In general, services offer practical help and company when it is needed, often during hours of the day not usually covered by the statutory services and this is managed with volunteers giving just a few hours of their time on any one occasion.

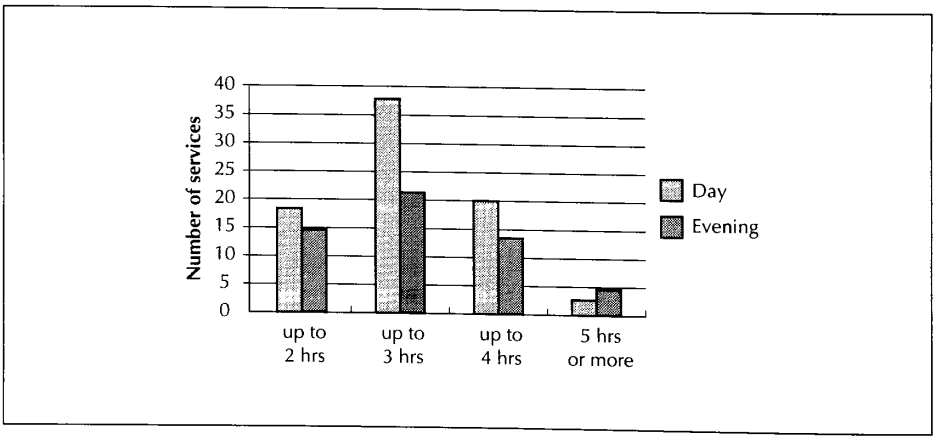

Figure 4 Number of services indicating usual length of volunteer visit

Table 4 Services using trained laypeople and unpaid professionals as volunteers for counselling, nursing and physiotherapy

	No. services using qualified personnel	*No. services using trained volunteers*	*All services offering*	*all as % of total 88*
Counselling	7	35	35	40
Nursing	10	7	13	15
Physiotherapy	7	2	9	10

Caring in the community

Co-ordinators work alongside and in co-operation with primary care teams and any specialist palliative home care services[36] that are operating. What is done by volunteers will in part depend on referrals and what is asked of them. Seventy-four co-ordinators indicated they worked with a specialist palliative home care service and named the service. The majority of co-ordinators, 84 per cent, took referrals from these specialist palliative services and 85 per cent took referrals from hospice staff generally[37].

Roughly half the co-ordinators also took referrals from community sources that were not specialists in palliative care, that is district nurses, GPs and self-referrals from patients and carers[38] (Table 5). Quite a large group, 38 per cent (31) accepted referrals from five or even six sources, which included community referrals and specialist palliative care staff. Referrals from the community may take a while to get established.

Table 5 Sources of patient referral for volunteer visits

Source of referral	*Number of services*	
Specialist team nurse/doctor	67	84%
Hospice staff	68	85%
District nurse	47	59%
GP	42	52%
Self-referral	38	46%
Other referrals	18	22%
		Base number 80

Other: social workers 10; hospital workers 5; church/chaplain 3; volunteers in hospice 1; friends 1

Both St Francis Family Support Group and St Clare Hospice Trust established community visiting before they had any in-patient beds or day-care facilities[39]. For St Francis Family Support Group there was no hospice yet opened to focus people's attention and to help pass the word around and

> *It took us a long while to get recognised ... There were notices in GP's surgeries, clinics, dentists, hospitals and local shops. In the early days we had meetings with local GPs but it was only a few who came, even though it was a GP who called the meeting.*

For St Clare Hospice Care Centre too 'We weren't known ... and referrals were low and confined to the Harlow area'. The sitting service at St Clare grew alongside and partly from the equipment loan scheme which people tended to use first and then gradually got to know more about what St Clare Hospice Care Centre could offer them. However, for Cotswold Care, which already had day-care operating from a well-established venue and which launched 'in a very

small way' into a befriending and sitting service for guests at the day hospice, the service was picked up quite quickly and within six months outside agencies were wanting to refer people who did not attend the day hospice; but it wasn't easy going and it was a deliberate tactic to appoint a nurse to head the service. She told us:

> *We are offering a service that is complementary to community care. It was not received with open arms by everyone at the outset. We have had to 'sell' the service. We have needed to build up trust with doctors and nurses. We could be seen as a threat. Me being a nurse helps curtail this because it made the operation less threatening. As a former community nurse, I know their work and was able to assure them that we were not taking over their responsibilities. Some of them knew me and were able to say what they felt.*

Professionals sometimes had to be won over and in this instance a nurse co-ordinator helped. When referrals from the community (primary care teams) are being looked for, it may be that the involvement of professionals with and on behalf of volunteers in setting up the service helps to establish a good rapport with other professionals in the field and thereby creates a good base for maintaining a working relationship and an understanding of what volunteers can do. Paid staff may always have anxieties about work being undertaken by volunteers[40] but if anxieties are fully aired, aims clarified and confidence established before work begins the service is in a good position to move forward on a basis of co-operation. Even so there may be difficulties. Twenty-four co-ordinators (29 per cent) said they had at some stage experienced difficulties with paid colleagues over defining the work of home care volunteers, with colleagues more likely to overestimate than underestimate what volunteers could do and the time they could give. Among 82 respondents, 14 per cent believed paid colleagues had overestimated the time volunteers could give and 22 per cent felt they had overestimated what volunteers could do[41]. The difficulties referred to involved expecting volunteers to take on nursing duties, clinical work and to work unsocial hours.

If a service takes a lot of community referrals much time may have to be invested nurturing contacts and keeping professionals informed of what is being done. The groundwork sometimes has to be retrodden, especially over what are considered to be statutory responsibilities.

> *One of the problems is the turnaround of staff in the community. People you have educated about the service move out and you have to start all over again. Meanwhile we haven't changed our goal posts.*

Co-ordinators must tread carefully when deciding how often and what sort of help volunteers can give in the home. One-off requests for help that would normally be undertaken by a home visitor[42] might be responded to, to see a patient through a short crisis, while a regular commitment to such work would be refused. Hard-pressed statutory services short of personnel or low on out-of-normal-hours coverage will naturally look to organised and trained volunteer services for help if they can.

> *There was a man living on his own and he wanted to stay at home. His washing machine had broken and two nights running he'd passed faeces. Home visitors are not allowed to do hand washing. I couldn't ask volunteers to do this, yet this [not being able to ask] was all that was preventing him being admitted. We have to be careful not to be a stopgap for social services. We are constantly being pulled to do things that are not part of our service because the need is there. This is a constant danger at the moment.*

Once a service is established in the community, it seems that a co-ordinator might have to give as much effort to containing referrals as to encouraging the right use of volunteers. As the co-ordinator explained:

> *We complement the statutory services. We work with them. It is team work. We don't want to play off one organisation against another. But the statutory services are not providing what they are supposed to be providing. Patients need help now, not in six months time. They may not be here then ... We have several volunteers who are willing to befriend patients and carers for a few hours a week ... But what patients actually need is nursing care, not always qualified nursing care but the kind of help that could be provided by a nursing assistant. The district nurse cannot give eight-hour cover and relatives are often exhausted and so they [statutory services] ask us for someone to go in every day, sometimes from 9 in the morning to 6 at night.*
>
> *As a nurse I can discuss with colleagues what has been set up for patients. I can ask the pertinent questions so that the statutory services assume what their role is.*

One co-ordinator found herself being asked to use volunteers to fill in when the district nurse went off duty until the twilight nurse came on at 6.30pm. A new rota with a district nurse doing one long day from 8.00am to 6.30pm now helps to get rid of this grey area of time. In such ways co-ordinators may find themselves under pressure to fill in gaps in community services and it must be difficult to say no if there is a willing body of volunteers and a real need staring you in the face. As one co-ordinator put it, 'There is always the practical question, is this statutory or not?' Volunteer co-ordinators are in the front line, setting boundaries for their service in relation to statutory provision and perhaps easing or stretching those boundaries under local pressure so as not to seem unreasonable in the face of need and because they are there to help. Co-ordinators have to be free to say what they will not do without drawing criticism. It cannot be easy. Asked what home care volunteers bring for patients and carers that professionals could not or were unable to provide, three co-ordinators referred to covering the short-fall of NHS provision, releasing trained staff for further duties and providing 'a back-up to paid staff'. One service anticipated growing future pressure on the volunteer service in the face of anticipated shortfalls in NHS provision with a need for volunteer specialists such as nurses and doctors. Pressure from the community for extra nursing help and the expectation by some nurses that volunteers could take on some nursing tasks[43] do not help. Although making clear that nursing help was not given, a number of co-ordinators nevertheless had some qualified nurses as volunteers who could be used if it was anticipated their skills and/or knowledge might be useful for a patient, though they would be advised not to perform nursing tasks.

There is a grey area where co-ordinators may feel they should not be using volunteers, especially unpaid qualified professional staff. They want to respond where there is need but may need to exercise a strong hand if they are not to be exploited for cheap labour to supplement out of hours provision, shortage of qualified staff or lack of co-ordination between social services and district health authorities to cover for the range of need that can arise in 24-hour community care. In this respect co-ordinators must be constantly defining and clarifying the boundaries of work that can be undertaken by volunteers[44].

Future – expansion

Among 165 co-ordinators who at present do not use volunteers in home care and who were spoken with on the telephone during the first stage of the study, 14 were thinking of introducing

such a service. Thames Valley Hospice has a new service which is in the process of being implemented. Three others, Iain Rennie Hospice at Home, Douglas Macmillan, Stoke, and Springall Hospice have feasibility studies going or schemes in the pipeline. A further eight said they have intentions and ideas for services which have not yet been implemented and two more are thinking of introducing bereavement services.

Among those already working with home care volunteers, a handful of co-ordinators spoke of reducing the service, one to local District Health Authority boundaries and another after assessing day-care needs. However, more than two-thirds of services had plans to expand. These plans were presumably a response to need. Co-ordinators have a fairly good idea of what demand is because 82 per cent (66) of those answering said they kept records of all requests for home visiting volunteer services whether they could respond or not and 83 per cent (63) said they evaluated their service. Of those undertaking an evaluation, nearly two-thirds (39) did so by personal contact between the co-ordinator and patients and carers and the same proportion (38) did so through observations made by paid staff. Only 13 per cent (10) used a questionnaire. Co-ordinators are reluctant to bother people at this difficult time and will not want to trouble them with such details in their bereavement and clients will not normally want to make observations on a service to those who have helped them in case their comments look like criticism. There are different ways such information could be gathered. A form is one way. It suggests that comments on the service are looked for and welcomed and that carers and patients are expected to give feedback. People can choose whether to participate. Another way would be to employ an independent person to interview the bereaved. This has the advantage that it would also give the bereaved an opportunity to talk about their loss.

Table 6 Plans for expansion

Co-ordinators stated intentions	*Number of co-ordinators*
Recruit more volunteers	14
Add to service by training volunteers in more skills	13
Extend physical reach of service	5
Add bereavement services	5
Extend number of days when service is available	1

Some of the 58 who had plans to expand explained their intentions. For a few who viewed expansion in the totality of what their hospice was offering to patients and families, it meant expanding into new buildings, adding or expanding day-care and home care or an in-patient facility or extending the number of in-patient beds available. For one service, expanding and financing the all-round care and support which supplements nursing care but which is not defined as medical care was difficult[45].

> *A major problem is the ongoing battle regarding whether the responsibility for care lies within the health or social budget. There appears to be little concern about the patient's or carer's welfare just an overwhelming desire to pass the buck. Within palliative care, social and health needs very often overlap or are intertwined and patient and carer situations can change very rapidly, moving from one to the other overnight*[46].

A few co-ordinators were thinking more of a qualitative change. One day hospice proposes to add to its volunteer home visiting services by setting up a full 'hospice-at-home' service[47]; another with in-patient beds and day-care facilities proposes to have its home visiting

volunteers work with paid staff as a 'hands-on-care' team[48]. A third, St Teresa's Hospice, has conducted a pilot survey[49] to decide how to take its home care provision forward. Staff at St Teresa's were concerned about home care volunteers being asked to do things which were beyond their ability and training; the fact that the home care volunteers service was constantly stretched; and finally being able to meet rapid changes in circumstances and needs of patients and carers which if not responded to, could precipitate a patient's admission. Staff said that one of their aims was to help a patient stay at home if they wanted to die at home. The pilot explored how to achieve this, introducing a nurse-led scheme with the addition of paid work by trained carers and nurses in the home to complement the volunteer sitting service. The aim was to give as far as possible, 24-hour cover over seven days in the week which could respond at relatively short notice. On the basis of experience over the last year, a slightly modified scheme is being advanced for financial backing[50]. If community care is to allow people to stay at home to die when that is their wish, then experience indicates it must be 24-hour cover if it is to work. A co-ordinator described the difficulties of one patient:

> *Recently a man was admitted to the hospital who wanted to stay at home. It is the consistency, or lack of it, in the (general) services which is creating the gaps. It is not that this man didn't have the care he needed, he was very well cared for, including input from social services but the input has to be there over a 24-hour period. Patients don't stop having needs during changeover in work periods.*

The experience and work of other services illustrates the importance of such cover. In 1990 The Ellenor Foundation established a Respite Care at Home Service which now comprises 12 qualified paid nurses and 30 trained volunteers. This team has succeeded in reducing the number of emergency late admissions to the hospice and more patients are realising their wish to die at home.[51] They noted that 'contrary to our belief, families were not looking for 24-hour respite care, but coped best when they had regular respite, possibly for three to four hours in a day'[52]. In 1994 St Christopher's Respite Care Team was set up because of the number of patient referrals to the Home Care Team, more of whom wanted to stay at home to die, and the evident strain on carers which often precipitated 24–48 hour admissions. Because they were working in the final stages of illness, 12 trained nurses working with three volunteers were appointed to be available at short notice and to offer virtually 24 hour cover for a short period.[53] If volunteers are to work in the community to help patients who want to stay at home to die, this may need to be done with volunteers working closely with qualified staff who can undertake the intensive nursing that might be needed in the last days of an illness over a 24-hour period.

Future – take-up of services

Two co-ordinators noted that the take-up of volunteer home visits seemed to have declined following the introduction of day-care services suggesting that day-care and home visits were catering to the same client group. Either patients liked to get out of the home if at all possible and/or carers preferred this arrangement because it gave them more relief.[54]

Very occasionally a co-ordinator referred to the take-up of volunteer help being lower than they expected. 'I thought there would be more demand but there hasn't been' and 'it is not used as extensively as it was when first set up'. Nearly a fifth, (18 per cent) (14), thought they had more volunteer time than they could use[55] but as Table 7 shows, co-ordinators were less likely to indicate this if their service took community referrals from the primary care team and self-referrals from patients and their families.

Table 7 Source of referrals and availability of suitable volunteers

Referrals	*Specialist Nurse/Dr*	*Hospice Staff*	*District Nurse*	*GP*	*Self-referral*	*All*
Volunteers						
Too few	21 (64%)	26 (67%)	19 (70%)	17 (74%)	15 (75%)	30 (39%)
More than can use	12 (36%)	13 (33%)	8 (29%)	6 (26%)	5 (25%)	14 (18%)

An explanation for lower take-up of volunteer help may be that 'Accepting help is difficult. Many people don't like to feel they're taking help.'[56] One co-ordinator thought the stigma of not managing might deter some carers from accepting volunteer help because carers would 'worry about what other people will say if outsiders are seen to be doing what they *ought* to do'.

Other studies have noted how caring tends to be focussed on one person and how difficult it is for the carer to move away from this; the cared-for may object to being cared for by others[57]. The sheer effort of caring, especially if loss of sleep is involved, can leave carers too exhausted to even contemplate more activity. People grow into a caring role[58] assuming more responsibility as the patient's illness progresses until they find it occupies most of their time. Some then find it difficult to withdraw from any of their responsibilities. If care for a terminally ill patient is an extension of the responsibilities they have carried throughout life as wife or husband, companion or carer, the carer may well feel they are falling down on their task if they accept help.

> *Carers are sometimes anxious about letting a stranger in – hence last minute changes of mood. They are also reluctant to leave the patient. They feel they are needed and if they leave the patient for a while, they may regret it. They can feel guilt if a carer comes in to sit. It is another guilt to add to those that appear after the death*[59].

'Any failure – perceived or real – to achieve the appropriate though ill-defined standard of care is ... liable to generate feelings of inadequacy and guilt.'[60] Carers are doing at home, possibly alone, what in other contexts may be done by professionals and they may measure themselves against professionals. Open discussion of the support needed by both professionals and carers in this work may make it easier for some otherwise reticent people to embrace the help offered. It may be easier for carers to accept volunteer help when it is presented as part of a total service or package of support that is deemed necessary for home-care, rather than when it is offered as a separate service, which may look to carers like a supplement for a few who are unable to manage.

As stated before, volunteers work alongside specialist palliative home care teams and it is possible that carers perception of volunteer help may be influenced by their contacts with the specialist palliative home care services. Many specialist palliative services are principally advisory, giving specialist advice to the primary care team and only very occasionally giving practical care to a patient. Other specialist services however, offer what is called 'hands-on-care'[61]. Hands-on-care means that as well as giving advice, the specialist team undertake to give practical care to the patients they visit. The distribution of volunteer visits in 1995 suggests there may be a link between specialist palliative teams offering hands-on-care and the number of volunteer visits made. Fifty-eight respondents gave information on volunteer visits made in 1995 and the average for each service was 301 visits. Forty-five of these also gave us details about the specialist palliative care services they worked alongside.

Table 8 Specialist palliative services and volunteer visits

Specialist Palliative Care Services	*Number*	*Total volunteer visits*	*Average no. vol. visits*
All offering hands-on-care	13	4802	369
Some offering hands-on-care	12	4336	335
None offering hands-on-care	20	4021	218[62]

Table 8 shows that volunteer services which worked alongside specialist palliative home care services offering hands-on-care made significantly more home visits in 1995. It is possible that when a specialist palliative care team gives hands-on-care in the home, this leads to a closer relationship between the professionals and the patient and carer. This in turn may lead to a greater confidence on the part of the patient and/or carer to accept recommendations from the professional team about receiving help from volunteers. It may also be that when giving care in the home, such palliative care teams are in a better position to judge when patients and carers could do with extra help, especially if they are reluctant to ask for it. Either the close involvement of the specialist palliative home care team with the physical care of the patient makes it easier to introduce other forms of help to the family home or those services providing care as well as advice have for some reason organised themselves to make more use of volunteers. Co-ordinators of home visiting volunteers and specialist palliative home care services may wish to explore this further.

Conclusions

- Volunteers principally offer companionship and time to patients and carers at home, so helping to relieve isolation and potential loneliness.
- The companionship offered can often be augmented by volunteers giving practical help with light duties in and outside the home.
- Relief care which carers are able to take up is offered by 40 per cent of home volunteer services bringing short term relief in a form not usually available from the statutory services. Nearly three-quarters of volunteer services offer help with personal care of the patient which can be given in the absence of the main carer.
- All services offer volunteer help during weekdays but more than half also offer the same help outside normal weekday working hours.
- This help is managed with most volunteers giving no more than three or four hours of their time on any one occasion.
- More than half the services take referrals from primary team personnel as well as from specialist palliative care teams.
- Establishing services to take community referrals can be a slow process for a number of reasons. The involvement of professional nurses in this process on behalf of the volunteer service may facilitate its acceptance among professionals in the community, helping to allay fears about roles and responsibilities.

- Volunteer services in the community may sometimes feel under pressure to meet needs in the community that are not being adequately covered by statutory services.

- The majority of agencies have plans to expand their services; only a few have plans to reduce them.

- Volunteer co-ordinators must constantly confirm and clarify the boundaries of what constitutes volunteer work in the home as they strive to complement the statutory services and not supplement for them.

Chapter 3

Supporting the volunteer

The volunteer

> *There is the apprehension of the unknown, the 'what if' syndrome. Will you let anyone down? You are conscious of representing something with a good reputation and you are conscious that people in these situations are very vulnerable. You are entering people's lives at a crisis time. For example, will you find anything to talk about? Can you cope with them not talking or if they want to talk, have you got enough that is common between you to do so? It is easier as you feel more experienced and as you deal with unexpected situations and cope*[63].

Home visiting volunteers enter patients' lives at a difficult time, unsure perhaps of what may be asked of them and how they will manage. Why do people volunteer for this kind of work, befriending the terminally ill and their carers when it can be so demanding of them? For some it is straightforward.

> *I'd always wanted to be a nurse. When the opportunity came I thought I'd love to do voluntary work and I've met such lovely people. It was an opportunity*[64].

and for others, not quite so specific,

> *I knew I needed to feel I was contributing something*[65].

One volunteer pointed out that they themselves are helped by the work: 'I've gained an enormous amount. Undoubtedly, you meet your own need by doing the work'. People who volunteer their time to help others do so for a multitude of reasons: because they were asked; to use skills that would otherwise go to waste; to learn new skills and gain experience; for social contact and for altruistic reasons[66]. 'Without such outlets individuals can become frustrated emotionally. Many people have discovered their own potential true selves through volunteering.'[67] For home care volunteers there is the association for many (though not all) with a hospice whose bricks and mortar represent the practical help from which a family member or friend may have benefitted. For many, the work is local. The hospice serves their locality and they return help in kind. Almond found that among volunteers working in a hospice 'over 33 per cent ... had chosen to offer their services precisely because the survey hospice was perceived by them to be a valued resource within their community[68]. Co-ordinators told us more than a third of the home care volunteers 36 per cent (29) were recruited by word of mouth. So, people who have already come into contact with the hospice by volunteering for in-house activities or through contact with someone they know using its services, form a significant number of the volunteers employed to visit patients in the community. A larger group of volunteers, 43 per cent (34) were found by recruitment drives and word of mouth together. Volunteers found from recruitment drives only were a small percentage 7 per cent (6)[69].

But why choose this work and not some other? For some it can be the spark of personal experience which projects them this way rather than another.

Part was pure timing and part was personal experience. The advert was in the right place and at the right time and I was ready to get involved in something.

There was an experience I had a little while ago when a couple, literally a couple, quite close to me, died within two and a half weeks of each other. She was expected to die of cancer quite soon and he was looking after her and he died in the night suddenly. She died a fortnight later.

They were fortunate in having lots of friends who got together and drew up a rota so there was always someone with her and I wondered what would happen in that situation for someone else. It was something that I could make contact with when I saw the advertisement. I had been unable to do anything for the lady because of the distance she lived from me. A little bit of me is doing it for her.[70]

Altruism needs a focus and where better than the place that has helped someone you know through the terminal stages of an illness. We did not ask about volunteer's motives but do know that some services have a policy of excluding applicants who have been recently bereaved, that is within the preceding 12 months. People who have lived through loss and watched a friend or family member die, may intuitively want to help others in the same position. At the King's Mill Hospice, 'half the respondents ... identified their personal experience of bereavement as important in deciding to offer help at the hospice'[71] and a survey of volunteers working in a hospice organisation in Leicestershire (LOROS) noted a third reported they were influenced by personal experiences of death when offering to become a volunteer[72].

A significant number of the volunteers who visit patients at home also work in-house, that is inside the hospice in an in-patient unit and/or a day-care unit. Forty-two per cent (34) of volunteer co-ordinators said 'all' or 'most' of their home care volunteers also worked in-house[73] and another 49 per cent (40) said 'some' did so[74]. Some volunteers may start this way before offering themselves for home visits and in a few services, it is a pre-requisite that volunteers work in the hospice before putting themselves forward for home visiting. More than two-thirds of home visiting co-ordinators also organised volunteers in an in-patient unit or day-care unit. This would give them an opportunity for informal exchanges with workers, a helpful way to elicit a volunteer's interest and aptitude for home visiting because not all in-house volunteers are drawn to work in the community, some initially eschewing close contact with patients.

When I started I said, 'I don't think I want to get involved with patients' but I enjoy driving and they wanted drivers and so I started off taking a lady to hospital for therapy. ... I don't normally do home visits ... I talk to patients at the day centre but to actually go round and sit with someone for two to three hours, I might find that difficult.[75]

Unique work

Volunteering out of compassion and understanding comes from the very highest motives but these alone may not be sufficient to carry the volunteer through what can be demanding work.

I remember feelings of anxiousness as I walked in and wondering how ill this woman was going to be. I also wanted to 'do it right' and not make things worse by my inexperience. Never having had any nursing experience, I had no idea what to expect.

There were lots of feelings of inadequacy, wanting to do it properly and not cause her any pain or indignity. I had to keep remembering that I was there to help and not be repulsed[76].

A volunteer knocks on the door of someone whom they may not have met before (although they may have spoken with them on the telephone), walks into a home they have not seen before and a context where those living there face great uncertainty because someone is terminally ill. To do this a volunteer needs to be supported. The patient and carer may be just as unsure themselves about the volunteer and whether they really want a stranger coming into their home at this time. Patients and carers might not understand how a volunteer, who has offered their services because they are concerned and want to help, may feel obliged to give more time than they can really spare or become involved in a way which they do not know how to handle.

Volunteers find it difficult to walk away from need and difficult situations ... they may be tempted to take on too much. Feeling responsible is common and a line has to be drawn over this. Leaving a home can sometimes be very difficult for a volunteer. They just have to be 'a good neighbour' otherwise they're vulnerable if something goes wrong[77].

In their keeness to help, volunteers may not be aware of difficulties they could be inviting upon themselves. Giving your telephone number to a carer and finding a few weeks later that someone else in the street has it too and would like you to call by with some shopping, can come as a shock to the unprepared. Volunteers may take risks of which they are unaware in their keenness to be of assistance. They may find themselves taking responsibility for a situation in the absence of family or professional personnel because they do not feel they can leave it. All this has to be prepared for and counselled. What follows is an outline of the nature and pattern of some formal procedures which co-ordinators consider necessary for this work and which they have developed and now oversee or implement themselves. It does not take account of informal networks and procedures which may also contribute support to volunteers.

Maintaining the anonymity of volunteers is one step towards this support. Most of 76 co-ordinators gave patients and carers quite minimal information about volunteers, confining information to details of the time of the visit (99 per cent), the task (97 per cent) and the volunteer's first name (97 per cent). Three-quarters of these co-ordinators gave the volunteer's surname, otherwise details tended not to be given, so making it difficult for a further engagement with the volunteer that is not initiated by the service. Only 14 per cent of co-ordinators gave a volunteer's telephone number and 5 per cent their address[78].

Secondly, guidelines for volunteers are the norm. Patients and carers are frequently told in advance what volunteers can do and just as important, what they cannot do. Approximately 86 per cent (67) co-ordinators usually pre-arrange with the patient and carer the task to be done and the duration of the visit. On occasions, 'volunteers went in and over-stepped the boundaries that were being set' and 'volunteers knew what they were there to do but ended up doing something else because they couldn't say no.' Circumstances and needs do change and guidelines help volunteers if negotiations have to take place. Most co-ordinators, 83 per cent (68) indicated there were recognised limits on the recommended length of a visit. A quarter 'stipulated' a time limit while 57 per cent 'suggested' such limits, allowing volunteers some discretion to respond to need and what they felt they could give. Seventeen per cent (14) of co-ordinators did neither and they were more likely to be from services which had been operating for ten years or longer. If any negotiations had to take place, just 37 co-ordinators said they had guidelines for them and 21 had them written down (under one quarter of all respondents); this

might be because volunteers are generally not allowed to negotiate and have to refer all changes back to a co-ordinator, 89 per cent (72) of whom said a responsible person could be contacted by the volunteer when visiting, giving volunteers a reference point if there were unanticipated difficulties or worries. Again, the longer the service had been in operation the less likely it was to have guidelines written down.

Recruitment and selection

More than half the co-ordinators (66 per cent) (44) said they had between one and 20 volunteers leave in 1995. Quite small numbers leaving could represent a high percentage of the workforce and maybe an even higher percentage of the work done and so be unsettling. Fluctuations in demand throughout the year, month by month, made it difficult for co-ordinators to say whether they had enough suitable volunteers. As one put it, 'with volunteers it's either feast or famine' and 'demand is very much up and down and depends on the patients' conditions'. However, in spite of this, a significant proportion 43 per cent (33) felt they had about the right number[79]. Nearly as many (39 per cent) (30) thought they had insufficient suitable volunteers for the work available but we don't know whether they were looking for more reliability, more skills, or more availability from their volunteers[80]. Co-ordinators were less likely to say they had insufficient suitable volunteers,[81] when 'all' or 'most' of the home care volunteers also worked in-house, suggesting that having a body of volunteers close by from which you might occasionally recruit is helpful in meeting commitments.

A number of studies have indicated that word of mouth is the most effective way to recruit volunteers[82] and we have already mentioned that a third (36 per cent) of home care volunteers were reached this way. Advertising can be 'important to back up direct word of mouth methods which may continually favour the same kind of people'[83] and co-ordinators were more likely to use recruitment drives and did so as frequently as using word of mouth, when they did not also organise volunteers in an in-patient unit or day unit. When recruiting from among in-house volunteers and by word of mouth, co-ordinators are reaching people sympathetic to the philosophy of the organisation[84]. Although such volunteers are perhaps easier to locate and make requests of at short notice, they have other responsibilities which may reduce or limit their availability for community work. In the view of some co-ordinators, this raises the danger of their being over-used. Volunteers can find it difficult to say no, and if approached from two quarters, they could over extend themselves. For this reason, in some services, the home visiting volunteers are a distinct group who do not work in the hospice.

Not every volunteer wants to do this sort of work and not everyone is suitable. Volunteers have to be able to cope.

> *I wouldn't recommend it to someone going through a vulnerable patch in their own life*[85].

Co-ordinators speak of looking for that special something in people which means they can feel fairly confident about sending them into the community knowing they will be able to exercise discretion and common sense, remember the guidelines they have been given and be able to establish some rapport with the patient and carer. Volunteers, in the main, are visiting as friendly neighbours offering company and support. Their compatibility and facility for listening and getting on with people is important. Not everyone who comes along is felt able to manage and co-ordinators use a significant number of procedures to help them with selection.

Application forms, references and interviews formed the basis of selection procedures for eighty co-ordinators (Table 9). More than half used job and task descriptions to elicit information and preferences from volunteers and a substantial number used a probationary period and health checks to finalise selection. A significant number, 77 per cent (62) also used observations of volunteers in training sessions. Among co-ordinators who referred to 'other' procedures, three quarters also described 'observing' volunteers and half of these had not used training sessions[86]. Six observed previously known volunteers in other hospice settings, three used post-training interviews and two used the discussion of guidelines and induction procedures as a means of guaging volunteer response.

Table 9 Methods used by co-ordinators for selecting home care volunteers

Application forms	76	95%
References	76	95%
Interview	75	93%
Training session	62	77%
Job description/tasks	46	57%
Probation period	36	45%
Health check	33	41%
Other	15	18% Base number 80

The extent to which these several procedures, application forms, references, interviews and observation are used suggest a lot of care is taken by co-ordinators to protect both the client and the volunteer. What is more unusual is the consideration given to observing volunteers with other volunteers, staff and patients, which in its various forms, is done by approximately 84 per cent of co-ordinators.

Training

Like recruitment, ongoing training is needed to maintain a service whether or not the service is committed to any expansion. It is in training that the unique nature of the work can be fully explored and volunteers encouraged to talk through whether this is really what they want to do. Home care volunteers are outreach representatives of their organisation, its standards and philosophy.

> *We are building a bridge of trust with patients. We are trying to offer security without taking over and not offering false hopes. It should be special without being instrusive. It is the way we go into the home. We go from the hospice which they know and feel secure about.'*[87]

Volunteers visit patients living alone and patients in family units. They have to exercise discretion about how they introduce themselves to someone's home, how make themselves available for help without intruding on a private domestic scene, how to negotiate requests which do not come within their brief and then how to take themselves away without entering a binding relationship nor yet severing links that can be a support to those who received them.

> *A lot of attention is obviously paid in training to awareness of family dynamics and the changes going on and how a volunteer's presence may change these*[88].

> *Some people make it quite clear they don't want to talk. You have to take it at their level. Some are very angry. You want to make it better but it isn't appropriate. We can be left feeling fustrated*[89].

Training is preparation for what volunteers might expect to encounter. It opens up awareness so volunteers can think through how they might react in certain situations and what they might need by way of assistance. Not being sure of what you are going to meet with is made easier when you have been prepared for a number of possibilities. Preparation is reassuring.

> *I was really quite shocked at how yellow he was. I have no medical background and I thought he was Asian to start with. I've learnt now to look round for pictures of people in normal family photographs to see how the person was quite recently before the illness took over*[90].

'How much information do you give the volunteer about the nature of the patient's illness and the home situation and how much do you leave them to make up their own mind?'[91] Co-ordinators have to address such questions. Volunteers may not be told the diagnosis of a patient but they do need enough information to be adequately prepared for a situation. How much information they should be given about a patient can sometimes be an issue because it raises the question of confidentiality. Hoad noted in his study that the issue of confidentiality was a sensitive one; it illustrated a more general point about the boundaries of volunteering which was one 'of real practical concern in at least some hospices'[92].

Some services offer volunteers as befrienders who are prepared to develop a long-term relationship with the patient and/or carer, sometimes into bereavement.

> *I'll never forget him and he'll always have a place in my heart but afterwards you've got to cut yourself off. You learn how to do it in the training. You cannot get too attached to people*[93].

Others, while offering company, take care to minimise the possible attachment between a volunteer and patient or carer, rotating visiting volunteers and keeping their involvement in a patient's domestic situation and its internal dynamics to a minimum. These are different approaches which may require different kinds of preparation and support. One co-ordinator felt that no training was needed if volunteers had common sense but common sense is determined in part by experience and training can expand experience by allowing people to learn from the experience of others. For the majority of co-ordinators, the number of training hours they used and its compulsory nature indicate that training was considered to be important. Volunteers

> *... are given guidelines in training and it will cover what to do in an emergency. It is to give them confidence that they can cope with a situation. It is important also that they know of the risks they can do to themselves*[94].

Ninety per cent (71) of co-ordinators said they gave training that was specific to the home care volunteers role and 65 of them gave us details about when the training was given and for how long. Training was more likely to be compulsory than optional with 61 co-ordinators giving a total of 866 hours compulsory training, an average of 14.2 hours, compared to 32 co-ordinators giving 382 hours of optional training, an average of 11.94 hours. Compulsory training was more likely to precede visits and optional training was twice as likely to be after visits had begun[95].

Apart from helping volunteers understand what they are taking on and giving them guidelines on how to conduct themselves, many co-ordinators said training was an opportunity for them to observe volunteers prior to making a final selection. Co-ordinators who used compulsory training before visits to observe volunteers (56) averaged 12.02 training hours, whereas those not using compulsory training in this way (7) averaged fewer training hours before visits, 6.71.

Table 10 Number of services offering training and average hours

	Before visiting	*Av. hours*	*After visits began*	*Av. hours*
Training				
Compulsory	59 (91%)	12.2	20 (31%)	7.3
Optional	11 (17%)	7.27	26 (40%)	11.88
				Base number 65

Table 11 Compulsory training before home visits

	Home care volunteers working in-house			
	All	*Most*	*Some*	
Training hours				
12 hours or less	81%	63%	60%	
Over 12 hours	18%	36%	40%	Base number 57

Observing volunteers working in house may obviate the need to observe them in training because co-ordinators who had all or most of their community volunteers also working in-house showed a tendency to invest in shorter periods of compulsory training before home visits.

Debriefings

Training may include showing volunteers how to lift patients, should it be necessary but there are emotional risks in the work as well as physical ones.

> *Feelings of being pathetic, over reacting, not caring enough and questioning whether I was up to being a volunteer went through my mind. I had a long talk with the Home Care Sister and met up with another volunteer who also had visited the same woman and talked things through and realised that all those feelings seemed to be quite natural*[96].

The recently bereaved are deterred from applying for this sort of work and perhaps in this more than any other voluntary work, co-ordinators have evolved support structures to help volunteers[97]. Debriefings are as important as any support yet mentioned. They enable a co-ordinator to gather information on how the service is operating, whether a visit went as anticipated, whether circumstances have changed, if a patient's needs are being met or if the patient and carer have made requests that should be communicated to the palliative home care team. They also enable co-ordinators to check that volunteers do not take home burdens or worries, to learn how the volunteer feels about visits, if they had sufficient information on the domestic situation and whether the volunteer has anxieties, specific or general. The well-being of the volunteer is paramount if the service is to continue.

Co-ordinators used a mixture of procedures, many of which convey to the volunteer that feedback is not just anticipated but expected and experience should be talked through on a regular basis. The procedures used by 82 co-ordinators (93 per cent) are not mutually exclusive and most co-ordinators used more than one. A fifth (21 per cent) used only one.

The commonest method used by more than half the services is the telephone call made after *each* visit between the volunteer and a co-ordinator, nurse or other staff member. More than a fifth of co-ordinators indicated these calls were made after *several* home visits. The large number

Table 12 Procedures used for debriefing and their frequency

Procedure	*After each visit*	*After several visits*
Form/record filling	28 (34%)	10 (12%)
Telephone VSC/nurse/other	44 (54%)	19 (23%)
One-to-one, volunteer/VSC	9 (11%)	17 (21%)
One-to-one, volunteer/HCT	10 (12%)	12 (15%)
Group volunteers & VSC	8 (10%)	29 (35%)

of volunteers and volunteer visits and their scattering over wide areas make the telephone call a necessary part of debriefing procedures.

A third of co-ordinators had volunteers complete forms after each visit. Formal records point to written liaison between different groups of workers. Services with more volunteer visits in 1995 had a tendency to make more use of forms, indicating their use may in part be a consequence of size and the need to organise information[98].

The next most frequent procedure was a group meeting between the co-ordinator and volunteers. These gave co-ordinators an opportunity to reaffirm guidelines, tap into what was happening in home visits and hear when volunteers might need to talk to someone on a one-to-one basis. Such meetings were most likely to happen after several home visits and could vary from an informal and optional affair,

> *There are general sessions for all volunteers. All are invited but they do not all attend*[99].

to a quite formal arrangement.

> *There are compulsory monthly supervisions which are structured with two trained people overseeing the group, one a Macmillan social worker who is trained in supervision. It is an extension of the structured support and supervision which is given to all employees of the hospice. Continuing as a volunteer is conditional on attendance at these supervisory meetings*[100].

Volunteers talking with each other can sometimes be even more helpful than a co-ordinator's assurance that difficulties, awkwardness or frustration are nothing unusual, like patients who group together in hospital waiting rooms who share and in sharing find support.

> *Sometimes I think for a long time and then I just pick up the phone and share with someone. I talk a lot to other volunteers, here at meetings. You go out of your way to talk to people. It's crucial*[101].

Group meetings for volunteers to meet each other, sometimes voluntary and sometimes compulsory, were organised by 80 per cent (61) of co-ordinators. The frequent presence of the co-ordinator at these meetings reflects an importance attached to them. For those volunteers who also worked in-house, there was the possibility of informal support from volunteers and staff in that context as well.

Table 13 Volunteer group meetings

	Voluntary	*Compulsory*
Co-ordinator always present	57%	24%
Co-ordinator sometimes present	10%	3%
Co-ordinator not present	7%	Base number 76

Generally, form filling and telephone calls were more than twice as likely to take place after each visit, rather than after several visits. One-to-one meetings between a volunteer and co-ordinator, nurse or member of the home care team were less frequent and just as likely or more so to take place after several visits. A telephone conversation may be the quickest way to elicit what goes on in a visit but it perhaps doesn't allow for anxieties and awkwardness to surface as easily as they may in one-to-one sessions which allow a co-ordinator to reassure her/himself that the volunteer is managing and feels that what they are doing is valued not just by the client but by the organisation as well. Just over half, 59 per cent (48) of co-ordinators had a debriefing procedure which involved them, or a member of the home care team, in a one-to-one meeting with every volunteer at some stage after a number of visits. It is an important difference whether co-ordinators wait for volunteers to come to them with their needs or whether there is an inbuilt structure to check with each volunteer at regular intervals how that volunteer is coping with what they are doing. If volunteers are left to come to a co-ordinator when they need to, those more relaxed about using this help may come forward more often than others who are less confident about presenting themselves. It cannot be assumed that volunteers not presenting themselves are managing better. It may in fact be the reverse.

There may be a tradition of relying on more informal methods. Several co-ordinators emphasised that volunteers were encouraged to pick up the telephone if a problem was identified during their visit or if they felt anxious in any way, and not to wait to be contacted by a co-ordinator.

> *We have counsellors here and we encourage sitters to come to us to talk things through. They are asked to contact us if they've got any reason to do so. Our workload is such that we say don't wait for us to contact you. We usually know a situation well and what is going on there*[102].

This sort of availability can be important to volunteers. Unexpected feelings may surface or events occur, a death for instance.

> *It was such a momentous thing to happen to be there at that time, a crucial time for everyone, a humbling experience ... I needed to talk about it. After the death I came straight up here and spoke for over an hour with Jane [co-ordinator]. If I had had to go on holding that it would have stayed with me for a long time.*

> *The comforting thing is if Jane is not there you can talk to anyone here and they will make themselves available. Because you are lovingly looked after here you go out with confidence and you are not frightened of screwing up and not frightened to admit something was wrong*[103].

Such a commitment from all staff to the work that volunteers undertake and the needs this work might generate shows why volunteers, having embarked on the work, carry on with it when it can be so demanding of them. Avoiding 'getting sucked into the drama'[104] may not always be possible and just as professionals need support, so do volunteers.

Debriefings are one more example of how volunteer co-ordinators take responsibility for and support their workers. The kind of service offered to patients and carers, patients' circumstances, the idiosyncratic arrangements of different organisations and the number and availability of staff will all dictate the particular debriefing pattern adopted. Some services offer a befriending which may involve the volunteer closely with the patient and carer and one of the rewards for the volunteer may be just that personal relationship with the dying. Other services discourage long term befriending. Either way, a responsibility has to be taken for the volunteer that is one more indication of the special nature of this work.

Appraisal

Almond's study of one hospice's volunteers noted that reasons for coming to volunteering were not necessarily the same as the reasons for staying with it and that when volunteers stayed it was partly because they got something out of volunteering, implying that 'successful volunteering, albeit initially non-selfish in intent, flourishes in a climate of "reciprocal exchange"'[105]. This 'exchange' can come from clients, from other volunteers and from the organisation and some of the benefits for volunteers, mentioned by Almond, were appreciation, gratitude and friendship. Maintaining the morale of volunteers who work on their own a great deal and when so many demands may be made of them is obviously important.

> *There has to be a professionalism towards volunteers so that we don't smother people and treat them like children yet we must protect them so that the service is not taken for a ride*[106].

Co-ordinators strive to get the balance right so that volunteers feel free to give. Most co-ordinators (83 per cent) said they appraised the work of home care volunteers. Well over half of these, (58 per cent) (38), used a group meeting for appraisal and just over half, (51 per cent) (26), used a training session with the volunteer co-ordinator. This must be general appraisal and review of direction and work in line with the work of the organisation. Forty-five per cent (30) used one method of appraisal, the remainder more than one. One co-ordinator indicated that there was an annual appraisal as well.

Volunteers like to feel valued, to know what they are doing matters and that they are making a contribution[107]. They feel valued by patients and carers.

> *It's just such a joy to give your time to something where people are grateful*[108].

But it is only to the organisation they can express frustration or from the organisation and its representatives that they can get feedback on how their work fits into the overall service and how well they as an individual are going about giving help and representing the institution.

> *You are conscious of representing something with a good reputation and you are conscious that people in these situations are very vulnerable*[109].

Personal appraisal of a volunteer's development, management and future direction can only really take place on a one-to-one basis and 42 per cent (27) of co-ordinators replying gave one-to-one sessions. Appraisal is different from other kinds of support. It allows those involved to explore general issues of personal satisfaction, expectation, confidence and self-development. It relates to reasons for coming to the work in the first place, whether hopes have been realised and whether abilities are being effectively used. It is uniquely different from the support that

volunteers can give to each other. Its privacy allows it to be more personal and to address aspirations and morale and whether volunteers feel happy in this kind of work. Such meetings can also give a clear message to volunteers that they are expected to have views on their work and their involvement in the organisation and to express them. At LOROS, when volunteers were asked what was important in making hospice in-house work rewarding, there were differences in the answers of different groups, but the majority of volunteers referred to feedback[110].

The volunteer co-ordinator

Most of this chapter has been about the work of the volunteer co-ordinator who is the lynch-pin and central point of reference for all volunteers. The co-ordinator is the person who sets up the training and support and see volunteers through their work on a daily basis. Home visiting services vary in the number of paid staff employed and their working relations with other professional personnel. Of 85 co-ordinators, 48 (57 per cent) worked full-time and 37 (43 per cent) worked part-time with two job shares included. Thirty-one of the part-timers indicated their hours ranged from 12 to 30 hours per week, an average of 21.3 hours. Six part-time co-ordinators were unpaid volunteers themselves. Just under three-quarters (73 per cent) (55) had a job description relating to their work with home care volunteers and the proportions with job descriptions were similar for full and part-time workers[111].

We have mentioned before that more than two-thirds (71 per cent) (57) also organised volunteers in an in-patient or day-care unit. For the majority of co-ordinators, overseeing volunteers is only part of their work and nearly two-thirds (64 per cent) (49) also carried out quite different responsibilities which ranged from financial and fund-raising to management administration and record keeping. Twenty (23 per cent) were qualified nurses, most of whom indicated their office also carried nursing responsibilities[112].

The consignment of responsibilities varies. Some services are run by a voluntary service co-ordinator who recruits, selects, trains and places volunteers, working alongside a specialist palliative home care team (if there is one). In others, the volunteer co-ordinator recruits, selects, trains and then passes volunteers on to the specialist home care team leader or nurse who allocates visits. In yet other services, it is a nurse who leads the specialist palliative home care service (or sometimes a day-care sister) who undertakes all these responsibilities. In 23 instances a nurse co-ordinated volunteers to visit patients. Some of these nurses were wholly responsible for all professional and volunteer home visits; others were responsible for day-care and/or home care visits; and some were solely responsible for organising volunteers, in-house as well as home care volunteers. Eight worked alongside a volunteer co-ordinator who in most instances undertook recruitment, selection and training and then passed chosen volunteers to the nurse/sister to arrange home visits.

A service co-ordinated by a nurse may be a deliberate choice – as it was for some – or an accident of history. One service that was being run by a nurse would have liked to appoint a voluntary service co-ordinator but had not the resources to do so. Another had recently replaced the voluntary service co-ordinator with a qualified nurse because it wished to review the direction of work and felt there were advantages in having the review led by a nurse[113].

The way the work is organised and the nature of contact between professionals and home visiting volunteers is an integral part of the organisation of a service and may well make a difference to volunteer morale and the relevance with which volunteers see their contribution. The pattern

varies very much from service to service with a spectrum of different working arrangements between professional staff and volunteers. In some services, volunteers had little contact with professional staff,

> *the work of volunteers is obviously seen as an incidental supplement when people ask or need a little extra help and nurses refer*[114].

and liaison between the two is undertaken by the volunteer co-ordinator. In others, there were fairly close working relationships with volunteers expected to meet 'formally' with professionals at regular intervals. Co-ordinators were not asked about these relationships but they did tell us about arranged contacts between volunteers and professionals. Ten co-ordinators (12 per cent) referred to one-to-one contact between volunteers and a member of the home care team for debriefing after one visit and 12 (15 per cent) to the same after several visits[115]. In a few services, home visiting volunteers are a fully integrated part of the home care team, working to specialist nurses and in regular contact with professional staff.

A volunteer's commitment to the work may derive in part from the nature of their involvement with professional staff. A look at the number of visits made by services co-ordinated by nurses and those not so co-ordinated does suggest that volunteers who are more closely involved with members of the professional team may enjoy better morale and do more as a result. The average number of visits in 1995 for 58 services giving details was 301 whereas the figure for the 16 of these services co-ordinated by a nurse was 372[116]. Similarly, the average number of visits per volunteer in 1995 for 55 services was 8.7 but for 15 services run by nurses, the average was 12.8 visits. Though these last numbers are small and some figures for visits may be estimates, they do suggest the closer engagement of volunteers with professional staff, which a nurse co-ordinated service implies, might be an encouragement to volunteers.

Another explanation could be that in a team where nurses and volunteers work closely together, the nurses have more personal knowledge of the volunteer service which they are then in a position to pass on to the patient and carer. This can be reassuring because patients and carers may have reservations about letting strangers who are volunteers into their homes at such a difficult time. It is not known whether patients and carers take different views of volunteer services which are closely or less closely tied to the operation of a visiting specialist palliative care team but it may be that clients find it easier to accept help from volunteers if they see volunteer contributions as part of a 'total service package' that is being offered to them and not a separate service which might imply that they as carers were not managing.

Commitments

Prior to and after selection, some co-ordinators ask volunteers to make commitments, and not just to training. Significant numbers of home care volunteers are asked for a commitment to one or some of the following: a minimum period of time during which they will be available to work, a minimum number of working hours per week/month, training sessions and perhaps supervision. This seems to flow naturally from the nature of the volunteer co-ordinator's work. We have been told how unpredicatable its flow can be, coming in waves as patients' conditions and the number of patients looking for help, change. It is unpredictable for many reasons.

> *You can set up a lot then it is all cancelled. Cancellations come because some people go into hospital, because some people change their mind and also because I tend to plan ahead in*

anticipation of needs and developments so that I am not rushing at the last minute or trying to find people at short notice over a weekend.[117]

One week there were five referrals, then two changed their mind and three died[118].

Added to this, the work force is not immediately on hand. Volunteers have to be located, possibly at the end of a telephone: 'Sometimes I seem to do nothing but stay on the telephone'[119]. Volunteers may not be there but if they are, their availability has to be negotiated, the amount of time they can spare and when. If the co-ordinator is to meet anticipated demand without spending an inordinate amount of time on the telephone she or he needs a realistic idea of what can be offered to clients so that those making arrangements with the patient and carer do not mislead them. Seeking some commitment from volunteers would seem a natural and necessary step for co-ordinators if they are to predict minimum levels of volunteer availability and order their workload. Otherwise, how can those referring indicate the level of service that might be provided for clients and how can co-ordinators have confidence in meeting requests that come forward? The co-ordinator needs an accurate picture of how much time the volunteer has to offer and with what degree of regularity, their means of transport and when, during the day and week, the time is usually available. A minimum commitment tells organisers what resources they have to offer patients and carers.

Similarly, organisers investing in training will be keen to see a minimum return from that investment. A volunteer always has the right to say no but this can be a reason why such a commitment needs to be asked for in the first place. It encourages volunteers to think through the implications of what they are volunteering for. One respondent pointed out that as these were 'volunteers' it was difficult to ask for any such commitments. The fact that so many are asked illustrates the demands of the work and the way the nature of some 'volunteer' work may be changing.

Table 14 Commitments asked of volunteers

	Number of services	
Ongoing training	60	76%
Attending meeting with co-ordinator	47	60%
Attending meetings with volunteers	44	55%
Minimum period of time	26	33%
Minimum hours per week/fortnight etc.	24	30%
Other	9	11%
N/A	6	Base number 79

There was no relationship between the size of service and any commitments asked for. Three-quarters of co-ordinators (76 per cent) (60) asked volunteers for a commitment to ongoing training and like training, the commitments most often asked for related to helping volunteers do their work rather than helping co-ordinators do their job. Under 'other', four respondents asked volunteers to commit themselves to meetings with a professional nurse, the home care sister (these were usually in addition to meetings with the co-ordinator); others to ask volunteers to commit themselves to reporting back after visits, attending an education programme, to a 'case' (one patient and the liaison work that might entail) and one, a general commitment to the aims of the group. Volunteers comply with these requests because 'volunteering can be an expression of need just as much as the client ringing to request a home help.'[120]

It's not difficult for me. I had more out of it than I give[121].

I've gained an enormous amount[122].

Work boundaries

Mention has already been made of a co-ordinator's need to watch the boundaries of work undertaken by volunteers. There are other boundaries which relate to the volunteer's position in the organisation for which they work. Interviewing, selection, training and commitments mark home care volunteers as different from other volunteers though perhaps not so different from hospice volunteers generally[123]. The majority of home care volunteers, 93 per cent, had an initial interview compared to 7 per cent of all volunteers nationally and 90 per cent of co-ordinators said they gave training specific to home care volunteers while nationally only 17 per cent of volunteers received any training[124]. Training was treated as compulsory by 85 per cent of the co-ordinators giving it. Differences such as these illustrate Hoad's reference to the ambiguous position of hospice volunteers as neither professional nor simply 'lay' carers because of the great range of work done and the skills acquired in doing that work[125]. This is very much the case for home visiting volunteers, some of whom are very qualified and experienced 'friendly neighbours'.

When you invest in training, when do people stop being neighbours and lay carers and become experienced personnel? As volunteers take on more commitments, how far do they remain technically outside the organisation, especially when they work alongside professionals and/or if their organisation contracts for work taking into account contributions from volunteers? One co-ordinator, asked 'are volunteers part of the organisation and if they are, how much information or real knowledge do they need to cope with a situation?' So, there are boundary issues for volunteers relating to things like confidentiality where limits are defined but which may yet make it difficult for the volunteers to perform to the standard and in the way they would like. Hoad observed 'the maintenance of boundaries can give rise to tension between staff and individuals'[126]. Although this can be an area of concern for volunteers and staff[127], just 61 per cent of co-ordinators said details of relationships between volunteers and paid staff were specified in documentation, suggesting that for a third they were not (Table 16). When looking at its training for in-house volunteers, King's Mill Hospice concluded that 'it became essential to recruit, train and access these workers in a professional way so that they could understand what was required of them and could play a full part in the service'[128]. Being part of an organisation that works with volunteers has implications, for volunteers who need to be consulted, and for staff who need to understand exactly the boundaries of volunteer work and how they (staff) should relate to volunteers and their responsibilities towards them.

The organisation

Another dimension of potential support afforded volunteers comes from the organisation behind the co-ordinator. Volunteers do not have a contract of employment and expectations from other parties and maybe the organisation itself could be beyond what a volunteer had intended when first volunteering. Volunteers can feel buttressed against inadvertantly high or unreasonable expectations if their rights are clearly stated. Although volunteers can say no, services will not unnaturally want to maximise the potential of individual workers and encourage others to come forward. Furthermore, not all parts of an organisation may be committed in the same way to the involvement of volunteers or if committed, they may not understand what volunteers can bring to a service. A stated policy on the contributions of volunteers can help to engage the

commitment of all staff and clarify what is expected of volunteers and what they in turn are entitled to expect. Forty-seven co-ordinators, not quite two-thirds of those replying, told us their organisation had a written policy on the use of volunteers in home care services[129]; the proportions were the same for full and part-time co-ordinators[130]. They showed a tendency to be services set up more recently (Table 15). About a third of those asking for commitments from volunteers did not have a written policy statement towards volunteers.

Table 15 Length of service and volunteer policy statement

Years operating	*Services with policy*	*All services*
Under 3 years	30%	22%
3–10 years	47%	45%
10 years plus	23% Base number 78	33% Base number 83

If there is no written policy, other written documents of an organisation may specify rights and duties of volunteers as part of a contractual arrangement in which each recognises the needs and rights of the other (Table 16). Organisations with a stated policy for volunteers were twice as likely to have written documentation relating to their work in all areas. A substantial number of co-ordinators, three-quarters or more, said their service had such documentation on volunteers' responsibilities, insurance, health and safety, support, training and rights. Fewer had documentation on roles and relationships and equal opportunities and only a quarter had documentation on resources. This last may reflect the stretched resources of voluntary organisations in a competitive market but could also suggest a failure to understand what resources are needed to organise volunteers. Twenty-nine per cent of co-ordinators had a budget which they controlled and this was slightly higher for full-time than for part-time co-ordinators.

Table 16 Percentage of services with documentation on volunteer work

Documentation	*Percentage of services*
Responsibilities of the volunteer	98%
Insurance, health and safety	84%
Volunteers' support and training	83%
The rights of volunteers (grievance etc.)	75%
Volunteer roles/relationships with paid staff	61%
Equal opportunities	47%
Resources for volunteers	25%
	Base number 64

Many hospices evolved from the first efforts of volunteers and this partnership has been the core of their approach and organisation of services. This chapter describes co-ordinators' work in recruitment and training to maintain a sufficient body of volunteers to do the work available and the support they organise and give to volunteers when doing that work. It shows that while there appears to be much consensus on the need for training and support, there are many different ways this may be organised. Volunteer co-ordinators walk a difficult territory between the requirements of an organisation established to meet clients' fluctuating needs and staffed with paid personnel and the realm of the volunteer whose commitment has to be won, nurtured and sustained. Co-ordinators are hence at the interface of two different kinds of work and they will have needs of their own for support and guidance; supporting the co-ordinator is one way of supporting the volunteer. It is a testimony to co-ordinators' efforts that so much support is

organised and maintained for volunteers when so few have budgets of their own or documentation on resources for volunteers. From comments proffered, this range of support is growing rather than diminishing.

Conclusions

- Home care volunteers' work with terminally ill people can be demanding and needs to be prepared for and supported.

- The majority of co-ordinators maintain the anonymity of volunteers, issue guidelines on work and length of visits and pre-arrange tasks and visit times, all of which protect volunteers from over-extending themselves.

- A significant proportion of home care volunteers are recruited by word of mouth. Just under half the volunteer co-ordinators think they had the right number of volunteers for the work available in 1995.

- Home care volunteers generally differ from the national picture of volunteers because of the interviews, training and commitments most are asked to undertake.

- Preparation for the work is mostly organised by co-ordinators in training sessions which are specific to home care volunteers, which are likely to be compulsory and which more usually take place before visits commence. Other support organised includes debriefing procedures and group meetings for volunteers by 80 per cent of co-ordinators and one-to-one sessions with volunteers by 59 per cent of co-ordinators.

- General group appraisal of work was undertaken by more than three-quarters of co-ordinators and one-to-one appraisal with volunteers by under half of co-ordinators.

- The close involvement of volunteers with professional staff may encourage or facilitate the use of volunteers in the home.

- Services seeking to broaden the age range and sex ratio among their volunteers might consider using other methods of recruitment in addition to word of mouth.

- More recently established services are more likely to have a stated policy towards volunteers, to have documentation on volunteers' roles and rights, to stipulate rather than suggest guidelines for work and to have any guidelines written down.

- Two-thirds of services had a written policy on the use of home care volunteers; three quarters had documentation on volunteer responsibilities, health and insurance and training. Smaller numbers had documentation on relationships with staff, equal opportunities and resources for volunteers.

- Training and support costs money but resources are low on the list of items given attention by management.

Chapter 4

Towards good practice

This survey outlines the work which home care volunteers contribute nationally to the care of terminally ill patients at home and to support for their carers. It describes the activities home visiting volunteers undertake and how they are recruited, prepared for and supported in this work. The range of services that are provided show that local initiative around the country, sometimes linked to hospices, has spontaneously generated similar forms of help in the face of need. The services outlined draw attention to the nature and breadth of support that is needed and can be provided in the home, as much for the carer as the patient, sometimes over a 24-hour period. The help that is given combats isolation which can happen when patient and carer are increasingly confined to home as the patient's illness progresses. It includes practical help to both patients and carers and can include short periods of relief for carers from a role they may be loath to relinquish but which can sometimes be physically and emotionally exhausting.

It is care which for the most part complements statutory provision and which aims to enhance the quality of life of patients but which also points the way to necessary care in the home if patients are to be able to stay at home and die there when that is their stated wish, which is the stated aim of community care. If carers become too worn down by the experience of caring, patients may have to be admitted to hospital or hospice. This would defeat the point of community care. Financing this kind of ancillary care sometimes falls between the social services and the health services while people on the ground struggle to cope.

While the work home care volunteers do points to the way statutory services might develop their provision, the experience of co-ordinators shows others how they might proceed when organising such work in the community. Throughout there is concern for supporting the volunteer and establishing boundaries for the work which is seen as complementing statutory provision. Where volunteers work closely with specialist home care teams, services are demonstrating how social care is integrated with health care in the home and how volunteers and professionals can work closely together. It is evident that establishing such services needs groundwork development followed by continual support. Home care volunteers differ from many other volunteers because they are selected, trained and are often asked for some element of commitment and the majority of co-ordinators have adopted a number of procedures to support volunteers. All this must consume resources. The experiences of co-ordinators and volunteers quoted indicate why some of these procedures are in place and deemed necessary and as such they are indicative of what is felt to be good practice.

Conclusions

The following are suggestions on how some of these procedures might be explored further to enhance good practice.

- *An organisation's commitment to its volunteers*
  Organisations offering services in the community have to be concerned with standards and consistency. The selection, training and support of volunteers are part of this. In calling for a commitment from volunteers, organisations should check the balance of commitment on

their own side to information, rights, evaluation and appraisal of volunteers which will bear in different ways on a volunteer's morale.

- *Boundaries of work*
  There is sometimes pressure from outside sources for volunteers to take on work that could be provided by statutory bodies. Clarification of work boundaries at a local level will help the expectations of both volunteers and professional staff, rather than these being worked out in practice. While it may not always be possible to draw clear lines between the work of volunteers and the work of employees, an attempt to do so will mean exceptions are more likely to be understood as such and services less likely to feel they may be substituting for paid work.

  It is recommended that professionals be engaged in the exercise of establishing these boundaries so that they can feel confident with the service and understand what volunteers can and cannot do.

- *Guidelines*
  There has to be a balance between protecting volunteers and allowing them discretion to give and exercise their skills. Volunteers working close to people who are facing the ultimate loss can find it difficult to say no and sometimes exceed suggested boundaries unless they are carefully watched. Consideration might therefore be given to stipulating some guidelines rather than suggesting them.

- *Relations with staff*
  Some volunteers, because of their training, experience and qualifications draw close to being employees in all but name and payment. As with tasks, attention should be given to the nature of relationships and frequency of contact with professional and paid staff with recognition of the level of responsibility that may devolve – for however short a time – on volunteers. It is possible that the closer the contact between professionals and volunteers the greater the contribution of volunteers.

- *Debriefing*
  Volunteers may not necessarily present themselves to talk about their work and its negative effects on them might be cumulative which suggests that one-to-one meetings with staff, however infrequent, should be considered.

- *Appraisal*
  Individual volunteer needs and expectations which can affect morale should be dealt with on a personal basis, again suggesting the value to volunteers of one-to-one meetings with staff.

- *Having separate groups of in-house and home care volunteers*
  A risk of volunteers being over-used may be reduced if in-house volunteers and home care volunteers are overseen by the same co-ordinator or operate as two distinct groups with volunteers working for one or the other.

- *Evaluating the service*
  Services are well placed to hear about clients' preferences and reactions to this kind of home support. Using a form is one way of doing this. It implies that comments on the service are expected, even welcomed, and suggests that carers are expected to give feedback. It doesn't

have to be completed. Another way would be to employ an independent person to interview the bereaved which has the advantage that it would also give the bereaved an opportunity to talk about their loss.

- *Supporting the co-ordinator*
  Co-ordinators are balancing the needs of the organisation against the needs of the volunteer. They are negotiating boundaries of work and dealing with an absent workforce to meet what are universally agreed to be unpredictable demands. Consideration should be given to (a) their having personal supervision (where this is not the case) so they feel able to manage and organise support for themselves and (b) to having control of budgets so that they can plan.

Notes

1 Griffin J, *Dying with Dignity*, Office of Health Economics, 1991.
2 Survey procedure in Appendix 2.
3 See glossary for definition.
4 There are other agencies which may use volunteers to help patients and carers at home, some of which came to our attention and are noted in Appendix 3.
5 See glossary for definition.
6 See glossary for definition. There are no estimated numbers available according to the Hospice Information Service and Help the Hospice.
7 Hedley R, *Volunteering Today: facts and figures on volunteering in the UK*, The Volunteer Centre, 1992, p.7 & p.9. 51 per cent of the adult population volunteer once a year and 22 per cent once a week.
8 ibid, p. 13 and research by Mori, *Voluntary Activity: a survey of public attitudes*, The Volunteer Centre, 1990, p.17.
9 Hedley R, *Volunteering Today*, p.21.
10 The largest number were in the 56-65 age range; more than half (53 per cent) were described by co-ordinators as 56 and older. 36 per cent co-ordinators employed volunteers under 35 years old; these same co-ordinators had more men among their workers. Approximately 87.7 per cent of volunteers were women.
11 Hoad P, 'Volunteers in the independent hospice movement', *Sociology of Health and Illness*, 13, no.2, 1991, 231–248.
12 Field D, Ingleton C, Clark D, 'The costs of labour: the use of voluntary staff in the King's Mill Hospice', *Health and Social Care in the Community*, 5(3), 198–208, 1997.
13 Hedley, p.23.
14 The largest areas in square miles were not necessarily those considered rural but more often were viewed as a rural and urban mix.
15 One service catered for Aids patients only.
16 78 services operated from addresses which placed them as part of a hospice with an in-patient unit and/or day-care facilities.
17 The home support offered in this instance is based on the ideas and aims of the Brigitte Trust, Dorking, another independent charity which supports palliative care at home using volunteers.
18 Appendix 2, survey procedure.
19 It is not in fact unique.
20 St Francis Hospice Family Support Group, Tenth Anniversary Celebration Booklet, Havering 1982-92.
21 There are two other family support groups, one at Brentwood and one at Barking and Dagenham.
22 Allan G, 'Kinship, Responsibility and Care for Elderly People', *Ageing and Society*, 8, 1988, 249–268.
23 Co-ordinator.
24 Boyd K, *The working patterns of Hospice Based Home Care Teams* (unpublished paper)
25 There may be confusion about what is included in figures for driving. For the most part, figures for driving patients and carers to and from hospice and deliveries of equipment are – as several co-ordinators indicated – not included in home visiting figures but we cannot be

certain of this and there may be one or two exceptions. Some co-ordinators indicated this help was offered with a separate group of volunteers.

26 House of Commons Session 1989–90, Social Services Committee, Fifth Report, *Community Care: Carers*, para.46. The House of Commons Social Services Committee found this definition too narrow because it considers there is need for a whole range of 'respite' services from long periods of in-patient accommodtion to overnight accommodation, day-care facilities, skilled employment, access to lodging and family placements, holidays and other provision which is flexible enough and appropriate to meet the changing needs of the carer and cared for in the community.

27 Allan G, 'Kinship, Responsibility and Care for Elderly People', p.61

28 Jill Pitkeathley, Director of the Carers' National Association, 'Care in the Community', Joint Meeting with the Royal Society of Medicine, *RSA Journal*, December 1995, p.48.

29 Ibid p.49.

30 Silberston D & Lawman S, National Schizophrenic Fellowship, *Community Care: Carers*, House of Commons Social Services Committee, Fifth Report, HMSO, 1989-90, para 39.

31 Wilkes E, 'Dying Now' *Lancet*, April 1984.

32 Seale C, 'Caring for people who die: the experience of family and friends', *Ageing and Society*, No.10, referring to a 1987 sample.

33 Though this is as much to protect volunteers from injury and their organisation from claims.

34 Other forms of one-off assistance might be given on request to people at home depending on needs but was not considered usual.

35 Some services work with Marie Curie who offer night sitting.

36 See glossary for definition.

37 'Hospice staff' are not necessarily specialists in palliative care, for example priests and social workers. However, as the number of answers to this question are similar to the number given for specialist team nurse/doctor, it seems likely that respondents may have treated the two categories as the same.

38 Four of these offered a qualification that such referrals had to come 'through' hospice staff meaning 34 (42 per cent) took referrals from patients and their family.

39 Day care followed almost immediately upon home visiting for St Clare Hospice Care Centre.

40 See *Guidelines for Relations between Volunteers and Paid Workers in the Health and Personal Social Services*, 1990, available from the Library, The National Centre for Volunteering.

41 Only 7 per cent (6) experienced difficulties with paid colleagues underestimating the time volunteers could give and 11 per cent (9) underestimating what volunteers could do.

42 Formerly called Home Help.

43 See over-estimating what volunteers could do, p.15.

44 The National Centre for Volunteering has general *Guidelines for relations between Volunteers and Paid Workers in the Health and Personal Social Services*, 1990, available from the Centre library.

45 Sir William Utting said that 'it is to the advantage of the government to maintain the separation between health and social care. It wants to keep the job of the health services as narrowly defined as possible because they are the difficult and costly end of the business. The Department of Health will not tell us where the divide is and suggests that it should be worked out at local level.' Care in the Community, *RSA Journal*, December 1995, p.59.

46 *Home Care Pilot Review*, St Teresa's Hospice, Darlington and District Hospice Movement, 1996.

47 Where the pain control, nursing support, emotional and social support that are available in a hospice are brought to the patient's home.
48 Some specialist palliative care teams act principally in an advisory capacity to primary care teams. Those offering 'hands-on-care' also give practical care to the patient.
49 *Home Care Pilot Review*, St Teresa's Hospice.
50 Ibid.
51 *Hospice Bulletin*, July 1994, no.23.
52 Stone S, Blade S, *Respite Care Team 'Setting Up' Pack*, The Ellenor Foundation Hospice Care Team, July 1994.
53 *Hospice Bulletin*, December 1995.
54 Two others referred to the growth in community care services meeting carers' needs, 'which has led to more paid help being available who perform a much wider range of duties than just sitting', one to increased funding to Marie Curie nurses which lowered the call on volunteer night sitters and one other where nurse counsellors had undertaken more of the befriending work that had once been done by volunteers.
55 See page 24 for numbers of suitable volunteers.
56 Co-ordinator.
57 Allan G, 'Kinship, Responsibility and Care for Elderly People', p.261.
58 Finch J and Mason J, *Negotiating Family Responsibilities*, Tavistock/Routledge, 1993 and Allan G, op cit.
59 Co-ordinator.
60 Allan G, 'Kinship, Responsibility and Care for Elderly People', p.264.
61 24 per cent (17) respondents said 'all' the specialist palliative services they worked with offered hands-on-care; another 24 per cent (17) said 'some' of the specialist palliative services gave hands-on-care.
62 Figures rounded up or down.
63 Volunteer.
64 Volunteer.
65 Volunteer.
66 Hedley R, *Volunteering Today*, The Volunteer Centre, 1992, p.29. Health and welfare is first in popularity with volunteers generally (p.21) and visiting people was the second preferred activity (p.40).
67 Heginbotham C, *Return to Community: the voluntary ethic and community care*, Bedford Press, 1990, p.32
68 Almond L, *'Who cares: Community Care in action*, a study of one hospice's volunteers, University of Bath M.Sc. 1990, p.107.
69 Another 12 per cent (10) are recruited directly from hospice and day-care volunteers, though not necessarily by word of mouth.
70 Volunteer.
71 Field D, Ingleton C, Clark D, 'The costs of unpaid labour: the use of voluntary staff in the King's Mill Hospice', *Health and Social Care in the Community*, 5(3) 198-208, 1997.
72 Field D, Johnson I, 'Satisfaction and Change: a survey of volunteers in a hospice organisation', *Social Science and Medicine*, Vol. 36, no.12, pp.1625-1633, 1993
73 21 per cent (17) said 'all' their volunteers worked in-house.
74 For 8 per cent (7) the question was either not applicable or their volunteers did not work in-house.
75 Volunteer.
76 Volunteer.
77 Co-ordinator.

78 Sometimes other information was given such as hand-outs on what volunteers do, hospice and co-ordinators' telephone numbers, the occupation of volunteers if it was thought relevant to put patient and carer at ease and whether the volunteer lived locally, which was sometimes helpful in rural areas.

79 And 14 (18 per cent) felt they had more volunteer time available to them than they could use.

80 The National Council for Volunteering's survey found 31 per cent of NHS Trusts and 19 per cent of hospices who replied, claimed to have problems recruiting volunteers, NHS Executive, *Making a Difference: strengthening volunteering in the NH*, Report of the working group on volunteering in the NHS, 1996.

81 29 per cent compared to 35 per cent for the whole survey. Co-ordinators who had fewer suitable volunteers had a higher proportion of volunteers coming from recruitment drives, 18 per cent, than the sample as a whole, 7 per cent.

82 Hedley R, *Volunteering Today*, 51 per cent said their reason for volunteering was because someone asked them, p. 29. Research conducted by Mori for the Volunteer Centre, *Voluntary Activity*, 1990, showed a third of recent volunteers saying they first started because of a friend (34 per cent) or a relative (32 per cent), p.21.

83 Hedley R, *Volunteering Today*, p.31. Co-ordinators in this study who used recruitment drives had overall 5 per cent more people in the younger age range 26–45 years.

84 Co-ordinators with fewer suitable volunteers had a higher proportion of volunteers (18 per cent) coming from recruitment drives, than the sample as a whole (7 per cent).

85 Volunteer.

86 This percentage may well be larger given the number of home care volunteers who also work in-house and the number who are recruited by word of mouth.

87 Co-ordinator.

88 Co-ordinator.

89 Volunteer.

90 Volunteer.

91 Co-ordinator.

92 Hoad P, 'Volunteers in the independent hospice movement', *Sociology of Health and Illness*, Vol.13, no.2, 1991, p.246.

93 Volunteer.

94 Co-ordinator.

95 Thirteen other co-ordinators indicated training was available on a variable basis. For two more services it was done on hospice wards and encompassed general training and for one, constituted six months experience working in the hospice.

96 Volunteer.

97 23 per cent of all volunteers nationally felt they needed advice and support but this percentage was 65 per cent for those in advice and counselling work, Hedley, *Volunteering Today*, p.26.

98 Of services making less than 100 volunteer visits in 1995, 27 per cent used forms. Of services making 100–400 volunteer visits, 42 per cent used forms, and of services making more than 100 volunteer visits, 54 per cent used forms.

99 Co-ordinator.

100 Co-ordinator.

101 Volunteer.

102 Co-ordinator.

103 Volunteer.

104 Senior Nurse.

105 Almond L, *Who Cares?* p.111 & p.140.
106 Co-ordinator.
107 Hedley R, *Volunteering Today*, p.30.
108 Volunteer.
109 Volunteer.
110 Field D, Johnson I, 'Satisfaction and Change'.
111 Of those without job descriptions, 12 were full-time (a third of these were nurses), two were in a job share and six were volunteers themselves.
112 Their official titles were various, Macmillan Nurse, Senior Nurse Manager, Home Care Sister, Day-Care Sister/Leader, Home Care Team Leader/Co-ordinator and Nurse Counsellor.
113 They were looking at the use of volunteers alongside professional workers and the tasks that needed to be tackled in the home if patients were to be helped to stay at home to die when that was their wish.
114 Co-ordinator.
115 Two of the ten were nurse-led services and five of the 15 were nurse-led services.
116 Figures rounded up or down.
117 Co-ordinator.
118 Co-ordinator.
119 Co-ordinator.
120 Heginbotham C, *Return to Community*. The main benefit for volunteers is that they enjoy their work and have the satisfaction of seeing results, Hedley R, *Volunteering Today*, p.34.
121 Volunteer.
122 Volunteer.
123 King's Mill Hospice is probably not unique in requiring all potential recruits for working in the hospice 'to complete an introductory training course and to 'pass' an interview'. Field D, Ingleton C Clark D, 'The costs of unpaid labour'.
124 Hedley R, *Volunteering Today*, p.26.
125 Hoad P, 'Volunteers in the independent hospice movement'.
126 Hoad P, 'Volunteers in the independent hospice movement', p.244.
127 Although 'unlike Hoad's study there appeared to be no significant problems in the way volunteers experienced their relations with other paid and voluntary staff ... some negative attitudes towards volunteers by some staff were identified', Field and Johnson, 'Satisfaction and Change'. p.1630.
128 Kings Mill Hospice Trust. Leaflet on East Midland Region, Winner of 1994 National Training Awards granted by Department of Employment.
129 60 per cent. This is similar to findings by the National Centre for Volunteering, *Make a Difference*, Annexe D, 1996, in which over two-thirds of respondents in a postal questionnaire to English NHS Trusts and non NHS hospices claimed to have a formal volunteering policy.
130 Similar percentages of full and part-time co-ordinators (56 per cent & 55 per cent) had an organisation policy statement on the deployment of home care volunteers.

Recommended reading

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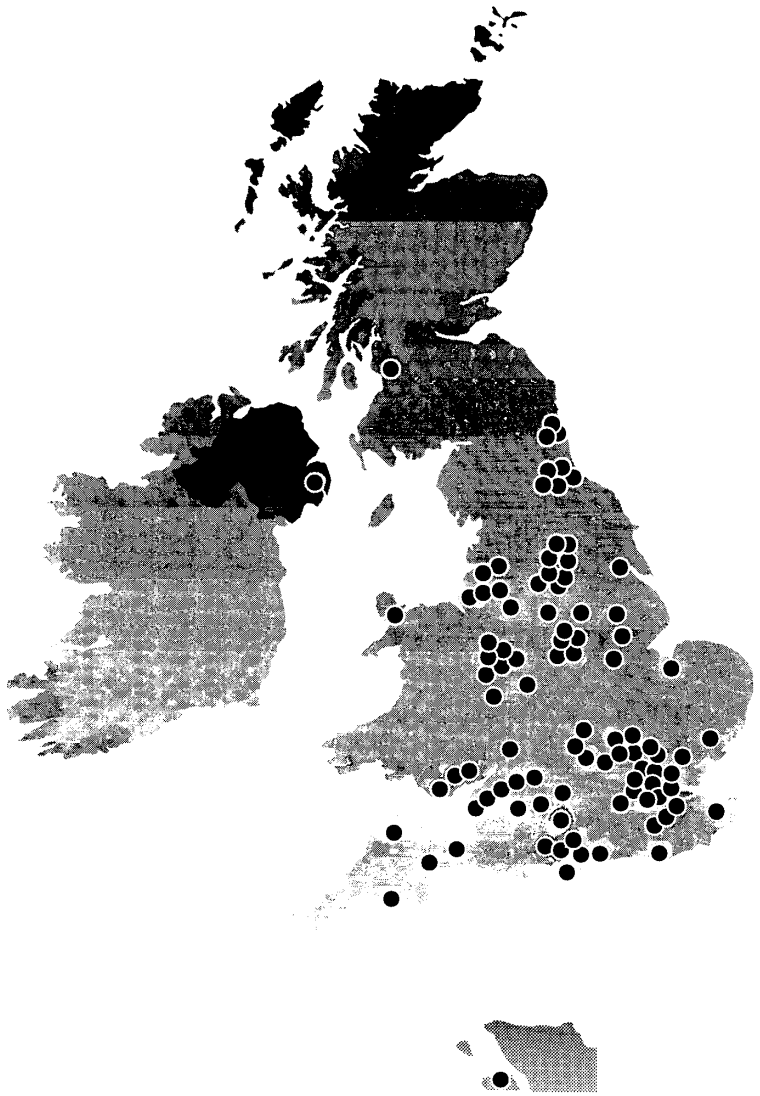
Part II

List of services

One hundred and six units were identified as organising volunteers to visit terminally ill patients and their carers at home and 88 of these supplied details of the work undertaken by the volunteers when visiting. Units which offer a home visiting volunteer service for which we do not have details are listed at the end. The services outlined under each unit are those considered to be usually given during the year 1995. This does not mean that other services are not given nor that they could not have been given if asked for. Abbreviations in the text for illnesses are:

C	Cancer
A	Aids
MND	Motor neurone disease
MS	Multiple sclerosis
OTI	Other terminal illness

Distribution of services using volunteers to visit terminally ill people at home in 1995



AVON

Service name **Home Care**

Contact
Address **Voluntary Services Co-ordinator**
Dorothy House Foundation, Winsley,
Bradford on Avon, Wiltshire, BA15 2LE *Tel:* 01225 722988

Befriends patients and families in the home and provides support and practical help in and out of the home. Established in 1976, the service works alongside 12 Macmillan nurses. Some of the home care services are linked to in-patient care and day-care. In 1995, 35 volunteers visited patients and carers at home. The voluntary services co-ordinator is also responsible for overseeing volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement sometimes offered
Sitting service during the day, weekend and evening
Personal care including help with feeding and toilet
Practical care including shopping, gardening, driving and escorting
Physiotherapy from qualified physiotherapists

Caring for C / A / MND
Area Bath Health District – urban and rural mix

AVON

Service name **Home Support Befriending Service**

Contact
Address **Voluntary Services Manager**
St Peter's Hospice, St Agnes Avenue, Knowle,
Bristol, Avon, BS4 2DU *Tel:* 0117 977 4605

Sitting service for patients and to give benefit to carers. Established in 1993, the service works with the St Peter's Home Care Service, which is linked to in-patient and to day-care. In 1995, 21 volunteers visited patients and carers at home. The voluntary services manager also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day
Personal care including help with feeding, toilet, washing, manicure and hair dressing
Practical help including shopping, gardening, ironing, light maintenance jobs, driving and escorting

Caring for C
Area Bristol / Avon – urban and rural mix, *approx.* 500 sq. miles

AVON

Service name **Home Care Volunteers**

Contact **Volunteer Co-ordinator**
Address Weston Hospicecare, Branton House, 21 Montpelier,
Weston Super Mare, Avon, BS23 2RJ *Tel:* 01934 625926

The service was established in 1991 and works alongside Weston Hospicecare home services which are linked to day-care. In 1995, volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day
Practical help including shopping, gardening, ironing, washing clothes, cooking, driving and escorting

Caring for C
Area Weston-super-Mare – urban and rural mix, *approx.* 100 sq. miles,
Population 80,000

BEDFORDSHIRE

Service name **Hospice at Home Volunteers, Leighton & Linslade Branch**

Contact **Volunteers Organiser**
Address Hospice at Home Volunteers, Leighton & Linslade Branch, c/o Crombie House,
36, Hockliffe St, Leighton Buzzard, Bedfordshire, LU7 9BL *Tel:* 01525 854713

An independent voluntary organisation with volunteers who will visit to listen and support but no nursing skills are offered. The Leighton and Linslade section is one local branch of Hospice at Home. Established in 1993 the independent charity works closely with Luton and South Bedfordshire Hospice Link Team, Macmillan nurses and Marie Curie. Some of the home care services are linked to in-patient beds and to day-care. In 1995, six volunteers from this branch visited patients and carers at home.

Volunteers Offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding, toilet and washing
Practical help including help with shopping, ironing, escorting and walking dog

Caring for C / A / MND
Area Leighton Buzzard, Linslade & surrounding villages – urban and rural mix
Population: 35,000

BERKSHIRE

Service name **Newbury and District Cancer Care Trust**

Contact Address
Trust Co-ordinator
The Newbury and District Cancer Care Trust, The Charles Clore Macmillan Day Unit, 214 Newtown Road, Newbury, Berkshire, RG14 7ED *Tel:* 01635 31542

Offers volunteers to visit as supportive friends. Established in 1986, the service is provided by an independent local charity which is based at the Charles Clore Macmillan Day Unit. The charity works to provide support and material help to cancer patients and their families within the Newbury area and supplies volunteers to the Day Unit and to the Sitting Service. The use of the sitting service has declined in the past three years and now most of the volunteers act as drivers taking patients to and from hospital.
In 1995, four volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day and very rarely at weekends
Practical help including help with shopping, ironing, cooking, driving and escorting

Caring for
C
Area
Newbury District Council – urban and rural mix, *approx.* 15–20 mile radius around Newbury

BUCKINGHAMSHIRE

Service name **Home Sitters**

Contact Address
Voluntary Services Manager
Florence Nightingale House, Stoke Mandeville Hospital, Mandeville Road, Aylesbury, Buckinghamshire, HP21 8AL *Tel:* 01296 394710

Established in 1990, the service works alongside Macmillan nurses and in 1995 20 volunteers visited patients and carers at home. The home care services are linked to in-patient care and to day-care. The voluntary service manager also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend, evening and night sitting
Personal care including help with feeding, toilet, washing, manicure, hair dressing and reflexology and aromatherapy
Practical help with shopping, gardening, ironing, maintenance jobs, washing clothes, cooking, driving, escorting and caring for young children
Nursing given by qualified nurses (but not including administering drugs or dressings)
Counselling given by volunteers trained in counselling skills

Caring for
C / A / MND
Area
Anglia and Oxford – urban and rural mix

CLEVELAND

Service name ***Sitting service***

Contact **Macmillan Nurse**
Address Hartlepool & District Hospice, Alice House, 13 Hutton Avenue,
Hartlepool, Cleveland, TS26 9PW *Tel:* 01429 221503

A sitter will visit to allow family carers time off for business or recreation. The service, which offers company and respite care was established in 1996 and in that time ten volunteers have visited patients and carers at home. It is run by a Macmillan nurse and works alongside Hartlepool Hospice's Home Care Team which is linked to in-patient care and to day-care.

Volunteers offer Companionship, listening and talking
Sitting service during weekdays and evenings

Caring for C
Area Hartlepool – mainly urban, *approx.* 16 sq. miles
Population 95,000

CLEVELAND

Service name ***Sitting service***

Contact **Volunteer Co-ordinator / Nursing Secretary**
Address Teesside Hospice Care Foundation, 1 Northgate Road, Linthorpe,
Middlesbrough, Cleveland, TS5 5NW *Tel:* 01642 816777

Volunteer sitters will go to a patient's home as a befriender to the patient and carer. Established in 1981, the service works alongside seven Macmillan nurses. Some of the home care services are linked to in-patient care and day-care. In 1995, 19 volunteers visited patients and carers at home. A separate bereavement service is offered. The volunteer co-ordinator also oversees volunteers who work in house.

Volunteers offer Companionship, talking and listening
Befriending for carers that continues into bereavement
Sitting service during the day, weekend, evening and night sitting
Personal care including help with feeding, toilet and hairdressing
Practical help including help with shopping, gardening, driving and escorting
Counselling from volunteers trained in counselling skills

Caring for C / MND / MS
Area North and South Tees Health Authority (except Hartlepool) and part of North Yorkshire.
approx. 600 sq. miles – urban and rural mix
Population 476,775

CLEVELAND

Service name **Sitting service**

Contact
Address
Volunteer Co-ordinator & Day-care Sister
Butterwick Hospice, 96 Bishopton Road,
Stockton on Tees, Cleveland, TS18 4PA *Tel:* 01642 607742

Volunteers are able to sit with a patient while the carer goes out or takes a rest, and will undertake non-nursing duties and escort people out. They are always able to contact the hospice if necessary. Established in 1994, the service is run jointly by the Day-care Sister, who co-ordinates the volunteers on a daily basis and the Volunteer Co-ordinator. The service works with the North Tees Macmillan nursing service. In 1995 eight volunteers visited patients and carers at home. The Day-care Sister and Volunteer Co-ordinator also oversee volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding and toilet
Practical help including help with shopping, ironing, washing clothes and escorting

Caring for C / A / MND
Area North Tees – urban and rural mix
Population 250,000

DERBYSHIRE

Service name **Home Care Support Service**

Contact
Address
Senior Nurse Manager
Ashgate Hospice, Ashgate Road, Old Brampton,
Chesterfield, Derbyshire, S42 7JE *Tel:* 01246 568801

Established in 1994, the service works with the North Derbyshire Macmillan Team and the Ashgate Hospice Home Care Team. Some of these services are linked to in-patient care and to day-care. The three volunteers who visited patients and carers at home during 1995 work as part of the Home Care Team under the Senior Nurse Manager.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Personal care including help with feeding, toilet and washing
Practical help including help with shopping, ironing, cooking and escorting

Caring for C / A / MND / OTI
Area North Derbyshire – mainly rural
Population 400,000

DERBYSHIRE

Service name **High Peak Hospicecare Home Support Scheme**

Contact **Day-care Leader / Home Support Co-ordinator**
Address High Peak Hospice Care, 137 Manchester Road,
Chapel-en-le-Frith, Derbyshire, SK12 6TN *Tel:* 01298 815388

Specially trained volunteers who have experience of helping people with cancer will visit people at home and help by taking over tasks for the carer, or simply chat, keep company or just be there. Established in 1992 the small service is run by the nursing day-care leader who started the scheme and who because of its size is able to assess the home situation, place volunteers and monitor what happens. Administrative help is to be provided to give extra support. The service works in close association with Ashgate Hospice (Chesterfield) and five Macmillan nurses. In 1995 eight volunteers visited patients and carers at home. The day-care leader also oversees volunteers in the day-care centre. A separate volunteer co-ordinator oversees a different group of volunteers who work in the hospice.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day and occasionally weekends and evenings
Personal care including help with feeding
Practical help including help with shopping, ironing, cooking, driving, escorting and caring for young children
Nursing given by trained volunteers who help with giving medication/fluids and assisting to toilet

Caring for C / MND / MS
Area The High Peak (North Derbyshire) – mainly rural, *approx.* 400 sq. miles
Population 86,000

DERBYSHIRE

Service name **N.M.C.C.U. Home Sitting Service**

Contact **Voluntary Services Manager**
Address Nightingale Macmillan Continuing Care Unit, 117a London Road,
Derby, Derbyshire, DE1 2QS *Tel:* 01332 254905

Enables carers to have time away from home whilst being reassured that their relative will have company and support. Established in 1993 the service used 12 volunteers to visit patients and carers at home in 1995. The voluntary service manager also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend and evening

Caring for C
Area South Derbyshire – urban and rural mix

DEVON

Service name **North Devon Hospice Care Trust**

Contact
Address
Volunteers' Liaison Officer
North Devon Hospice Care Trust, Deer Park, Deer Park Road, Rumsam,
Barnstaple, Devon, EX32 OHU *Tel:* 01271 44248

To sit with patients and be available for identified tasks. Established in 1985 the service works alongside six hospice home care nurses and two hospice day-care nurses. Some of the home care services have access to day-care. In 1995 nine volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend and evening
Practical help including help with shopping, driving and escorting

Caring for C
Area North Devon – urban and rural mix. *approx.* 850 sq. miles
Population 140,000

DEVON

Service name **Hospiscare Home Care Helpers**

Contact
Address
Voluntary Service Co-ordinator
Hospiscare, Exeter and District Hospice, Dryden Road,
Exeter, Devon, EX2 5JJ *Tel:* 01392 402555

Trained helpers who are used to visiting, visit people in their homes and will do what a caring friend would do. Established in 1982 the service covers a wide area and works with eight home care teams based at Exeter, Budleigh Salterton, Axminster, Exmouth, Honiton, Okehampton, Ottery St Mary and Sidmouth. All these services have access to in-patient care and to day-care. In 1995, 35 volunteers visited patients and carers at home. Exeter Hospiscare started as a palliative care nursing service along Macmillan lines in an urban area and this remains the bulk of the workload. As the service was extended to rural areas, volunteer groups were established in each locality to work with the local nurses. The service co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend, evening and occasionally night sitting
Personal care including help with feeding and toilet and massage
Practical help including help with shopping, gardening, ironing, washing clothes, cooking, maintenance jobs, driving, escorting and running errands
Nursing given by qualified nurses and trained volunteers equivalent to what a relative or carer would do
Counselling given by qualified counsellors

Caring for C / A / MND / OTI
Area Exeter and District – urban and rural mix, *approx.* 1500 sq. miles
Population 318,000

DEVON

Service name **Befriending**

Contact
Address **Voluntary Services Co-ordinator**
St Luke's Hospice – Plymouth, Stamford Road, Turnchapel,
Plymouth, Devon, PL9 9XA *Tel:* 01752 401172

Established over two years ago, the service works closely with the Hospice Social Work department and Macmillan nurses in the community. In 1995 *approx.* 13 volunteers visited patients and carers at home. The voluntary services co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding
Practical help including help with shopping, ironing and escorting
Counselling given by qualified counsellors and trained volunteers

Caring for C / A / MND
Area Plymouth & District including South East Cornwall, Tavistock and South Hams – urban and rural mix

DORSET

Service name **West Dorset Macmillan Service**

Contact
Address **Volunteer Co-ordinator**
West Dorset Macmillan Service, The Undercroft, (Joseph Weld House),
Herringston Road, Dorchester, Dorset, DT1 2SJ *Tel:* 01305 269898

Volunteer helpers are willing to be called in to help with personal, social and practical needs as they arise. Established in 1986, the service works with Macmillan nurses and *approx.* 120–150 volunteers undertook to make home visits in 1995. Home care services are linked to day-care and some to in-patient care. As well as the services listed below, volunteers help with the running of social groups which have outings, speakers and other activities. The volunteer co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding and hairdressing
Practical help including help with shopping, gardening, ironing, washing clothes, cooking, driving, escorting and caring for young children

Caring for C / A / MND / MS / OTI
Area North and West Dorset – urban and rural mix, *approx.* 670 sq. miles
Population 203,000

DURHAM

Service name **South Durham Hospice Voluntary Sitting Service**

Contact
Address
Volunteer & Sitting Service Co-ordinator
South Durham Hospice, Macmillan House, Woodhouse Lane,
Bishop Auckland, Durham, DL14 6JU *Tel:* 01388 603003

Offers support usually of two to three hours to allow carer time off or company for a patient if they live alone, with longer sessions available if needed. Established five years ago, the service works alongside day-care and with the Macmillan service at Coundon. The hospice is setting up a palliative home care team which will offer 'hands-on' care and it is anticipated there will be a demand for more volunteers once this is established. In 1995, 14 volunteers visited patients and carers at home. The volunteer service co-ordinator also oversees volunteers working in the day centre.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding and toilet
Practical help including help with shopping, cooking (light meal), driving and escorting
Physiotherapy given by qualified physiotherapists

Caring for C / MND
Area South Durham – urban and rural mix, *approx.* 800 sq. miles
Population 150,000

DURHAM

Service name **Sitting Service**

Contact
Address
Home Care Sister
St Teresa's Hospice, Harewood House, 14 Harewood Hill,
Darlington, Durham, DL3 7HY *Tel:* 01325 380634

A presence and support in the home which can be practical. Established in 1987 the service works alongside Macmillan nurses and in close co-operation with Marie Curie and district nurses. Home care services are linked to day-care. In 1995, 34 volunteers visited patients and carers at home. The sitting service was recently changed to a nurse-led service to review developments for the future and a one-year pilot scheme offering respite care with paid staff using nurses and auxiliaries was completed in March 1996.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend, evening and night sitting
Personal care including help with feeding, toilet, hairdressing, reflexology and aromatherapy
Practical help including help with shopping, gardening, ironing, cooking, driving and escorting

Caring for C / A / MND / OTI
Area Darlington and District – urban and rural mix, *approx.* 40 – 50 sq. miles,
Population 200,000

DURHAM

Service name ***Sitting Service***

Contact **Administrator / Volunteer Co-ordinator**
Address St Cuthbert's Hospice, Park House Road, Merryoaks,
Durham, DH1 3QF *Tel:* 0191 386 1170

An informal sitting service mainly to allow the main carer to go to work, keep appointments or have a break. The service works with the Palliative Care and Cancer Support Team and in 1995, 20 volunteers visited patients and carers at home. The volunteer co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding, toilet
Practical help including help with driving
Counselling given by volunteers trained in counselling skills

Caring for C / A / MND / MS
Area urban and rural mix, *approx.* 942 sq. miles
Population 221,000

ESSEX

Service name ***Sitting Service***

Contact **Volunteer Co-ordinator**
Address St Luke's Hospice, Fobbing Farm, Nethermayne,
Basildon, Essex, SS16 5NJ *Tel:* 01268 524973

Established in 1987, the service is managed on a daily basis by a sitting service co-ordinator who works closely with the visiting Macmillan Nursing Service and Marie Curie nurses. In 1995, 23 volunteers visited patients and carers at home. The volunteer co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Counselling given by trained volunteers
Physiotherapy given by qualified physiotherapists

Caring for C
Area Basildon District Council & Thurrock Council – urban and rural mix
Population 300,000

ESSEX

Service name **Farleigh Sitting Service**

Contact Address
Volunteers Co-ordinator
Farleigh (Mid Essex) Hospice, 212 New London Road,
Chelmsford, Essex, CM2 9AE *Tel:* 01245 358130

A good neighbour service to sit with a patient and allow the carer time out. Established in 1984 the service was the first support the hospice was able to offer before it was fully open. No nursing is involved but sitters are trained in moving and handling. In 1995, 39 volunteers visited patients and carers at home. Home care services are linked to in-patient care and day-care. The volunteer co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding
Practical help including help with shopping, driving and escorting
Counselling given by volunteers trained in counselling skills and who belong to the Family Support Bereavement Group

Caring for C / MND
Area Mid Essex – urban and rural mix

ESSEX

Service name **Family Support Services**

Contact Address
Voluntary Services Manager & Family Support Manager
St Clare Hospice Centre, West Essex Care Trust, Stone Barton, Hastingwood Road,
Hastingwood, Essex, CM17 9JX *Tel:* 01279 413590

Offers befrienders and good neighbours. Established in 1991, the service works closely with two Community Macmillan nurses from Princess Alexandra Hospital, Harlow. It is run jointly by the Family Support Manager and the Voluntary Services Manager which allows for extra direction to be given to home care volunteers. In 1995, 50 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Practical help including help with shopping, driving, escorting and giving company
Counselling given by qualified counsellors and trained volunteers.

Caring for C / A / MND / MS
Area West Essex – urban and rural mix

ESSEX

Service name **Sitting Service**

Contact
Address **Home Care Co-ordinator**
St Clare's Day Hospice, Bentalls Complex, Colchester Road, Heybridge, Maldon, Essex, CM9 7NW *Tel:* 01621 857727

A good neighbour service for patients and carers. Established in 1984, the Home Care Co-ordinator herself works voluntarily under the Macmillan nurse and Day-care Sister of St Clare's and in close co-operation with the Volunteer Service from Farleigh Hospice. Farleigh Hospice provides in-patient care for this area.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding and toilet
Practical help including help with shopping, ironing, driving, escorting and caring for young children

Caring for C
Area Dengie and Maldon, Essex – urban and rural mix, *approx.* 100 sq. miles
Population 70,200

ESSEX

Service name **Family Support, 'Befriending'**

Contact
Address **Administrator**
St Francis Hospice Family Support Group – Havering Branch, c/o The Hall, Broxhill Road, Havering-atte-Bower, Romford, Essex, RM4 1QH *Tel:* 01708 756223

Practical help with friendship is offered in and outside of the home to families caring for a relative with cancer. Established in 1982 the service is one of three local Family Support Groups, each part of St Francis Hospice and its services but each independently run with its own management committee. It works closely with the Palliative Home Care services of St Francis Hospice some of which are linked to in-patient care and to day-care. The Family Support Group raises funds and trains volunteers and can look to St Francis Hospice for support and assistance. In 1995 around 57 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Befriending, for carers that continues into bereavement sometimes given
Sitting service during the day, weekend and evening
Personal care including help with feeding and toilet
Practical help including help with shopping, cooking, occasional maintenance jobs, driving, escorting, caring for young children, reading and walking dog

Caring for C
Area London Borough of Havering – mainly rural
Population 250,000

ESSEX

Service name **Family Support Befrienders – practical help and support**

Contact
Address **Chairman**
St Francis Hospice Family Support Group – Brentwood Branch, c/o The Hall, Broxhill Road, Havering-atte-Bower, Romford, Essex, RM4 1QH *Tel:* 01277 823388

Volunteers offer a free service, sitting with patients or undertaking light tasks including shopping, child minding and driving. Established in 1983 the service is one of the Family Support Groups that comes under the umbrella of St Francis Hospice but is run independently with its own management committee. It raises funds and trains volunteers and can call on the assistance of the hospice if it needs to do so. The Family Support Group works with the Hospice Palliative Home Care Team and with Macmillan nurses. Some of the home care services are linked to in-patient care and to day-care. In 1995, 18 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding, toilet, washing and manicure
Practical help including help with shopping, cooking, driving, escorting and caring for young children

Caring for C / MND
Area Brentwood – mainly rural, *approx.* 5 mile radius from centre

GLOUCESTERSHIRE

Service name **Home Care Support Service**

Contact:
Address **Day-Care Leader**
Sue Ryder Day Centre, Leckhampton Court, Church Road, Leckhampton, Cheltenham, Gloucestershire, GL51 5XX *Tel:* 01242 230199

An extension of day-care provision, so that when a patient cannot attend, a trained volunteer might visit to help ensure their comfort and safety. Established in 1995, the service is new and run by the day-care leader. During the last five months of 1995, 15 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Personal care including help with feeding and toilet
Practical help including help with shopping, cooking, driving and escorting
Counselling given by trained volunteers

Caring for C / A / MND / OTI
Area Cheltenham – urban and rural mix
Population 450,000

GLOUCESTERSHIRE

Service name **Macmillan Volunteers**

Contact **Administrator**
Address Macmillan Cancer Information Centre, Rheola House, Belle Vue Centre, Cinderford, Gloucestershire, GL14 2AB *Tel:* 01594 826368

A Macmillan nurse identifies the needs of a patient or carer and explains what a volunteer can do to help. The service is new, having started in the summer of 1995. At the moment it is available only to patients who are being visited by one of the two Macmillan nurses who work with GPs, district nurses and social services. In 1995 four volunteers visited patients and carers at home.

Volunteers offer Companionship, listening and talking
Sitting service during the day
Practical help including help with shopping, gardening, ironing, maintenance jobs, driving and escorting

Caring for C
Area Forest of Dean, Gloucestershire – urban and rural mix, *approx.* 200 sq. miles
Population 85,000

GLOUCESTERSHIRE

Service name **Cotswold Care at Home**

Contact **Home Care Sister**
Address Cotswold Care Hospice, Burleigh Lane, Burleigh, Minchinhampton, Gloucestershire, GL5 2PQ *Tel:* 01453 886868

Complementary practical help and psychological support which enables carers to take a few hours break is offered to patients and family in the community as an extension of the love and care offered to guests attending the Hospice. The service was established in 1994 when it gave the kind of support that was given in the day hospice to those patients at home who were unable to attend. This care and support is now extended to families whose relatives do not attend Cotswold Care Hospice. From June to December 1995, 27 volunteers visited 61 patients and carers at home. The service is run by the home care sister. Another co-ordinator oversees a different group of volunteers who work in the day hospice.

Volunteers offer Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Practical help including help with shopping, gardening, ironing, washing clothes, snacks, driving, escorting and light household duties

Caring for C / MND
Area South Gloucestershire – urban and rural mix, *approx.* 175 sq. miles
Population 106,500

HAMPSHIRE

Service name **S.H.A.R.E. *(Support, Help And Relief Extended)***

Contact Address
Community Volunteer Co-ordinator
S.H.A.R.E., working with St Michael's Hospice, Basil de Ferranti House, Aldermaston Road, Basingstoke, RG24 9NB *Tel:* 01256 840357

A team of volunteers offer help and support to patients and their families that a caring relative might give during illness and sometimes into bereavement. Established in 1987, this independent charity works alongside the community nursing service and in close liaison with district nurses in an area where the primary care teams are responsible for terminally ill patients at home. SHARE offers a volunteer service to patients in the community whether or not they are patients of St Michael's Hospice which opened several years after the community services had been in operation. There are close links with the hospice and community volunteers work for SHARE in St Michael's Hospice for six months prior to being offered training for work in the community. In 1995 20 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day and very occasional weekend and evening sitting
Personal care including help with feeding and toilet
Practical help including help with shopping, gardening, ironing, cooking (light meals) escorting and caring for young children

Caring for C / MND / OTI
Area Basingstoke and North Hampshire – urban and rural mix, *approx.* 245 sq. miles
Population 145,000

HAMPSHIRE

Service name ***Befrienders***

Contact Address
Voluntary Services Co-ordinator
Countess Mountbatten House, Moorgreen Hospital, Botley Road, West End, Southampton, Hampshire, SO30 3JB *Tel:* 01703 477414

The service works alongside the Countess Mountbatten House Clinical Nurse Specialist and in 1995 eight volunteers visited around 25 patients and carers at home. These form a small part of a larger voluntary service department for which the same co-ordinator is responsible. The home care services are linked to in-patient care and day-care.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day
Practical help including help with driving, escorting, excursions, form filling
Counselling given by qualified counsellors and volunteers trained in counselling skills

Caring for C
Area Southampton, Portsmouth, Winchester – urban and rural mix, *approx.* 300 sq. miles
Population 1,000,000

HAMPSHIRE

Service name **Home Care Volunteers**

Contact
Address
Voluntary Support Co-ordinator
The Rowans, Portsmouth Area Hospice, Purbrook Heath Road, Purbrook, Waterlooville, Hampshire, PO7 5RU *Tel:* 01705 250001

When there is an evident need the home care sister or hospice doctor or nurse may offer volunteer support to the patient and carer. Established late in 1994, this new service works closely with the Portsmouth Healthcare NHS Trust Palliative Care Team. Home care services are linked to in-patient care and to day-care. The home care sister was appointed in June 1995 and as more home care personnel are appointed it is anticipated the call upon volunteer services will grow. Volunteers are currently being trained in counselling and to offer a befriending service for carers that continues into bereavement. In 1995 three volunteers visited patients and carers at home. The voluntary support co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Sitting service during the day and evening
Practical help including help with shopping, driving and escorting

Caring for C / A / MND / MS / OTI
Area Portsmouth and South East Hampshire Health District – urban and rural mix
Population 500,000

HEREFORDSHIRE & WORCESTERSHIRE

Service name **Home Care**

Contact
Address
Volunteer Services Co-ordinator
St Richard's Hospice, Rose Hill,
Worcester, WR5 1EY *Tel:* 01905 763963

Volunteers can help by sitting with patients or in another room and give assistance with making drinks and snacks, or helping in and out of bed or to the toilet. Established in 1984 the volunteer home care service works alongside St Richard's home care service which is linked to in-patient care and day-care and with the Macmillan Unit at Evesham. The volunteer services co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending that continues into bereavement
Sitting service during the day, occasionally weekend, evening and night sitting
Personal care including help with feeding, toilet, manicure, chiropody, hair dressing and aromatherapy
Practical help including help with driving, escorting and caring for young children, occasional help with shopping, gardening, ironing and cooking
Nursing given by qualified nurses
Counselling given by volunteers trained in counselling skills
Physiotherapy given by qualified physiotherapists

Caring for C / MND / MS
Area South Worcestershire – as covered by Worcester District Health Authority -urban & rural mix
Population *approx.* 250,000

HERTFORDSHIRE

Service name **Home Visiting Service**

Contact
Address
Voluntary Helpers Organiser
The Hospice of St Francis, 27 Shrublands Road,
Berkhamsted, Hertfordshire, HP4 3HX *Tel:* 01442 862960

Company and practical help for patients and relief for carers. Established in 1994 the service works with the Hospice of St Francis's own home care team. The home care services are linked to day-care. In 1995 six volunteers visited patients and carers at home. The voluntary helpers organiser also oversees volunteers who work in house. A separate group of home visitors offers a befriending service for carers that continues into bereavement.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Personal care including help with feeding, toilet, manicure and reflexology
Practical help including help with shopping and escorting

Caring for C /A / MND / MS
Area *approx.* within 5 mile radius of hospice – urban and rural mix

HERTFORDSHIRE

Service name **Home Sitting**

Contact
Address
Voluntary Services Co-ordinator / Housekeeper
The Peace Hospice, Cassiobury Drive, Watford,
Hertfordshire, WD1 3AD *Tel:* 01923 211816

A visiting volunteer can give help and respite to a carer and comfort to the patient. Established early in 1995 the service works with three Macmillan nurses, and four volunteers visited patients and carers at home during the year. Home care services are linked to day-care.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Personal care including occasional aromatherapy
Practical help including help escorting

Caring for C / A / MND / OTI
Area South West Hertfordshire – urban and rural mix

HUMBERSIDE

Service name **Volunteer Sitters**

Contact **Volunteer Staff Co-ordinator**
Address Dove House Hospice, Chamberlain Road,
Hull, Humberside, HU8 8DH *Tel:* 01482 784343

Established in 1984 the service offers help to patients and carers who are referred by one of the six Macmillan nurses of the Dove House Community Team. Home care services are linked to in-patient care and to day-care.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including aromatherapy
Practical help including help with shopping, ironing, washing clothes, cooking, driving, escorting and caring for young children
Nursing given by qualified nurses
Physiotherapy given by qualified physiotherapists

Caring for C / A / MND / MS / OTI
Area North Humberside – urban and rural mix

ISLE OF WIGHT

Service name **Earl Mountbatten Hospice Home Volunteers**

Contact **Voluntary Services Manager**
Address Earl Mountbatten Hospice, Halberry Lane,
Newport, Isle of Wight, PO30 2ER *Tel:* 01983 522106

The service was established in 1992. Volunteers are an integrated part of the hospice service of care for patients and families, working closely with visiting home care personnel. Home care services are linked to in-patient care and to day-care.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend and evening
Personal care including help with manicure, hairdressing and aromatherapy
Practical help including help with shopping, driving and escorting
Physiotherapy given by trained volunteers

Caring for C / A / MND / MS
Area Isle of Wight – mainly rural
Population 120,000

KENT

Service name **Sitting Service**

Contact Address
Sitting Service Co-ordinator
Pilgrims Hospices in Canterbury & Thanet, 56 London Road,
Canterbury, Kent, CT2 8JY *Tel:* 01843 230277

Day sitting with patients while carers can go out and have a break or take a rest. The service was established in 1981 before the hospice opened and now works alongside 14 home care nurses. Home care services are linked to in-patient care and to day-care. In 1995, 20 volunteers visited patients and carers at home while another group of hospice volunteers assisted patients with driving and escorting them to places. The sitting service co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement sometimes given
Sitting service during day and night sitting

Caring for
C

Area
Canterbury and Thanet Health Authority & South Kent – urban and rural mix

KENT

Service name **Volunteer Community Service**

Contact Address
Volunteer Service Co-ordinator
The Heart of Kent Hospice, Preston Hall, Aylesford,
Maidstone, Kent, ME20 7NJ *Tel:* 01622 792200

To provide respite help for carers of people who are very ill and at home and companionship for those living alone. Support and help are offered to carer and patient with the focus on quality of life. Established in 1991 the service works alongside Macmillan nurses and GPs and district nurses. Home care services are linked to in-patient care and to day-care. The volunteer service co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend, evening and night sitting
Personal care including help with toilet and hairdressing
Practical help including help with shopping, ironing, driving, escorting
Counselling given by volunteers trained in counselling skills

Caring for
C / A / MND

Area
Maidstone and surrounding area – urban and rural mix

KENT

Service name **Respite Care**

Contact **Respite Care Co-ordinator**
Address Ellenor Foundation, Conifers, 347 Singlewell Road,
Gravesend, Kent, DA11 7RL *Tel:* 01474 365828

Aims to provide a complementary care service for patients living alone and to enable carers to have a break or a rest so that patients can remain at home as long as possible and to die at home if that is their wish.
The Ellenor Foundation Respite Care at Home Service is a Christian team which began in 1990 and has cared for over 700 patients and their families. The service consists of both nurses and volunteers working jointly under the banner of Respite Care at Home. The volunteer service caring for patients was set up in 1985 and amalgamated with the Respite Care Service in 1994. It now consists of 12 qualified, paid nurses and 30 trained volunteers.
The information given relates to professionals and volunteers working together. Respite Care works with Ellenor Home Care and Marie Curie (night service). There is a separate bereavement care team. In 1995 two hundred and 50 patients and their families were being cared for in their own homes.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend, evening and occasional night sitting
Personal care including help with feeding, toilet, washing, manicure, hair dressing, touch massage and clinical nursing care
Practical help including help with shopping, gardening, ironing, washing clothes, cooking, driving escorting and caring for young children
Nursing given by qualified nurses and trained volunteers including care of terminally ill children
Counselling given by trained volunteers
Physiotherapy given by trained volunteers

Caring for C / MND
Area Dartford and Gravesham area – urban and rural mix , *approx.* 40 sq. miles

KENT

Service name **Sitting Service**

Contact **Volunteer Co-ordinator**
Address South Bromley Hospiscare, Orpington Hospital, Sevenoaks Road,
Orpington, Kent, BR6 9JU *Tel:* 01689 605300

Established in 1983 the service works with South Bromley Hospiscare. Home care services are linked to day-care and in 1995, 19 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day and occasional weekend and night sitting
Personal care including help with toilet and washing
Practical help including help with shopping, gardening, ironing, washing clothes, cooking, maintenance jobs, driving and escorting

Caring for C / A / MND / OTI
Area South Bromley – urban and rural mix

KENT

Service name **Volunteers from the Macmillan Team**

Contact
Address
Voluntary Services Co-ordinator
Macmillan Palliative Care Team, Queen Mary's Hospital,
Sidcup, Kent, DA14 6LT *Tel:* 0181 308 3014

Offers any help which is needed except personal care and nursing. The service was established in 1993 and works alongside Bexley Palliative Care Team. In 1995, 35 volunteers visited patients and carers at home. Some of the home care services are linked to in-patient care and to day-care.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with manicure, hairdressing (small fee) and aromatherapy
Practical help including help with shopping, gardening, driving, escorting and caring for young children
Counselling given by volunteers trained in counselling skills

Caring for C
Area London Borough of Bexley – mainly urban

KENT

Service name **Home Care Volunteer Service**

Contact
Address
Volunteer Co-ordinator
Hospice in the Weald, Allen Gardiner House, Pembury Road,
Tunbridge Wells, Kent, TN2 3QU *Tel:* 01892 544877

Offers support and help to patients and families in those areas not covered by other members of Hospice in the Weald. This involves companionship and relief to carers for short spells including help with light tasks in and out of the home. Established in 1989 the service works with Hospice in the Weald as part of the hospice team and in 1995, 20 volunteers visited patients and carers at home. The home care services are linked to day-care. The service co-ordinator also oversees volunteers who work in house; a separate bereavement service is run by another person.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Personal care including help with feeding and toilet
Practical help including help with shopping, gardening, ironing, cooking, driving, escorting, caring for young children and going on outings
Counselling given by volunteers trained in counselling skills

Caring for C / A / MND / OTI
Area West Kent and East Sussex – urban and rural mix, *approx.* 400 sq. miles
Population 270,000

LANCASHIRE

Service name **Home Care Sitters**

Contact
Address **Voluntary Services Co-ordinator**
East Lancashire Hospice, Park Lee Road,
Blackburn, Lancashire, BB3 2NY *Tel:* 01254 54064

To support the patient and the family/carer in their own home by helping them to be as self sufficient as possible so that the patient is able to carry on their normal family life. The sitter provides an extra support service under the guidance of professional staff. The service was established around 1992 and works with three Community Macmillan nurses and one Hospice Macmillan nurse. In 1995, 11 volunteers visited patients and carers at home. Some of the home care services are linked to in-patient care and to day-care. The voluntary services co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day and evening and very occasionally at weekend
Personal care including help with feeding and toilet
Practical help including help with escorting and caring for children

Caring for C
Area Blackburn, Hyndburn & Ribble Valley Health Authority – urban and rural mix
Population 266,000

LANCASHIRE

Service name **Hospice Home Care**

Contact
Address **Sister-in-Charge**
Rossendale Hospice, Rossendale General Hospital,
Rawtenstall, Lancashire, 0L11 4DE *Tel:* 01706 233230

The service was established in 1989 with Rossendale Hospice Home Care. Day-care was established in the following year. An in-patient facility was to be set up in 1996. Home care volunteers include qualified nursing staff and night sits are available. In 1995, 23 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend, evening and night sitting
Practical help including help with shopping, driving and escorting

Caring for C
Area Rossendale Borough – urban and rural mix, *approx.* 53 sq. miles
Population 65,000

LEICESTERSHIRE

Service name **Sitting Service**

Contact **Volunteer Sitting Service Co-ordinator**
Address LOROS Leicestershire Hospice, Groby Road,
Leicester, Leicestershire, LE3 9QE *Tel:* 0116 231 3771

Volunteers can sit with patients to give them company or to relieve carers. They can help with the toilet and light tasks but do not give nursing care. Established in 1992, the service works alongside the Home Care Sisters from the Leicestershire Hospice. Home care services are linked to in-patient care and to day-care. In 1995 23 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Personal care including help with feeding and toilet
Practical help including help with cooking light meals and occasional escorting

Caring for C / A / MND
Area Leicestershire – urban and rural mix
Population 866,000

LINCOLNSHIRE

Service name **Gifts Day Hospice Services**

Contact **Volunteer Organiser/Administrator**
Address GIFTS Day Hospice, 70 Barrowbygate, Grantham,
Lincolnshire, NG31 7LT *Tel:* 01476 591010

A flexible service available for when patients and carers want to ask for assistance. Established in 1992, the service consults with three Macmillan nurses based at the local hospital. Home care services are linked to in-patient care and to day-care. The volunteer service organiser oversees 60 volunteers who work in house and in 1995 a number of these volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with manicure and hairdressing
Practical help including help with shopping, escorting and conveying loaned equipment
Counselling given by qualified counsellors and trained volunteers

Caring for C/ A / MND / OTI
Area Grantham and District – urban and rural mix, *approx.* 15 sq. miles
Population 40,000

LINCOLNSHIRE

Service name **Home Support**

Contact
Address **Home Support Team Co-ordinator**
St Barnabas Hospice Trust Home Support Team, 1 St Anne's Close,
Lincoln, Lincolnshire, LN2 5RB *Tel:* 01522 539892

Offers practical help to families and support and friendship to patients suffering from a life-threatening illness. Established in 1993 the service works with the palliative care team, Marie Curie and district nursing teams. Some home care services are linked to in-patient care and to day-care. In 1995, 35 volunteers visited patients and carers at home. A separate befriending service that continues into bereavement is offered by another group of volunteers who are overseen by another co-ordinator.

Volunteers offer
Companionship, listening and talking
Sitting service during the day and evening
Practical help including help with shopping, gardening, ironing, washing clothes, cooking and escorting

Caring for C / A / MND / OTI
Area North Lincolnshire – urban and rural mix

LONDON

Service name **ACET London Home Care**

Contact
Address **Volunteer Trainer Co-ordinator**
ACET, (Aids Care, Education & Training), London Home Care, PO Box 3693,
London, SW15 2BQ *Tel:* 0181 780 0455

Practical home care to men and women who are unwell with HIV/Aids. ACET is a national and international Christian AIDS charity. Established in 1988, volunteers for ACET work with home care services across the London region, some of which are linked to in-patient care and to day-care. Staff and volunteers are drawn from churches of all denominations and in 1995, 120 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend, evening and night sitting
Personal care including help with feeding, toilet and washing
Practical help including help with shopping, gardening, ironing, washing clothes, cooking, driving and escorting

Caring for A
Area London – mainly urban, *approx.* within the M25

LONDON

Service name **Greenwich Support Team**

Contact Address
Voluntary Services Co-ordinator
Greenwich Support Team, Shooters Hill, Memorial Hospital, Woolwich, London, SE18 3RZ
Tel: 0181 856 5511 ext. 4200

To give help that is not given by the statutory and social services. Established in 1989 the service is an integrated part of the Greenwich Support Palliative Care Team and in 1995, 25 volunteers visited patients and carers at home. Some of the home care services are linked to in-patient care and to day-care.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend and evening
Personal care including help with hairdressing
Practical help including help with shopping, gardening, cooking maintenance jobs, driving and escorting

Caring for C / A / OTI
Area London Borough of Greenwich – mainly urban
Population 214,836

LONDON

Service name **Home Care Volunteers**

Contact Address
Volunteer Co-ordinator
St John's Hospice, Hospital of St John & St Elizabeth, 60 Grove End Road, St John's Wood, London, NW8 9NH
Tel: 0171 286 5126 ext. 450

Volunteers who already work in the hospice would be happy to call by for a chat or to accompany people going out shopping or elsewhere. Established around 1989 the service works with the St John's Hospice Home Care Team which is linked to in-patient care and to day-care. In 1995, 23 volunteers from a large group of volunteers working in the hospice visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service not a regular service but very occasionally given
Personal care very occasionally for hairdressing, manicures or massage
Practical help including help with shopping, driving and escorting

Caring for C / A / MND / OTI
Area London Borough of Westminster and parts of Camden – mainly urban

MANCHESTER

Service name **South Manchester Call Carers**

Contact **Call Co-ordinator**
Address South Manchester CALL CARERS, Neil Cliffe Cancer Care Centre, Wythenshawe Hospital, Southmoor Road, Manchester, Greater Manchester, M23 9LT *Tel:* 0161 946 2911

Volunteers who are pleased to visit patients in their own homes can accompany them to hospital, help with tasks in and out of the home, look after children and sit with patients to give carers a break. Established in 1992, this independent charity based at the Neil Cliffe Cancer Care Centre works closely with Macmillan nurses. Home care services are linked to in-patient care and to day-care. The service is one of four Call Carers agencies which operate under a common philosophy but which are separately funded. The others are in Stockport (the first to be established), Trafford and North Manchester.
In 1995, 42 volunteers visited patients and carers at home. The call co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and night sitting
Practical help including help with shopping, gardening, ironing, washing clothes, cooking, driving, escorting and caring for young children
Counselling given by trained volunteers

Caring for C
Area South Manchester – mainly urban, *approx.* 10 miles radius
Population 150,000 – 200,000

MANCHESTER

Service name **Home Care Support**

Contact **Volunteers' Co-ordinator**
Address Wigan Hospice, Poolstock Lane, Poolstock, Wigan, Greater Manchester, WN3 5HL *Tel:* 01942 496092

Volunteers help to share the care at home by giving support when required. Established in 1981 the service works with the Hospice team of Home Care Sisters and Macmillan nurses. Home care services are linked to in-patient care and to day-care. In 1995 ten volunteers visited patients and carers at home. The volunteers' co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend, evening and night sitting
Personal care including help with feeding, toilet and washing
Practical help including help with escorting
Counselling given by volunteers trained in counselling skills

Caring for C / A / MND / OTI
Area Wigan Metropolitan Borough – urban and rural mix, *approx.* 76 sq. miles
Population 310,000

MERSEYSIDE

Service name **Home Sitting**

Contact Address
Hospice Co-ordinator
Queenscourt Hospice, Town Lane, Southport,
Merseyside, PR8 6RE *Tel:* 01704 544645

Offers respite for carers similar to a good neighbour service which does not include nursing tasks. Established in 1988 the service consults closely with two community based Macmillan Teams who also operate with a Marie Curie Nursing Service. In 1995 five volunteers visited patients and carers at home. The co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service, mainly to allow carer time off, during the day, weekend and evening
Personal care including help with feeding and toilet
Practical help including help with driving and escorting

Caring for C
Area Southport and Formby – urban and rural mix
Population 130,000

NORFOLK

Service name **Home Care Support**

Contact Address
General Manager
West Norfolk Home Hospice Support Group, Tapping House, 22a Common Road,
Snettisham, King's Lynn, Norfolk, PE31 7PE *Tel:* 01485 543163

Established in 1984 the volunteer service works as part of the Home Hospice Support Group whose primary role is to provide hospice care in the home. Home care services are linked to day-care and some are linked to in-patient care. The Hospice Sister is responsible for volunteer allocations to home visits and in 1995, 40 volunteers visited patients and carers at home. It is hoped to expand the home support in a westerly and easterly direction and proposals for a night sitting service are also being considered.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening.
Personal care including help with feeding, toilet, washing, manicure and hairdressing
Nursing given by volunteers trained in basic skills under the guidance of a registered nurse
Counselling given by trained volunteers

Caring for C / MND
Area West Norfolk – mainly rural
Population 210,000

NORTHUMBERLAND

Service name **Volunteer Care and Support**

Contact **Care Co-ordinator**
Address Tynedale Community Hospice, c/o Hexham General Hospital,
Hexham, Northumberland, NE46 1QJ *Tel:* 01434 600388

Volunteers offer practical help and company at home for those living alone and someone to sit with patients while carers go out or take a rest. Established in 1994 the service started by recruiting volunteers who would give care and support to patients and families in their homes. Later a bank of paid nurses was set up to provide nursing care. Tynedale Community Hospice works in liaison with primary health care teams, care managers and social services to provide a planned and integrated care package for patients and their families. In 1995, 21 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend and evening
Personal care including help with feeding, toilet, washing, manicure and hair dressing
Practical help including help with shopping, gardening, ironing, washing clothes, cooking, maintenance jobs, driving and escorting

Caring for C / A / MND / OTI
Area Tynedale – mainly rural, *approx.* 857 sq. miles,
Population 67,000

NOTTINGHAMSHIRE

Service name **Community Care**

Contact **Voluntary Services Manager**
Address Newark and District Hospice Aid, Beaumond House, 32 London Road,
Newark, Nottinghamshire, NG24 1TW *Tel:* 01636 610556

Volunteers offer practical help in the home and support to patients and their carers. The service was established in 1992 and works alongside a Macmillan nurse. Home care services are linked to short respite in-patient care and to day-care. In 1995, 49 volunteers visited patients and carers at home.
The voluntary services manager also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day
Personal care including help with feeding, toilet, washing, manicure, hair dressing and aromatherapy
Practical help including help with shopping, gardening, ironing, washing clothes, cooking, driving and escorting

Caring for C / MND / MS
Area Newark and District – urban and rural mix, *approx.* 15 miles radius,

NOTTINGHAMSHIRE

Service name **Volunteer Sitting Service**

Contact
Address
Senior Nurse Manager
The Nottinghamshire Hospice, Fernleigh, 384 Woodborough Road,
Nottingham, Nottinghamshire, NG3 4JF *Tel:* 0115 960 6265

Offers extra care and support to patients and carers with a respite service to give carers time off from the care they provide. Established in 1988, the service works with the Nottinghamshire Hospice Liaison Sisters, the Haywood House Macmillan Team and Hospital Macmillan Teams at the City Hospital and Queens Medical Centre. Some of the home care services are linked to in-patient care and to day-care. The volunteer service is used on a minimal *ad hoc* basis to complement hospice at home services given by qualified nursing staff and experienced auxiliaries. The volunteer service is run by the senior nurse manager who also oversees volunteers in house. In 1995 eight volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day and occasionally evening and night sitting
Personal care including help with feeding, toilet, washing and hairdressing
Practical help including occasional help with shopping and cooking
Nursing given by qualified nurses involving general nursing care, listening and supporting

Caring for C / A / MND / OTI
Area Nottingham – urban and rural mix, *approx.* 10 mile radius from city centre,
Population 550,000

NOTTINGHAMSHIRE

Service name **Haywood House Community Sitter Service**

Contact
Address
Voluntary Services Manager & Bereavement Co-ordinator
Haywood House Macmillan Unit, City Hospital, Hucknall Road,
Nottingham, Nottinghamshire, NG5 1PB *Tel:* 0115 962 7619

Home sitting service to give carers short periods of respite for activities which enhance their lives and its quality. Established in 1993 to give carers a break, the service works alongside four Macmillan nurses and has since been extended to provide companionship and listening. Home care services are linked to in-patient care and to day-care. In 1995, 14 volunteers visited patients and carers at home. The voluntary services manager oversees other volunteers who work in house. Separate driving and bereavement services are offered.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend and evening
Personal care including help with feeding and toilet

Caring for C / MND
Area Nottinghamshire – mainly urban

NOTTINGHAMSHIRE

Service name **Hospice at Home**

Contact **Care Co-ordinator**
Address Bassetlaw Hospice of Good Shepherd, North Road, Retford,
Nottinghamshire, DN22 7LN *Tel:* 01777 869239

Offers social sitting and a befriending service with help that complements the statutory services. Established in 1993 the service works closely with the Macmillan Team under the management of the care co-ordinator who oversees the provision of Palliative Care Services from the hospice. Volunteers provide an essential component of all the services given and in 1995, 45 volunteers visited patients and carers at home. They also work closely with Marie Curie and Crossroads. The home care services are linked to in-patient care and to day-care.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day and evening and rarely but if necessary at weekends
Personal care including help with feeding and aromatherapy
Practical help including help with shopping, gardening, ironing, washing clothes, cooking, driving, escorting and caring for young children
Counselling given by volunteers trained in communication and listening skills

Caring for C / A / MND / MS / OTI
Area Bassetlaw – urban and rural mix
Population 108,000

OXFORDSHIRE

Service name **Community Volunteers**

Contact **Voluntary Service Co-ordinator**
Address Sir Michael Sobell House, Churchill Hospital, Old Road, Headington,
Oxford, Oxfordshire, OX3 7LJ *Tel:* 01865 225868

Volunteers, who are ordinary people from all walks of life with experience of being with people who are poorly, offer support as a caring relative or neighbour might do. They may provide company, give help or allow carers to take a break. Established in 1989, the service works with Sir Michael Sobell House Macmillan nurses. Home care services are linked to in-patient care and to day-care. In 1995, 13 volunteers visited patients and carers at home. The voluntary service co-ordinator also oversees volunteers who work in house. A separate bereavement support service is available which offers counselling.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Personal care including help with feeding, toilet and manicure
Practical help including help with shopping, ironing, driving and escorting

Caring for C /A / MND / OTI
Area Oxfordshire – urban and rural mix
Population 586,000

SOMERSET

Service name **Home Care Befrienders**

Contact Address
Voluntary Services Co-ordinator
St Margaret's Somerset Hospice, Heron Drive, Bishops Hull,
Taunton, Somerset, TA1 5HA *Tel:* 01823 259394

The service was established in 1990 and works with home care services in Wells, Yeovil, Taunton, Minehead and Burnham-on-Sea, all of which are linked to in-patient care and some with day-care. In 1995 eighty volunteers visited patients and carers at home. The voluntary service co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day and very occasionally weekend and evening
Personal care including help with feeding, toilet, manicure, reflexology and aromatherapy
Practical help including help with shopping, washing clothes, cooking, driving, escorting and caring for young children
Nursing given by qualified nurses and volunteers trained in basic skills
Counselling given by qualified counsellors and volunteers trained in counselling skills

Caring for Area
C
Somerset – urban and rural mix

STAFFORDSHIRE

Service name **Home Sitting**

Contact Address
Voluntary Service Manager
St Giles Hospice, Fisherwick Road, Whittington, Lichfield,
Staffordshire, WS14 9LH *Tel:* 01543 432031

Established around 1992 the service works with the home care sisters of St Giles Hospice. The voluntary service manager, who also oversees volunteers working in house, recruits and trains volunteers for the home sitting service which is organised by the senior home care sister. A befriending service is offered by a different group of volunteers.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Personal care including help with toilet

Caring for Area
C
25 mile radius of hospice – urban and rural mix

STAFFORDSHIRE

Service name **Stafford Hospice at Home**

Contact **Co-ordinator of Volunteers**
Address Katharine House, Stafford Hospice at Home, Weston Road,
Stafford, Staffordshire, ST16 3SB *Tel:* 01785 255785

Trained volunteers are available to sit quietly with patients and befriend patients for a few hours during the day. Established in 1990 the service works closely with Macmillan nurses. The co-ordinator of volunteers also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Sitting service
Practical help including help with shopping, ironing and cooking (if pre-arranged) and driving

Caring for C / A / MND / OTI
Area Stafford – urban and rural mix, *approx.* 8-10 mile radius of Stafford,

SUFFOLK

Service name **Sitting Service**

Contact **Voluntary Services Manager**
Address St Elizabeth's Hospice, 565 Foxhall Road,
Ipswich, Suffolk, IP3 8LX *Tel:* 01473 727776

Volunteers act as good neighbours and visit to give carers a break. Established in 1989 the service works closely with Macmillan nurses. Home care services are linked to in-patient care and to day-care. In 1995, 15 volunteers visited patients and carers at home. The voluntary services manager also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day
Practical help including help, sometimes with shopping and ironing, and driving and escorting
Counselling given by trained volunteers

Caring for C / A / MND / OTI
Area East Suffolk – urban and rural mix, *approx.* 1800 sq. miles,
Population 400,000

SURREY

Service name **Community Care**

Contact
Address **Voluntary Services Co-ordinator**
The Princess Alice Hospice, West End Lane, Esher,
Surrey, KT10 8NA *Tel:* 01372 468811

Aims to provide a few hours respite for carers either on a regular basis or as requested, social contact for patients without an established network of support and practical help for patients. Established in 1986 the service works with the Princess Alice Hospice Community Care Nursing Team. Some of the home care services are linked to in-patient care and to day-care. In 1995, 15 volunteers visited patients and carers at home. The service tries to offer a library and talking book service which ties in with volunteers' visits.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend and evening
Personal care including help with feeding and toilet
Practical help including help with shopping, gardening, ironing, driving and escorting

Caring for C / A / MND
Area
mainly urban, *approx.* 10 mile radius of Esher,
Population
1,300,000

SURREY

Service name **Hospice Home Support**

Contact
Address **Administrator**
Hospice Home Support, Rossmore House, 26-42 Park Street,
Camberley, Surrey, GU15 3PL *Tel:* 01276 675650

Trained volunteers offer support for people with terminal illness, including cancer, who are living at home. Established in 1993 the service is an independent registered charity working alongside and in co-operation with district nurses, Macmillan nurses, GPs and the Phyllis Tuckwell Hospice. Some of the home care services are linked to in-patient care and to day-care. In 1995, 20 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend and evening
Practical help including shopping, gardening, ironing, cooking, driving escorting and caring for young children
Counselling given by trained volunteers

Caring for C / A
Area
West Surrey, Basingstoke, North & Mid Hants. Health Commissions – urban & rural mix

SUSSEX

Service name **Home Care Volunteer Service**

Contact **Volunteer Co-ordinator**
Address St Wilfrid's Hospice, 2–4 Mill Gap Road, Eastbourne,
East Sussex, BN21 2HJ *Tel:* 01323 644500

Aims to provide additional help given by volunteers so that patients can have company or carers can go out for two to three hours. Established in 1993 the service works alongside the Eastbourne and Wealden Macmillan Service. Home care services are linked to in-patient care and to day-care. The volunteer service has been used on a fairly low key basis and in 1995 five volunteers visited patients and carers at home. The volunteer co-ordinator also oversees volunteers who work in house. A separate group of volunteers offer a bereavement service.

Volunteers offer
Companionship, listening and talking
Sitting service arranged as requested
Practical help including help with shopping and driving

Caring for C / A / MND / OTI
Area Eastbourne, Wealden and Seaford Health District, except Eastbourne and Seaford – urban and rural mix, *approx.*. 323,000 sq. miles
Population 250,000

SUSSEX

Service name **Homecare**

Contact **Volunteer Co-ordinator**
Address St Wilfrid's Hospice, Grosvenor Road, Donnington, Chichester,
West Sussex, PO19 2FP *Tel:* 01243 775302

Offers a sitting service to provide company for patients and a break for carers. Established in 1990 the service works with the Hospice Home Support Sisters. Some of the home care services are linked to in-patient care. The volunteer service is not used as extensively as it was when first set up and in 1995, 14 volunteers visited 30 patients and carers at home. The home care volunteers all work within the hospice and some are members of the Bereavement Team of Hospice Visitors. The volunteer co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day
Personal care including help with feeding, toilet and aromatherapy
Practical help including help with shopping, driving and escorting

Caring for C
Area Chichester, Bognor & surrounding villages – urban and rural mix

SUSSEX

Service name **Home Care**

Contact Address
Voluntary Service Co-ordinator
The Macmillan Service, King Edward VII Hospital,
Midhurst, West Sussex, GU29 OBL *Tel:* 01730 813884

Established in 1982, Home Care volunteers work for the Macmillan Service and in 1995, 37 volunteers visited patients and carers at home. The voluntary service co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding, lavatory, manicure and hairdressing
Practical help including help with shopping, gardening, ironing, cooking, maintenance jobs, driving and escorting
Counselling given by trained volunteers

Caring for
C /A / MND / OTI

Area
25 mile radius of Midhurst – mainly rural

SUSSEX

Service name **Community Volunteers**

Contact Address
Deputy General Manager / Volunteer Service Co-ordinator
St Barnabas Hospice, Columbia Drive, Worthing,
West Sussex, BN13 2QF *Tel:* 01903 264222

Established in 1991, this is a small service working alongside the St Barnabas Home Care Team. Home care services are linked to in-patient care and to day-care. The volunteer service co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending to carers that continues into bereavement
Sitting service during the day
Personal care including help with feeding and toilet
Practical help including help with shopping, cooking, driving and escorting

Caring for
C / MND

Area
Worthing Area Health District – mainly urban

TYNE AND WEAR

Service name **Volunteer Home Care Service**

Contact Address
Senior Home Care Sister
St Clare's Hospice, Primrose Terrace, Jarrow,
Tyne and Wear, NE32 5HA *Tel:* 0191 428 4601

Volunteers can do any task a neighbour might do and free the carer for time out. Established in 1991 the service works from St Clare's Hospice which has in-patient beds and day-care.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding and toilet
Practical help including help with driving and escorting
Counselling given by qualified counsellors and trained volunteers

Caring for
C
Area
South Tyneside – mainly urban

WARWICKSHIRE

Service name **Hospice at Home**

Contact Address
Hospice at Home Manager / Macmillan Nurse
Mary Ann Evans Hospice, N.Warwickshire NHS Trust, Palliative Care Team, The Lodge, Bramcote Hospital, Lutterworth Road, Nuneaton, Warwickshire, CV11 6QA
Tel: 01203 325236

Volunteers give support to patients and carers and help to allow the patient to remain in their own home. Established in 1994 the service works with the Hospice at Home team. Hospice at Home services are linked to day-care and offer a 'hands-on' service. In 1995 two volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding, toilet, washing, manicure, hair dressing, aromatherapy
Practical help including help with shopping, ironing, washing clothes, cooking driving, escorting and caring for young children
Nursing given by volunteers trained in basic skills
Counselling given by volunteers trained in listening skills

Caring for
C / MND
Area
Nuneaton & Bedworth – mainly urban

WEST MIDLANDS

Service name **Home Volunteers**

Contact
Address
Volunteers Manager
Acorns Children's Hospice, 103 Oak Tree Lane, Selly Oak,
Birmingham, West Midlands, B29 6HZ *Tel:* 0121 414 1741

Individual agreements are made with each family after discussions to elicit their needs. The biggest needs are for playwork with siblings, baby-sitting and evening minding. Established in 1994, the service works with The Acorns Community Team who are also known as Home Support Workers. Home care services are linked to in-patient care. In 1995, 22 volunteers visited families at home. The volunteers manager also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Practical help including ironing, driving and escorting but mostly looking after and playwork with siblings and minding children in the evening

Caring for C / A / MND / large percentage of genetic illnesses
Area West Midlands Regional Health Authority – urban and rural mix,
Population 5 million

WEST MIDLANDS

Service name **Volunteers Sitting Service**

Contact
Address
Voluntary Service Co-ordinator
Compton Hospice, Compton Hall, Compton Road West,
Wolverhampton, West Midlands, WV3 9DH *Tel:* 01902 758151

Volunteers offer help in the home to patients and carers as a back-up to paid staff. Established in 1992 the service works from Compton Hospice which has Home Care Services, in-patient beds and day-care. The voluntary service co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day
Personal care including help with feeding
Practical help with shopping, washing clothes, driving, escorting, caring for young children and accompanying them to and from school
Counselling given by trained volunteers

Caring for C
Area West Midlands – urban and rural mix, *approx.* 15 miles
Population 1,500,000

WILTSHIRE

Service name **Homecare**

Contact
Address **Manager of Voluntary Services**
Prospect Hospice, Moormead Road, Wroughton,
Swindon, Wiltshire, SN4 9BY *Tel:* 01793 813355

Volunteers offer a sitting service and help with specified tasks on a friendly-neighbour basis to give support to the patient and to help carers have a break. Established in 1986, the service works alongside Macmillan nurses in the home. Some of the home care services are linked to in-patient care and to day-care. In 1995, 39 volunteers visited patients and carers at home. The manager of voluntary services also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend and evening
Practical help including help with shopping, driving, escorting and hairdressing

Caring for C / MND
Area Wiltshire Health Authority – mainly rural

YORKSHIRE

Service name **St Michael's Hospice Home Care**

Contact
Address **Nurse Manager**
Saint Michael's Hospice, Crimple House, Hornbeam Park Avenue,
Harrogate, North Yorkshire, HG2 8QL *Tel:* 01423 879687

Established around 1991 the service in 1995 had about 12 sitters who on rare occasions are asked to undertake day or weekend sitting.

Volunteers offer
Companionship, listening and talking
Sitting service during the day and weekend

Caring for C / A / MND / OTI
Area Harrogate Health Care Trust Area – urban and rural mix

YORKSHIRE

Service name **Hospice Homecare Sitting Service**

Contact
Address
Volunteer Sitters Co-ordinator
Hospice Home Care, Room 29, West Wing, Friarage Hospital,
Northallerton, North Yorkshire, DL6 1JG *Tel:* 01609 777413

A free, non-emergency service in which volunteers will visit and sit or befriend, offering clients companionship and carers respite. Established in 1993, the service is an independent charity and works with the Northallerton Health Trusts Palliative Care Team which includes Macmillan nurses, and with other voluntary agencies in the area who offer a more general sitting service. Some of the home care services are linked to in-patient care. Hospice Homecare was constituted following a local appeal for the funding of two Macmillan nurses and a local survey which showed that people would prefer to remain at home during a terminal illness if support for the family was available. In 1995, 20 volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day, weekend evening and occasional night sitting
Personal care including help with feeding, toilet and washing
Practical help including help with shopping, ironing, cooking, driving and escorting

Caring for C / A / MND
Area Northallerton Trusts Palliative Care Team area – mainly rural, *approx.* 950 sq. miles
Population 121,000

YORKSHIRE

Service name **Breast Care Service**

Contact
Address
Macmillan Clinical Nurse Specialist
Breast Care Service, District General Hospital, Gawber Road,
Barnsley, Yorkshire, S75 2EP *Tel:* 01226 730000 ext. 2257

The Breast Care Nurse is supported by four volunteers who are all survivors of breast cancer and who offer a befriending service to in-patients of the hospital and give them a telephone follow-up after discharge. Patients are given the telephone number of a volunteer they have met while in hospital so that when they feel they would like to, they can ring and talk and possibly meet.

YORKSHIRE

Service name **Home Visiting Service**

Contact Address
Volunteer Services Co-ordinator
Rotherham Day Hospice, Wensley Court, District General Hospital, Moorgate Road, Rotherham, South Yorkshire, S60 2UD *Tel:* 01709 829900

Volunteers will visit patients and carers and help in the home. Established in 1995, this is a pilot scheme with two volunteers visiting patients and carers at home during 1995. The service operates alongside four visiting Macmillan nurses. Home care services are linked to day-care. The volunteer services co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Personal care including help with feeding and toilet

Caring for
C

Area
Rotherham – urban and rural mix

YORKSHIRE

Service name **St Luke's Marie Curie Carers Support**

Contact Address
Co-ordinator
St Luke's Hospice Marie Curie Carers Support, Little Common Lane, off Abbey Lane, Sheffield, South Yorkshire, S11 9NE *Tel:* 0114 262 0918

To give carers a short break once a week so they can re-charge their batteries. Established at St Luke's in 1984, the service works alongside 14 visiting Macmillan nurses and has the help of three paid nursing auxiliaries. Another co-ordinator oversees volunteers who work in the hospice.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day (night sitting is a separate service)
Personal care including help with feeding, toilet and washing
Practical help including help with driving and escorting

Caring for
C / A / MND / OTI

Area
Sheffield – urban and rural mix

YORKSHIRE

Service name **Befriending Service**

Contact Address
Family Care Team / Bereavement Counsellors
Kirkwood Hospice, Albany Road, Dalton,
Huddersfield, West Yorkshire, HD5 9UY *Tel:* 01484 512101

Offers volunteers to be with patients and carers during difficult times and to be available if needed. Volunteers will gradually withdraw to allow the bereaved to stand on their own feet but can remain in contact for a while if needed. Established in 1992, befrienders work voluntarily and directly under the control of the professional Family Care Team, comprising three nurse/counsellors. The home care services are linked to in-patient beds and to day-care. When patients are referred to the hospice, they are referred to the Family Care Team and befrienders will visit before a death to get to know the family. The befriending service was busy when first established but now as nurse counsellors do a lot of early work with families, as do primary care nurses, the befrienders are doing less. In 1995 eight befriender volunteers visited families. The nurse/counsellors also oversee volunteers in an in-patient unit.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Practical help including help with driving and escorting
Counselling given by trained volunteers

Caring for C
Area Kirklees – urban and rural mix
Population 280,000

YORKSHIRE

Service name **Befrienders**

Contact Address
Social Worker
Manorlands Hospice – Sue Ryder Foundation, Hebden Road, Oxenhope,
Keighley, West Yorkshire, BD22 9HJ *Tel:* 01535 642308

Supervised volunteers who are part of the hospice team can listen confidentially, offer assistance and are willing and able drivers. Established in 1993, the service works alongside Manorlands Hospice Home Care Team and the Bradford Palliative Care Team. Home care services are linked to in-patient care and to day-care. Another co-ordinator oversees volunteers who work in the hospice. In 1995 eight volunteers visited patients and carers at home.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day
Personal care including a little help with feeding and toilet
Practical help including help with shopping, gardening, driving and escorting
Nursing given by qualified nurses
Counselling given by trained volunteers
Physiotherapy given by qualified physiotherapists

Caring for C / A / MND / OTI
Area Keighley, Bingley – urban and rural mix

YORKSHIRE

Service name **Sitting Service**

Contact
Address
Voluntary Help Organiser
Wheatfields Hospice, Grove Road, Headingley,
Leeds, West Yorkshire, LS6 2AE *Tel:* 0113 278 7249

Offers a few hours respite care for carers to use how they wish. Established in 1992 the service is offered as part of the Hospice Community Nursing Team and also works with the community Macmillan nurse. The community nurses co-ordinate the volunteers and in 1995 three volunteers visited patients and carers at home. A separate service for carers that continues into bereavement is offered by a different group of volunteers.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Counselling given by trained volunteers

Caring for C / A / MND / OTI
Area Leeds – mainly urban

NORTHERN IRELAND – ANTRIM

Service name **Home Care Services**

Contact
Address
Manager, Volunteer Services
Northern Ireland Hospice, Somerton House, 74 Somerton Road,
Belfast, Antrim, BT15 3LH *Tel:* 01232 781836

Offers extra help to patients and carers at home based on a needs assessment. Established in 1988 the service operates over a wide area with three home care teams in North Down and Ards, Causeway Coast and Fermanagh and is in the process of establishing services in Belfast, Ballymena and Ballynahinch. Home care services are linked to in-patient care and some are linked to day-care. In 1995 around 150 volunteers visited patients and carers at home and were co-ordinated by local organisers. The manager of the home care volunteer services also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care with feeding, toilet, washing, manicure, hairdressing reflexology, aromatherapy and what needs assessment suggest is necessary
Practical help with shopping, gardening, ironing, washing clothes, cooking, maintenance jobs, driving, escorting, caring for young children
Counselling, some given by qualified counsellors and some by trained volunteers

Caring for C / A / MND
Area Northern Ireland – urban and rural mix, *approx.* 10,000 sq. miles
Population 2.5 million

SCOTLAND – AYRSHIRE

Service name **Ayrshire Cancer Support Group**

Contact **Administrator**
Address Ayrshire Cancer Support Group, 16 Portland Road, Kilmarnock, Ayrshire, KA1 2BS *Tel:* 01563 538008

Offers one-to-one counselling for patients or carers and a sitting service to allow respite for carers. Established in 1983 this independent charity offers a service which operates as a complement to home care services and works in co-operation with Ayrshire Hospice and local hospitals. Alongside visiting volunteers the service has a day centre which offers group support, reflexology, massage and relaxation for patients and also loans equipment.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day
Practical help including help with shopping, driving and escorting
Counselling given by trained volunteers

Caring for C
Area Ayrshire – mainly rural

WALES – GLAMORGAN

Service name **Sitting, shopping, driving & transport service**

Contact **Home Care Team Leader**
Address George Thomas Centre for Hospice Care, 10 Ty Gwyn Road, Penylan, Cardiff, South Glamorgan, CF2 5JE *Tel:* 01222 485345

To complement specialised nursing, a band of volunteers is always available to lend a hand helping, from running a patient to hospital to collecting subscriptions or sitting with a patient while the carer has break. Established in 1984 the volunteer service works with the two George Thomas Home Care Teams. Home care services are linked to day-care. In 1995 around 100 volunteers visited patients and carers at home. The home care team leader also oversees volunteers who work in house. There is a separate bereavement support group made up of volunteers under a paid bereavement counsellor.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day, weekend and evening
Personal care including help with feeding, toilet, hairdressing and aromatherapy
Practical help including help with shopping, gardening, driving, escorting and caring for young children
Nursing given by qualified nurses and trained volunteers
Counselling given by trained volunteers

Caring for C / A / MND / OTI
Area South Glamorgan and The Vale – urban and rural mix, *approx.* 50 sq. miles
Population 414,900

WALES – GWENT

Service name **Family Volunteers**

Contact Address
Nursing Team Leaders
St David's Foundation, Cambrian House, St John's Road, Maindee,
Newport, Gwent, NP9 8GR *Tel:* 01633 281811

Once a need is identified, then the role of a volunteer in meeting that need is discussed with the patient and carer. Established in 1982, the service is run by two Nursing Team Leaders who manage the home care nursing team. Some home care services are linked to in-patient care and all to day-care. During 1995 five volunteers visited patients and their carers at home.

Volunteers offer
Companionship, listening and talking
Sitting service during the day
Personal care including help with toilet and aromatherapy
Practical help with shopping, gardening, ironing, washing clothes, maintenance jobs, driving and caring for young children

Caring for C / A / MND / MS
Area Gwent – urban and rural mix

WALES – ANGLESEY

Service name **Volunteer Hospice Home Care**

Contact Address
Volunteer Co-ordinator
Gwynedd Hospice at Home, Hafan Menai, Dale Street,
Menai Bridge, Anglesey, LL59 5AW *Tel:* 01248 716782

To sit with patients and carers or perform tasks that can be undertaken by family, friends or neighbours. Established in 1993 the service works alongside Gwynedd Hospice at Home. Some of the home care services are linked to day-care. In 1995, 30 volunteers visited patients and carers at home. The co-ordinator also oversees volunteers who work in house.

Volunteers offer
Companionship, listening and talking
Befriending for carers that continues into bereavement
Sitting service during the day and weekend
Personal care including help with feeding, toilet, manicure, reflexology and aromatherapy
Practical help including help with shopping, gardening, driving and escorting
Nursing given by qualified nurses
Counselling given by trained volunteers
Physiotherapy given by qualified physiotherapists

Caring for C
Area Gwynedd – mainly rural

Appendix 1

Glossary

Day care/Day centre ***Day hospice***	Centres to which patients can go during the day for a range of creative, social and supportive activities and services, which may include facilities for the physical care of a patient.
Hands-on-care	Some specialist palliative care services act principally in an advisory capacity to primary care services. Those which offer hands-on-care also give practical care to the patient.
Home care	Generic term used to cover specialist palliative home nursing services
Home visiting volunteers	Volunteers who visit terminally ill people and their carers at home, sometimes referred to as home care volunteers.
Hospice	Hospice and hospice care refer to a philosophy of care. The philosophy embraces a commitment to holistic care which attends to the emotional, social and spiritual needs of patients as well as their physical care. It is a definition of care which includes the patient's family and the delivery of that care by specialists in a non-hierarchical multi-disciplinary context.
In-patient unit	Hospice or palliative care unit with beds for the better control of symptoms such as pain, nausea or vomiting.
Macmillan nurse	Nurse clinically experienced and trained in specialist palliative care
Palliative care	The active total care of patients and their families when the patient's disease is no longer responsive to curative treatment[1].
Primary care	General practitioner and district nurses who supervise and deliver medical care to patients at home.
Specialist palliative home care	Professional staff with clinical experience and specialist training in palliative care who visit patients and carers at home and who administer care themselves either directly to the patient and/or indirectly through advice to the patient's professional carers.
Terminally ill	People with active and progressive disease for which curative treatment is not possible or not appropriate and from which death can reasonably be expected within 12 months[2].

Volunteer co-ordinator / Voluntary services co-ordinator	Person appointed to co-ordinate volunteers, often but not always responsible for the recruitment, selection and training of volunteers as well as for their deployment.

1 *Specialist Palliative Care: Statement of Definitions*, National Council for Hospice and Specialist Palliative Care Services, Occasional Paper 8, 1995

2 op.cit.

Appendix 2

Survey procedure, questionnaire and response rates

The study set out to map services in the United Kingdom and Ireland which organise volunteers to visit terminally ill patients and their carers at home.

All hospices in the *1995 Directory of Hospices* listed with home care teams and/or day-care units and using volunteers were contacted and asked if any of their volunteers visited patients at home[1]. From this initial contact 106 volunteer co-ordinators were identified as running a volunteer home visiting service and they were each sent a questionnaire. Eighty-eight responded, a response rate of 83 per cent[2]. While the response rate is high, a number of London services did not participate and urban services may therefore be under-represented.

A final stage involved informal talks with four co-ordinators who had completed the questionnaire and who agreed to such talks together with a few of their volunteers. Time and money precluded selecting services scattered round the country. The four were chosen to represent a variety of features such as a service running for less than 18 months, another for more than 12 years, one with under 20 active volunteers and one with more than 50, a service run by a qualified nurse and a service run by a voluntary service co-ordinator who was not a nurse, and a service that was part of the local hospice organisation and a service that was an independent charity. They cannot be said to be representative of services in the UK and Ireland[3]; nor are they prescriptive of how a service should be run. Their experiences however give some indication of the very different work being undertaken.

Not all respondents answered every question. For this reason, base numbers are given in tables and percentages quoted in the text are followed by the number to which they refer. Response rates for individual questions are listed after the questionnaire. Response rates for some questions asking for statistics were quite low such as the number of home visits made (response rate 66 per cent) and the number of patients/carers seen in a year (response rate 57 per cent). This may be because co-ordinators did not want to release the information or it was not readily available. It is perhaps surprising that only two thirds had to hand figures on the number of patients visited and the number of visits made since such visits are the core of the work[4].

1 Respondents were also asked on the telephone if they used 'other' local organisations to send volunteers to visit terminally ill patients known to them.

2 Eleven of these replies were completed over the telephone, five giving full information and six giving minimal basic information on the service.

3 They do not for example include an inner city service.

4 A recent survey by the National Centre for Volunteering, sponsored by the Department of Health, *Making a Difference: strengthening volunteering in the NHS*. Report of the working group on volunteering in the NHS, 1996, also found that not all health providing organisations keep a record of the number of volunteers they utilise and may have no idea of the time volunteers give, Annexe D.

THE CO-ORDINATION OF HOME CARE VOLUNTEERS

Voluntary work is 'the giving of time, unpaid, for the benefit of other people'

Volunteers who visit terminally ill patients and their carers at home will be referred to as home care volunteers throughout. VSC is short for Voluntary Service Co-ordinator. Answers to question numbers not in bold will remain confidential.

1. Please state your OFFICIAL TITLE (*it may not be voluntary service co-ordinator*)

   .....

   the NAME and ADDRESS of your organisation (*block capitals*)

   .....

   .....

   .....

   TELEPHONE NUMBER .....

2. Are you responsible for co-ordinating home care volunteers to visit terminally ill people and their carers? ☐ Yes ☐ No

   and/or

   Do you liaise with a voluntary organisation in your area which can send volunteers into the homes of terminally ill patients? ☐ Yes ☐ No

   If yes, please name this organisation(s) .....

continue on back page

3. What is the name of the service given by home care volunteers

   .....

   .....

   What is the name of the area served?

   .....

   the approximate size of the geographical area covered?

   .....

   and its population? .....

   Would you describe it as, ☐ mainly urban,
   ☐ urban and rural mixed,
   tick one ☐ mainly rural

4. How long has the home care volunteer service been operating ? ..... years ..... months

5. How many specialist palliative home care service 'teams' do you work with? .....
   Please name them .....

   .....

continue on back page

   Are the specialist palliative home care services linked to
   a) in-patient care ☐ Some ☐ All ☐ None
   b) day-care centre ☐ Some ☐ All ☐ None
   Do the palliative teams offer a 'hands-on-care' service? ☐ Some ☐ All ☐ None

Tasks

6. When volunteers visit patients and carers at home, what tasks do they undertake?

Companionship / listening / talking ☐ Yes ☐ No

Is a befriending service for carers that continues into bereavement offered? ☐ Yes ☐ No

Tick all boxes which apply

Sitting ☐ Yes ☐ No

If a sitting service is given, when is this usually done?

- ☐ day sitting
- ☐ weekend sitting
- ☐ evening sitting
- ☐ night sitting

Personal care ☐ Yes ☐ No

If personal care is given, what does it usually include?

- ☐ feeding
- ☐ lavatory
- ☐ washing
- ☐ manicure / pedicure
- ☐ hairdressing
- ☐ reflexology
- ☐ aromatherapy
- ☐ other, please specify .....

Practical help ☐ Yes ☐ No

If practical help is given, what does it usually include?

- ☐ shopping
- ☐ gardening
- ☐ ironing
- ☐ washing clothes
- ☐ cooking
- ☐ maintenance jobs
- ☐ driving
- ☐ escorting (to hospital, shops etc.)
- ☐ caring for young children
- ☐ other, please specify .....

Nursing skills ☐ Yes ☐ No

If nursing skills are given, are volunteers

- ☐ qualified nurses
- ☐ volunteers trained in basic nursing skills

What sort of services do they give? .....

.....

6. *continued*

Counselling skills ☐ Yes ☐ No

If counselling skills are given, are volunteers

☐ qualified counsellors

☐ volunteers trained in counselling skills.

Physiotherapy ☐ Yes ☐ No

If physiotherapy skills are given, are volunteers

☐ qualified physiotherapits

☐ trained volunteers

7. Are services given which do not fall into the above categories? ☐ Yes ☐ No

If yes, please specify, ...

.....

.....

8. Have you plans a) to expand the service ☐ Yes ☐ No

b) to contract the service ☐ Yes ☐ No

If yes to either, can you say briefly what these plans are ?

.....

.....

9. Is there an upper limit to the duration of a visit made by a home care volunteer?

☐ Stipulated

☐ Suggested

tick one box ☐ Neither

10. How long does a visit made by a volunteer usually last?

a) during the day ..... hours b) during the evening ..... hours

11. When a volunteer visits a patient or carer,

	pre-arranged *or*	negotiated at the visit
is the task usually	☐	☐
is the duration usually	☐	☐

If either task or duration of visit are ever negotiated

a) are there guidelines for this negotiation? ☐ Yes ☐ No

b) if yes, are these guidelines written down? ☐ Yes ☐ No

12. Have you ever experienced difficulties with paid colleagues over defining what home-care volunteers should do? ☐ Yes ☐ No

If yes, is this because they

☐ overestimated the time volunteers could give

☐ underestimated the time volunteers could give

☐ overestimated what volunteers could do

☐ underestimated what volunteers could do

tick boxes which apply ☐ other, please specify .....

.....

.....

13. What do you think home care volunteers bring for patients and carers that professionals are unable to provide?

.....
.....
.....
.....

Patients and Carers

14. How many patients were visited by home care volunteers last year, 1995? .....

15. Which categories of illness do the specialist palliative home care service and home care volunteers cater for? Please indicate approximate % of patients if possible.

	%
☐ Cancer	.....
☐ Aids	.....
☐ Motor Neurone Disease	.....
☐ Other, specify	.....

tick boxes which apply

16. What information are patients and carers given about the volunteer?

☐ Time of visit(s)
☐ The task they will do
☐ First name
☐ Surname
☐ Address
☐ Telephone number
☐ Other, please specify .....
.....

tick boxes which apply

17. Who of the following can refer patients for home visits from volunteers?

☐ specialist team nurse or doctor
☐ G.P.
☐ district nurse
☐ hospice staff
☐ self-referral by patient or family
☐ other, specify .....

tick boxes which apply

18. Do you keep records of all requests for such volunteer services whether you can respond to them or not? j Yes j No

19. Do you evaluate the service offered by home care volunteers? ☐ Yes ☐ No

If yes, is this done by

☐ observations made by paid staff
☐ form / questionnaire
☐ personal contact by VSC with patient and carers
☐ other, please specify .....

tick boxes which apply

If yes, is this evaluation made

☐ before the patient's death
☐ after the patient's death

20. Please describe briefly the service offered by home care volunteers as described to prospective patients and carers.

.....
.....
.....

Home Care Volunteers

21. How many volunteers made home care visits last year, 1995? no. .....

22. How many volunteer visits were made last year? no. .....

23. How many home care volunteers left your service pool last year ? no. .....

24. Approximately how many of your home care volunteers fell into each of the following age groups last year?

-25,	26-35,	36-45,	46-55,	56-65,	66+ years
.....	.....	.....	.....	.....	.....

Approximately what number were men .....
women .....

25. Are volunteers who visit patients and carers at home people who regularly do other voluntary work in-house for your organisation?
☐ All ☐ Most ☐ Some ☐ None ☐ Not Applicable *tick one*

26. Do you recruit home-care volunteers
☐ mostly by word of mouth
☐ mostly through recruitment drives
☐ through word of mouth & recruitment drives
☐ other, specify .....
tick one

27. Having made contact with a prospective home visiting volunteer, do you use any of the following to help you with selection?
☐ application form (for basic information)
☐ interview
☐ job description or named tasks to elicit preferences in work
☐ references
☐ training session as part of selection
☐ probationary period
☐ health check
☐ other, specify.....
tick boxes which apply

28. Are prospective home care volunteers asked for a commitment to any of the following?
☐ a minimum period of time during which they will be available for work
☐ a minimum number of hours per week
☐ ongoing training
☐ attendance at specified meetings with VSC
☐ attendance at specified meetings with other home care volunteers
☐ other, specify .....
☐ not applicable *tick boxes which apply*

29. Considering the requirements made of your service in the last 12 months, do you have
☐ insufficient suitable volunteers *tick one*
☐ about the right number of volunteers
☐ more volunteers &/or volunteer time available than are being effectively used

Volunteer Support and Training

30. Does your organisation have a written policy on the use of volunteers in home care services for terminally ill people?

☐ Don't Know ☐ Yes ☐ No

31. Does the written policy or do other documents specify any of the following in relation to home care volunteers?

☐ roles and relationships (eg. with paid staff)
☐ rights of volunteers (eg. to say no, grievance procedures)
☐ responsibilities of volunteers (eg. respecting confidentiality)
☐ equal opportunities
☐ resources for the deployment of volunteers
☐ support and training
☐ insurance, health and safety

tick boxes which apply

32. Do you give home care volunteers training that is specific to their role? ☐ Yes ☐ No

If yes,

how many hours of <u>compulsory</u> training do they have in their first year?

a) before they make any home visits ☐ None ☐ ..... hours
b) after they have started home visits ☐ None ☐ ..... hours

how many hours of <u>optional</u> training are offered in their first year?

a) before they make any home visits ☐ None ☐ ..... hours
b) after they have started home visits ☐ None ☐ ..... hours

33. Can the VSC or other responsible person be contacted by a home care volunteer when a volunteer is home visiting?

always	sometimes	never	
☐	☐	☐	*tick one*

34. Following a visit by a volunteer, what is the procedure ?

	after each patient visit	after several visits
a. form / record filling	☐	☐
b. telephone report to VSC, nurse or other home care team member	☐	☐
c. one to one meeting between volunteer and VSC	☐	☐
d. one to one meeting between volunteer and member of home care team	☐	☐
e. group meeting between volunteers and VSC	☐	☐

f. other, specify .....

tick boxes which apply

35 Do you appraise work done by home care volunteers? ☐ Yes ☐ No

If yes, is this done in

☐ one to one meeting with VSC
☐ volunteer group meeting with VSC
☐ training session with VSC
☐ other, specify .....

36. Do home care volunteers have organised group meetings with each other ? ☐ Yes ☐ No

If yes, are these

	voluntary meetings	compulsory meetings
VSC always present	☐	☐
VSC sometimes present	☐	☐
VSC not present	☐	☐

tick boxes which apply

Can you say a little about your post?

37. Do you have a written job description governing your responsibilities as coordinator of home care volunteers? ☐ Yes ☐ No

38. Is your post ☐ full-time *or*
☐ part-time, (less than 30 hours per week) How many hours? .....

Is it ☐ paid *or*
☐ voluntary

39. Does your post include responsibilities for co-ordinating volunteers in an in-patient unit, day-care centre or other inhouse unit? ☐ Yes ☐ No

40. Does your post include other responsibilities, quite different and separate from overseeing volunteers? ☐ Yes ☐ No

If yes, please specify .....

41. Do you have a volunteer budget which you control? ☐ Yes ☐ No

42. There are probably individual aspects of your service for which this questionnaire has not allowed space and to which you would like to draw our attention. Please do so here and feel free to write about any aspect of the service, its nature, organisation or history which you think should be known.

.....
.....
.....
.....
.....
.....
.....
.....
.....
.....

P.T.O.

43. If possible we would like to talk confidentially to a few co-ordinators in a little more detail to try to capture some of the variety in provision and practice. In particular we should like to gather examples of how services really work with the patient in the home which would help convey to any reader just how valuable the work is. Please indicate if you would be willing to participate in such talks.

☐ Yes ☐ No

Question **2.** *continuation if needed*

.....

.....

.....

.....

Question **5.** *continuation if needed*

.....

.....

.....

.....

Thank you. Please return to Lesley Cullen in the enclosed stamped addressed envelope. Institute of Community Studies, 18 Victoria Park Square, London E2 9PF

RESPONSE RATES TO QUESTIONS

Circulation 106	Non-respondents	18	
	Respondents	88	*Response rate* 83%

Question		Respondents	
1. Official title		88	100 %
2. Co-ordinator		86	98 %
Liaison		79	89 %
3. Service name		85	97 %
Area name		82	93 %
Square miles		40	45 %
Population		47	54 %
Urban/rural		86	98 %
4. Years service operating		83	94 %
5. Home Care Teams *(this question is not applicable to all services)*			
Number		47	53 %
Team names		74	84 %
In-patient facility		58	(66 %)
Day-care		66	(75 %)
Hands-on-care		61	(69 %)
6. TASKS performed			
Companionship		87	99 %
Befriending		84	95 %
Sitting		86	98 %
Personal		87	99 %
Practical		86	98 %
Nursing		85	96 %
Counselling		86	98 %
Physiotherapy		85	97 %
7. Other tasks		67	76 %
8. Plans to expand		81	92 %
to contract		56	64 %
9. Upper limit on duration of visit		82	93 %
10. Hours	day	79	90 %
	evening	52	59 %

11. Pre-arrangement & negotiation		
Task	78	88 %
Duration	76	86 %
Guidelines	47	53 %
Written guidelines	44	50 %
12. Relationship with paid colleagues	82	93 %
13. What home care volunteers bring	70	79 %
PATIENTS AND CARERS		
14. Patients visited	50	57 %
15. Illness categories	86	98 %
16. Information given about volunteer	76	86 %
17. Referrals	80	91 %
18. Records	80	91 %
19. Evaluation of service	76	86 %
20. Service description	71	80 %
HOME CARE VOLUNTEERS		
21. Number of volunteers	75	85 %
22. Number of volunteer visits	58	66 %
23. Volunteers leaving	69	78 %
24. Age of volunteers	58	66 %
Male/female	69	78 %
25. Volunteers working in-house	81	92 %
26. Recruitment	79	90 %
27. Methods of selection	80	91 %
28. Commitment asked for	79	90 %
29. Sufficient numbers	77	87 %
VOLUNTEER SUPPORT & TRAINING		
30. Written policy	78	88 %
31 Policy specifications	64	73 %
32. Training	79	90 %
33. Contact during visits	81	92 %
34. Debriefing	82	93 %
35. Appraisal of volunteer work	78	89 %
36. Volunteer meetings	76	86 %
VSC POST		
37. Written job description	75	85 %
38. Full-time & part-time	85	97 %
Paid / voluntary	81	92 %
39. Co-ordinating 'other' volunteers	80	91 %
40. Other responsibilities	77	87 %
41. Volunteer budget	76	86 %
42. Further details offered	48	54 %
43. Further talks	76	86 %

Appendix 3

Services using volunteers to visit patients at home for which details are not available

BEDFORDSHIRE
Hospice at Home, Dunstable, *(independent charity)*
Hospice at Home, Luton, *(independent charity)*

BERKSHIRE
British Airways Macmillan House

DERBYSHIRE
Treetops Hospice

HEREFORD & WORCESTER
Kemp House *(also serving the home care team at Stourport)*

HERTFORDSHIRE
Garden House Hospice
Macmillan Runcie Day Hospice
Isabel Hospice

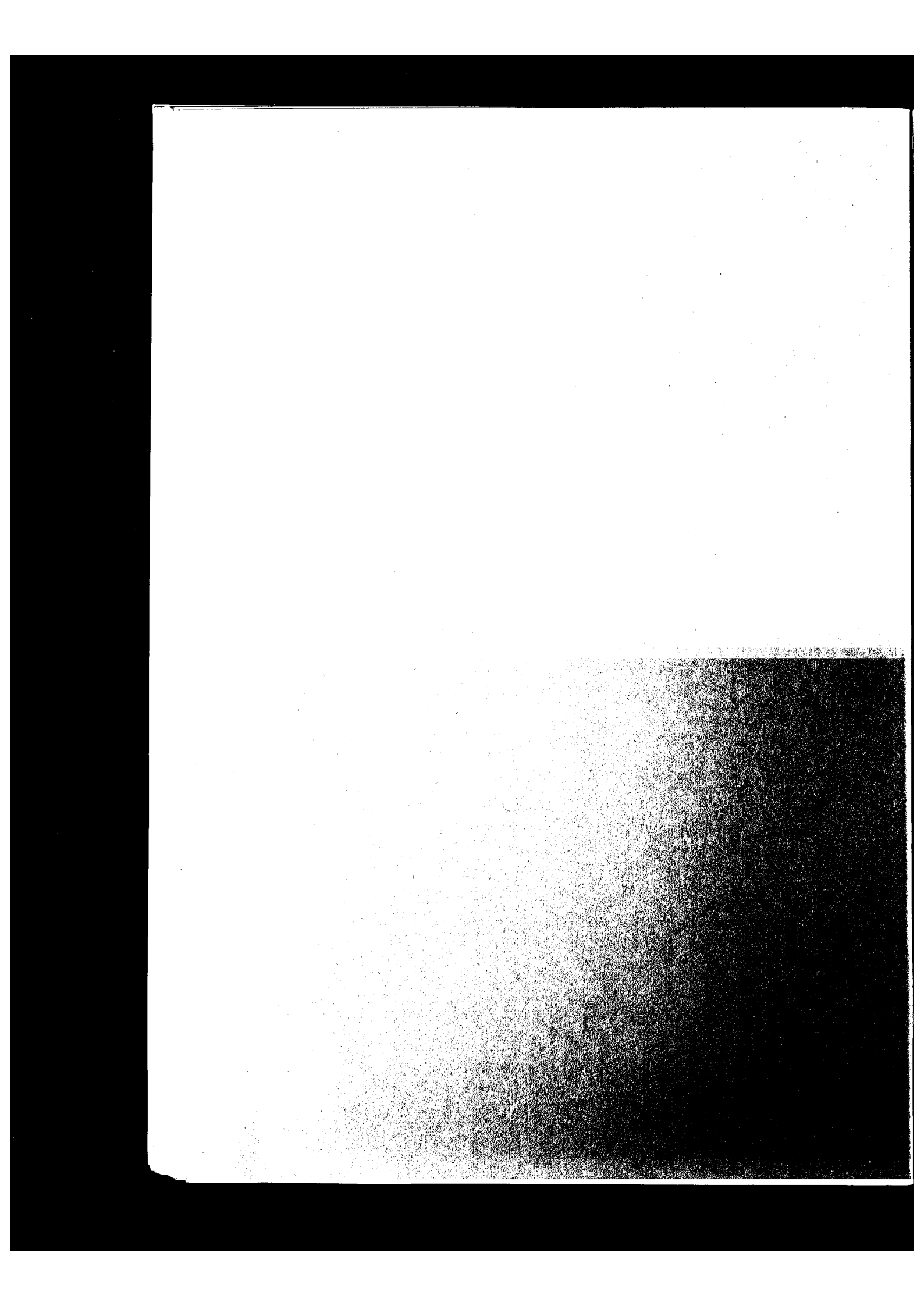
JERSEY
Jersey Hospice Care

LANCASHIRE
Hospice Care for Burnley and Pendle

LONDON
London Lighthouse *(independent charity)*
North London Hospice
Palliative Care Team, Royal Free Hospital
St Christopher's Hospice
St Joseph's Hospice
Wellspring Home Care Team *(a separate charity receiving part of its funding from Camden and Islington Care Trust and used exclusively by the Palliative Care Team. Together they provide a service 'Hospice at Home')*

MIDDLESEX
St Luke's Hospice *(serving Continuing Care Teams at Brent and Harrow)*

NOTTINGHAMSHIRE
Cynthia Spencer House *(volunteers work with its Macmillan team and the Macmillan service at Daventry)*



The major part of a patient's last year of life is spent at home where care is mostly carried out by families. A growing elderly population means a patient's needs in the home are likely to increase rather than decrease, creating extra pressures for carers. Schemes to help people save and insure for long-term care do not help those who need assistance now or who cannot afford to pay into such schemes.

This practical study outlines those services which organise volunteers to visit terminally ill patients and their carers at home. It looks at the work they undertake and the support they provide.

At a time when volunteers are working hard to meet the needs of patients, this report helps to clarify the boundaries between volunteer work and services provided by statutory agencies.

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