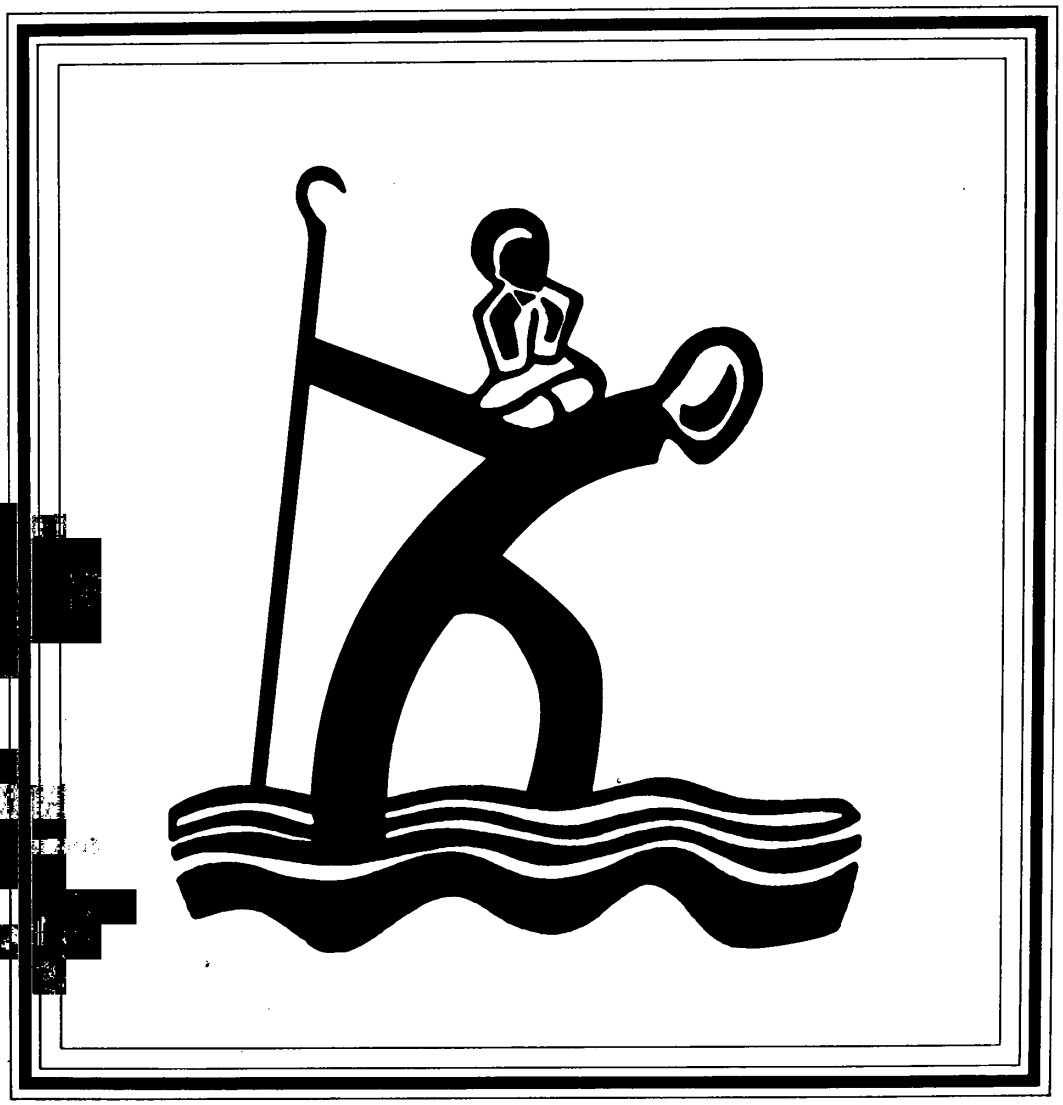
Bereavement Visiting

Edited by Geoffrey Dyne

Preface by Colin Murray Parkes MD FRCPsych



King Edward's Hospital Fund for London

Bereavement Visiting

King Edward's Hospital Fund for London

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Printed by Vitesse Printing Limited

Cover illustration by kind permission of St Christopher's Hospice

ISBN 0 900889 86 1

Distributed for the King's Fund by
Pitman Medical Limited

King's Fund Publishing Office
126 Albert Street
London NW1 7NF

Editor's Note

This book describes the St Christopher's Hospice Bereavement Service. The contributors, Dorothy Bodell, Horace Dales, Mary Drake, Vera Dyne, Mary Gamage, Paddy Yorkstone, are volunteer members of the service.

Though the service operates within a setting which has its own particular features, the contributors hope that what they have written may be of help and guidance to others who are doing, or would like to embark upon, similar work.

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Preface

In recent years a number of scientific research projects in Australia, the United States, Canada and Britain have demonstrated the value of counselling in reducing the damage to physical and mental health which can result from bereavement. In most of these studies, the counselling was given by psychiatrists and other professional workers. A study of the service given to the relatives of patients who had died at St Christopher's Hospice was the first to demonstrate that good results could also be obtained by using carefully selected, trained and supported volunteers. The use of volunteers for this type of work was regarded with suspicion by some professions whose own expertise was called in question by the very idea that people without years of training can be trusted to work with emotionally disturbed, grieving families. The view was expressed that either grief is a 'normal' process for which help is not needed, or it is an illness for which psychiatric or medical treatment is required. Our view, which conflicts with this, is that while most people come through the process of grieving 'with a little help from their friends', and there is a very small minority who urgently require psychiatric help, there is a sizeable intermediate group (a quarter to a third of the families of patients who die at St Christopher's) for whom the opportunity to talk through some of the problems of bereavement with a concerned person from outside the family will substantially reduce the risk of more serious problems arising later.

In many instances, help is needed because the support of a close family is missing, or because well-meaning family members are doing more harm than good by attempting to stop a bereaved person from 'breaking down'. In other cases, it is the bereaved person who is unable to ask for help from his family or friends perhaps because he is afraid to burden them with his grief. These are not problems which require a highly trained expert, and in setting up the service at St Christopher's, I was not attempting to create a team of 'mini-psychiatrists' who would analyse the hidden complexes of the bereaved, but to introduce gentle people of tact and sensibility who would be able to stay close to people in distress and encourage that healing process which we call 'grief'.

In this endeavour, the bereavement visitors have succeeded beyond my expectations. In the course of visits to many hundreds of people

over the last nine years, they have learned a great deal about the problems of bereavement and this has increased the effectiveness of their support and the confidence with which it can be offered. It is in the hope that this experience can be passed on to others who are supporting the bereaved, that they have produced this little book, a distillation of the visitors' practical experience rather than a theoretical research document.

The social workers who are responsible for the organisation and day-to-day management of the service, and the psychiatrist (myself), meet the visitors at a monthly conference. This is an essential part of of the service and ensures that a proper liaison is maintained between volunteers and professionals. Without this meeting, volunteers would feel unsupported and insecure in their work.

The function of the professionals is not to act as examples to be imitated or to instruct the volunteers in the art of psychotherapy, but to encourage them to develop the skills which they already possess and to help them to a deeper understanding of the people whom they are visiting. Each of us, from the day we are born, is learning to relate to and communicate with other people. After choosing as bereavement visitors people whose capacity to make supportive relationships is already high, the professionals must not then undermine the visitors' confidence by expecting them to behave in a way which, for them, would be unnatural.

Of course, there are times when the visitor will feel that he is getting out of his depth; when, for instance, the intensity of distress is such that a bereaved person may be tempted to suicide. In such cases, the visitor needs the immediate advice and support of the consultant psychiatrist. In other cases, where questions are asked as problems emerge which tax the knowledge of the visitor, it may be more appropriate to discuss them with the social work consultant. It is always better to ask for help than to keep silent, and visitors should not hesitate to make use of their support staff whenever they are in doubt. Even if a problem is insoluble, they will feel less inadequate if they discover that professionals too have their limitations!

People who have no experience may be apprehensive at the thought of visiting a newly bereaved person; they are afraid of intruding, of being at a loss for words ('What can you say?') or of causing people to become upset. But one has only to pluck up courage and to make such a visit to realise that these fears are unnecessary. Far from regarding the visitor as an intruder, most bereaved people are glad

of the opportunity to share their thoughts and feelings with a person who is not himself overwhelmed by grief. There is little need for the visitor to say anything—the bereaved will do the talking, and if they get upset, as they probably will, we should feel glad that they have allowed us to share their grief, for this is a time when it is all right to cry.

It is encouraging to find that, wherever terminal care units based on hospice principles are being developed, bereavement services are seen as an important component and they are included in the recommendations of official bodies concerned with the improvement of standards of care in Britain and the United States. It is important to emphasise, however, that the fact that bereavement support can be given by volunteers does not mean that it is easy and can safely be left in the hands of untrained staff, however enthusiastic they may be. Not all of the evaluations of bereavement counselling have succeeded in demonstrating its effectiveness and a high standard must be attained if this worthwhile work is to develop as it should.

A close link between the bereavement service and the other services of St Christopher's is maintained by the social workers. They are in touch with the wards and the home-care staff and are able to feed back to the nurses information about the bereavement visiting. Visitors themselves maintain this liaison with the wards. Nurses who particularly wish to do so carry out bereavement visits and members of the bereavement service take part in the inservice teaching programme for hospice staff as well as the teaching of visitors to the hospice. In this way, the bereavement service is integrated into the life of the hospice as a whole and can feed back to the staff any criticisms, suggestions or thanks which may help them to evaluate their own work.

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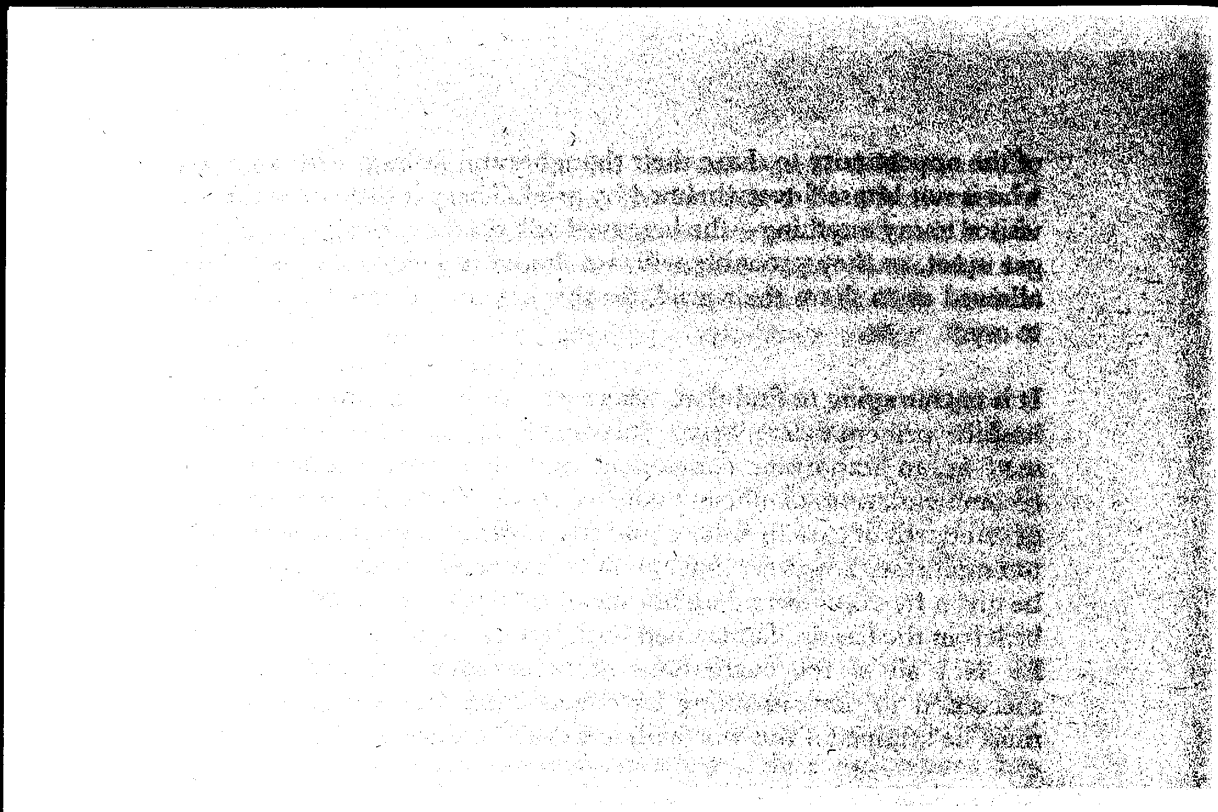

Contents

How the bereavement service began

Part of the vision which inspired the founding and growth of St Christopher's Hospice was the conviction that the hospice's concern was not only the individual patient, but the patient's family. One of the implications of this view was the development of some form of follow-up service for bereaved members of patients' families.

As with other branches of the hospice's work, the beginning of the service awaited the right combination of circumstances to make it possible. One development which later became an important element in this work with bereaved people was the starting of the Pilgrim Club. Another, the visiting of the bereaved, began to grow from small beginnings early in 1971. At that time, a number of factors came together to make such visiting seem both necessary and possible. Dr C M Parkes, for whom bereavement had for some time been an important concern, had started a piece of research on the subject at St Christopher's. The domiciliary unit was already doing follow-up visiting of the families with whom it was concerned. Some members of staff, including both the chaplain and the assistant chaplain, became convinced of the need amongst the families of the patients they met and talked with in the hospice for continued support of some members of families, in particular of widows and widowers, after the death of a patient.

It was not clear at first who would be able to take part in such work. Some members of the hospice staff, including the social worker, the chaplain and the assistant chaplain, had begun to visit a few bereaved people whose need seemed strong. Very tentatively, one or two volunteers were invited to take part.

Regular meetings were held where the visitors, including members of the domiciliary unit, met Dr Parkes to discuss their problems. Other volunteers were invited to join the group. It was discovered, as time went on, that visiting the bereaved could be a lay person's task. It was also discovered that it was possible to run the service in cooperation with the research work.

With increasing confidence the service grew. The main form of training for volunteers continued to be the discussions at the monthly meetings, supplemented by reading. In addition, they attended courses and conferences on subjects related to their bereavement visiting. More volunteers joined the group and, although some full-time members of staff, including nursing staff, continued to visit, as time went on the greater part of the work came to be undertaken by volunteers.

The visitors

People working with the bereaved have been variously called 'counsellors', 'visitors' or 'friends'. 'Counsellor' implies a professional status, which certainly does not apply to the team of volunteers at St Christopher's. 'Friend' suggests a continuous relationship or befriending which, apart from being impracticable, is not the aim of the bereavement service. It will be made clear that at no time are the bereaved encouraged to become too dependent, and that ultimately they will understand that visits will cease. 'Visitor', therefore, seems to be the most appropriate description.

What, then, are some of the qualities of a bereavement visitor? First, it should be emphasised that this sort of visiting is not something that just anyone can do. Someone who is likely to get over-involved with the bereaved person or who may pour out personal problems to him would be unsuitable. Conversely, a visitor who remained completely detached would be of little value. The balance between over and under involvement is a fine one, but it is a balance which must be maintained by the visitor if the visits are to be of any real value to those who are grieving for the loss of a loved one. However, if the visitor finds herself becoming involved for any reason, it is most important that the case is referred to the professional leader.

None of those who belong to the St Christopher's team has received any formal training for the work, but most have attended courses run by the hospice or by CRUSE* since becoming visitors. They also learn a great deal from the regular monthly sessions with Dr C M Parkes, when they discuss some of the problems of the families they are visiting. His advice and guidance are invaluable. Of equal importance are the support they receive from the social work department at the hospice, and the

*CRUSE: National Organisation for Widows and Their Children, see page 55.

help they are able to give to each other. Without all this teaching and support it would be difficult to function adequately as visitors. Indeed, it would be inadvisable for any bereavement service to attempt to function without some professional support such as that provided by a psychiatrist, psychologist or social worker. This professional leader should be readily available to the visitor to advise or to take up any case which needs specialist help, particularly that in which the bereaved person is in such a state that he might be a danger to himself.

Visitors are often asked if they get depressed by visiting bereaved people so frequently. The answer is that they do not in the main, but this is because of the excellent support they receive. Visitors should never function in isolation. They need the support of a group if they are to be able to give meaningful help to the bereaved and not to become depressed themselves.

Visitors need to be carefully recruited. All should have had experience of supporting others at times of distress, or should have known personal bereavement. If personally bereaved, however, it is important that they should have come through the experience so that they are now able to reach out to others, without leaning on them or finding that they are unable to cope with their own distress. This would apply particularly in the instance of a relative of a former patient.

The members of the St Christopher's service are drawn from all walks of life and very varied backgrounds. Some work full-time; some are retired; some are housewives with families to look after; some are members of the hospice staff. All have worked in the hospice in some way, either as volunteers or as full-time members of the staff, before being asked to join the team. The age range is wide, but most tend to be in the older age groups. There are more women than men. It should, therefore, be noted that in the following pages, reference to a visitor or client as 'he' or 'she' has no specific significance.

In our culture, it seems to be the accepted norm that someone who has suffered the personal loss of a loved one is permitted by society only to grieve until after the funeral. Up to that time, tears and talk of the deceased are quite acceptable. After the funeral, however, things are different. Tears and talk of the deceased are frequently regarded as morbid introspection, and many a sorrowing relative has been told, by well-meaning people, that he or she should not cry or talk about the loved one because it is morbid. If they ignore this advice they may be shunned. It is not the purpose of this book to discuss the reasons for this attitude but, whatever they are, the fact remains that the bereaved *need* to be able to cry and to talk frequently about the loved one, especially in the early months after the death. This is when the bereavement visitor can have a vital role to play, although it should be emphasised that she is not there to take the place of relatives and friends, but rather to supplement the support they give to the bereaved. Where there are no relatives, the relationship is different and the visitor may be the only help the bereaved person has.

It follows that the visitors should be sensitive and sympathetic to the needs of the bereaved and their relatives and friends. They should also be good listeners and willing to give as much time as the bereaved person needs. They should try to reassure and comfort those who are grieving for the loss of a loved one and help them to come through their grief back to a healthy normality. They need also to be able to recognise abnormal grief and to know where to get help if necessary.

Organisation of the service and the role of the visitor

The social workers will have some knowledge of the dying patient and his relatives. In many cases, they will have made their assessments of the likely needs of the bereaved family even before the death has occurred. The medical and nursing staff will have even more knowledge because they are constantly seeing the patient with his family and friends.

When the patient has died the ward staff fill in a form devised by Dr Parkes.* This is a questionnaire with eight groups of statements covering various aspects of family circumstances and attitudes. One numbered statement is ringed in each group. A score is obtained and this, with any additional observations, indicates the likely needs of the family and particularly those of the member closest to the deceased whom we call the 'key person'. If the home care unit has been involved, the unit staff are also consulted because they are able to assess the situation in a special way. These forms are passed to the social workers who are responsible for arranging visits. Some visitors think that ideally the closest relative of every patient should be visited at home at least once. However, time and the limited number of visitors available will not permit this to be done.

The social workers, therefore, study the assessment form and establish priorities. For example, urgent visits are made to all who might be considered a suicide risk. Visits are always arranged for those who have shown particular distress while the patient was in

*See page 59.

the hospice; for those who seem to have little or no family support; for those who are thought to have been clinging excessively; for those who have shown deep anger or self-reproach; and for those who are unlikely to be able to cope because of special difficulties. Widows and widowers with young children, especially if they have no occupation outside the home, also come into this category. All others are contacted, by telephone if possible, a few weeks after bereavement to see how they are getting on.

Bearing in mind that most of the visitors are volunteers, the social workers distribute the work load according to availability and location. There is no hard and fast rule for allocating visitors according to sex. Unless urgent, the first contact is normally made two to four weeks after the death of the patient.

The initial contact is made by the visitor and she will also decide on the frequency and number of subsequent visits. She may find that the support and understanding coming from family and friends are far greater than expected, and if the bereaved appears to be coping well only one or two visits will be necessary. From the first visit, the family will have the visitor's telephone number and will have been assured that help is always available. In normal circumstances, three or four visits at intervals of from two to four weeks are found to be enough. Even with more difficult cases it is hoped that visits will not extend beyond the first year of bereavement. Even so, the contact is never 'closed down', as the second of the case studies will illustrate, page 34.

The bereaved person should be gently helped to understand that visits will eventually cease, but that contact can be renewed if necessary. Most people will readily appreciate the practical necessity for this for themselves and will say 'Thank you for giving me so much of your time. I'm sure you have others to visit.'

Sometimes the visitor will be given a less direct indication that visiting is no longer needed. On the fourth visit to one elderly widow, the visitor was introduced to a brother who had also been

recently bereaved. The visitor had been told about him, but his presence on this occasion was clearly to demonstrate that the widow and her brother understood each other's problems, that in sharing many common interests they could support and help each other and that no further visits would be required. In this instance, the visitor felt that brother and sister could support each other well, but it should be borne in mind that bereaved people are not always the best people to support each other in the early stages.

It must be stressed that although the work of bereavement visiting does not involve a regular pattern of calls and visits, the organisation of a visiting service centres upon regular monthly meetings of visitors and their leader. These meetings provide the essential support, advice and sharing of problems so that the visitors need never feel alone in their work or overwhelmed and at a loss in dealing with the more intractable cases.

The bereavement visit is one of the means by which the care of the hospice, and indeed the community, is extended to the family. The support of the hospice is thus continued into the early months of bereavement. Sensitive responses to the bereaved person's thoughts and feelings are particularly important in the early visits. The bereaved accept that the visitor is there to listen and they make remarks like 'I can't go on like this to my family and friends'. Some feel their dependence on friends in their new situation, and will not risk 'wearing them out with my woes'. A talk with the visitor is a safety valve.

Because the visitor has studied the nature of normal grief and has probably encountered the problems of the bereaved before, he can be reassuring about their disturbing and frightening feelings. There are occasions when a widow cannot recall her husband's face, or cannot recall how it felt when they were together—a kind of disorientation. There are feelings of anger, particularly disturbing when they are directed towards the deceased. One widow felt that her children had supplanted her in her husband's affection because she had been obliged to continue working through most of

his illness. It is a relief to the bereaved to discuss these feelings and to be assured that they are not a threat to sanity.

When a visitor enquires how a person sleeps and eats, it indicates an understanding of the physical problems that may be experienced. Neighbours and friends are sometimes embarrassed if the bereaved wish to discuss their deepest feelings, and often to relatives it is too painful. This role is perhaps more acceptable in a new friend. It can also be the case if the bereaved wish to discuss financial matters. The visitor is able to give encouragement to all the practical efforts to come to terms with bereavement, such as rearrangements in the home, a special meal made, renewed social contacts and generally picking up the threads of life. The visitor may also be seen as an adviser and this aspect of the work is dealt with later.

The role of the bereavement visitor is one that is assumed naturally for, after all, it is but the attitude of a friend or neighbour with perhaps just a little more expertise which comes from knowing something of what to expect.

The visit

The visitor decides, from the details supplied, what time would be appropriate for the first visit. The initial contact may be made in one of several ways. She may decide just to call, the advantage being that she will find things as they are and not specially prepared for a visitor. On the other hand, this could mean several calls before contact is made. If there is a telephone number, she may ring and arrange a visit; if not, she may write a letter. The letter should indicate that no reply is expected. Most bereaved people are already heavily burdened with correspondence and business matters. If the bereaved person is elderly or deaf, a letter may be the best approach.

Visitors should be prepared for a refusal, in which case they will have to judge from the information they have whether to make a further attempt at a later time. There are occasions when the bereaved are prepared to talk at length on the telephone yet still unwilling to receive a visit. By a rough estimate, about ten per cent of those approached refuse a visit. Those refusing are almost invariably men: 'I've got to work this out for myself'. The visitor introduces herself by explaining her connection with the hospice and that 'we are wondering how you are getting on'. The mention of the hospice and an expression of sympathy usually ensure a welcome.

Once the visitor has been accepted as a sympathetic person concerned with the cares and problems of the bereaved, she will generally find that for the first part of the visit she has little to do but listen. The bereaved will regard her as a new audience: one who, unlike relatives and neighbours, knows little of all that has led up to the great personal loss. It is the experience of visitors that bereaved people are only too ready to give a full account, as they see it, of the terminal illness, the visits to the general practitioner, the hospitals, the x-ray examinations, the operations, and

so on. The story often includes accounts of vital decisions made and the subsequent mental anguish about whether those decisions were correct. 'If only we had gone to the doctor earlier.' 'If only the doctor had sent him to the hospital at once.' 'If only we hadn't consented to the operation.' 'If only he had had an operation.' The visitor will often detect a hint of anger in such remarks. Anger may be directed at the doctor, the hospitals, the relatives, or even the deceased. 'When we made plans for the future we always thought that I'd go first, but now I'm left.' But anger is a natural component of grief. It has to be expressed, and who better to hear about it than the visitor. Self-reproach is normal too, but it is important for the visitor to note if it is likely to become a major problem.

Friends and relations will come into the story. The visitor will often be told which of the children and other family members have been most supportive, and which have not; who came in to help with the nursing or who was most regular in accompanying the bereaved on hospital visits. Such information is important in enabling the visitor to assess future needs. If not provided, it may have to be elicited by tactful questions. Sometimes the bereaved will hark back to earlier events and bereavements. Happenings at the time of loss of a parent, a brother, sister or a child, may have an important bearing on the present grief and reaction to the latest loss. Often a much idealised description of the character of the deceased, and of the marriage, may be given. It is only during later visits that a more realistic picture will emerge.

Other important information may be less forthcoming, but with tactfully interposed questions the visitor should endeavour to ascertain what major problems the bereaved is encountering; in particular, those concerned with young children and teenagers. Not everyone will want to talk freely about housing, domestic and financial difficulties, and the visitor should certainly not probe into these matters, but he would hope to know if there were any such difficulties.

The health of the bereaved is also an important topic, but again the subject must be brought up with care. Is the bereaved seeing her general practitioner? Are tranquillisers or sedatives being prescribed?

Religion may be mentioned by the bereaved, often in reference to the funeral service. The visitor should be ready to discuss the subject, but very careful not to intrude. The initiative should always come from the bereaved. Lastly, the visitor should try to determine what other problems the bereaved has, or sees himself as having.

Much information is often given quite freely with little demand being made on the visitor, but some people are less communicative or articulate than others and with these the visitor must work with patience and care. It should be understood that it is very unlikely that all the pertinent information will be acquired in one visit. Only after the visitor and the bereaved get to know each other can a full assessment of the problems and needs be made.

Visitors have record forms* which they complete after visits. At all times strict confidence is observed in dealing with these forms and all information gathered during visits. The questions on the form are reminders of the things to observe. Notes are not made during the visit, but the form is completed as soon as possible after the visit and an account of the visit is always written. The account should include actual quotations whenever possible. It is useful to read the account before further visits. More notes are added as new information is gleaned and fresh attitudes are observed.

The time of subsequent visits depends on circumstances. The visitor may feel that another is needed in a few days, but normally one is arranged after about two to four weeks. If the visitor feels that the bereaved person is coping with his grief, a longer interval is left before another visit, with perhaps a telephone call in the interim.

*See page 61.

It sometimes happens that after a number of visits a bereaved person still shows little progress. She may expect, welcome, and ask for, more and more of the visitor's time. Recognising the lack of progress and growing dependence, the visitor should ask for professional help. Even with people who are coping with their bereavement, it is inadvisable to form a regular pattern of visiting. Most bereaved people realise that the visitor has continuing commitments and that her visits can only go on for a limited period.

Visits cease when the visitor feels that her function as a 'bridge to the future' has been fulfilled, but the way is always open for another visit if required.

Case studies

Mrs Brown

Mr Brown died aged forty-four. Mrs Brown was thirty-nine and there were two sons; Richard, seventeen, and John, twelve.

I telephoned Mrs Brown soon after her husband's death. I told her my name and that I was a visitor from St Christopher's Hospice. She expressed surprise and I explained that we were anxious to know how she was. Mrs Brown told me, 'I'm managing to keep things going somehow. The boys are very good, but there is such a lot to do.' I asked if she was working. Mrs Brown replied, 'I've started back at my old job (a comptometer operator) but I'm doing full-time now. The firm has been very good, but it's very hard and I forget things.' I asked if her colleagues were helpful and she said, 'Yes, they are kind and if I want to be left alone they understand.' I asked if I might visit her. Mrs Brown replied, 'Yes, that would be nice. I'd like to talk to someone from St Christopher's. I want to go back to see them. Sister J was so good to us. I'd like to see her again.' I arranged to visit the following Sunday.

As I walked towards the house I was anxious about my ability to help what must be a very shattered family. Mrs Brown had sounded 'flat' on the telephone. She answered the door and I introduced myself. Mrs Brown asked me in and said it was very good of me to come. She asked 'Did you know my husband?' I told her I had not known him, and went on to explain the concern of the hospice for the families of patients.

Mrs Brown introduced me to Richard and told me that John was at his friend's home. Richard told me that he had a friend helping him to tidy the garden that had been neglected 'while my Dad was ill'. Richard made some tea and then joined his friend in the garden. Mrs Brown looked tired and sad. She told me the story

of her husband's illness and of how frustrated he had felt at that time when no one was giving him sensible reasons why he felt so helpless. She said he was in the 'print' and when he was first ill he used to struggle to go to work and then would have to come home again because he felt so bad. 'They were very good at work and after a while they said not to worry about work, but to take off as much time as he needed and he wouldn't lose by it.' I asked Mrs Brown how she had felt at that time. She said, 'It was very worrying, but my main concern was to keep him from getting low. We've always done our own decorating so he thought he'd like to try doing a bit to the bathroom. I had this part-time job and I'd come home and find him stretched out on the settee and fed up because he couldn't get on with it.'

Her eyes filled with tears. I wanted to put my hand on hers, but it would have meant crossing the room to do so and I felt that this might interrupt the flow of her story. She went on, 'We kept going to the hospital, but we never had any satisfaction. Then we went back to our doctor and he could see that we wanted to know what was going on and he told us. I suppose by then we were not so surprised, but it was terrible.' The tears flowed now and I ventured to go across and put my arm round her shoulder. She said, 'I'm sorry, I hope I've not upset you.' I assured her there was nothing to be sorry for; and that it was the most natural thing that she should cry. We were quiet for a while and then she went on, 'As well as everything else he was worried about the boys and me and he wondered how we would manage. I told him that we would manage and that the boys were getting older and Richard was a serious and thoughtful boy. Then in bed at night we would both cry our eyes out with our arms round each other.' I asked Mrs Brown if they were able to comfort each other. She said, 'Yes, we used to go to sleep like children.'

I felt very inadequate in the face of such grief. It would have been very easy just to sit and cry with her, but I felt I had to hold myself back and be in control of the situation. I asked Mrs Brown if the boys had known that their father was dying. She replied,

'Richard seemed to cotton on to what was happening, but we didn't say anything to him.' I asked her if she was able to talk to him about it later. Mrs Brown said, 'Yes, I had to tell him, but he knew really. We didn't say anything to John, but I think Richard and he talked about it.'

Mr Brown's widowed mother lived in Hackney, as did three brothers and their families. Another brother and his wife lived in Brixton. The brothers were very helpful and supportive at this stage. They visited her regularly and took Richard and John to football matches on Saturdays. The mother was quite shattered, and Mr and Mrs Brown had found it difficult to cope with her grief as well as their own. She was being well supported by her other children. In spite of the difficulties, Mr and Mrs Brown decided they would have her to stay for a night on occasional weekends. Mrs Brown told me, 'I used to dread her coming in the end because she was so miserable always and made the house awful. When she wasn't there we could be happy, although we never forgot.' Mrs Brown went on to explain that she had always been very close to her husband's family. She told me of the happy times they'd had together. They always met on a Saturday, the men and boys went to football and the women would visit each other and take turns at entertaining the rest.

My visit seemed to end naturally at this point. I asked if I could come again and Mrs Brown said she'd be very pleased. I said I would telephone in a few days to arrange a day.

I was content that Mrs Brown and I had established a relationship. I felt deeply for her and the boys and wondered what help anyone could give in such circumstances. I reported on the visit at our next group meeting. I was encouraged to go on another visit and was assured that in encouraging Mrs Brown's expression of grief I was doing the only thing that would help at this time.

The second time I visited Mrs Brown, I met John. He is a friendly boy with lots of energy. I also met Mrs Brown's closest friend,

Mrs James, who had been very supportive. Mrs James's son and John were very good friends. We chatted for a while and then Mrs James and John left.

Richard stayed to talk. He had taken 'O' levels and was awaiting the results. A friend of his father was helping him to get a job with an insurance company. Richard talked about his father: the happy times they'd had; some of the things he'd learnt from his Dad and about how different it was now that he wasn't there any more. Richard said that John had been very upset about his father's death. Mrs Brown told me that John had been on holiday with his school when his father died. Richard and Mrs Brown had gone to meet him on his return. They had waited until they got home before telling him. John had rushed upstairs and shut himself in his bedroom. Mrs Brown and Richard were soon able to go in, and they all cried together. The following day they all went to see Mr Brown's body at the hospice. John had brought home a handkerchief as a present for his father. This he was able to put in his father's hand.

I felt overwhelmed by the sadness of the family and the fact that these two boys would have to grow up without the support of a very loving father. I searched for words of comfort, but finding none I realised that anything I could say would be irrelevant. They were supporting and comforting each other.

Mrs Brown was feeling more settled at work and was not so anxious about forgetting things. She was worried about her rent book. It had to be transferred to her name and the housing authority were very slow about it. No rent could be accepted until the transfer had been made. She did not wish to be faced with a large sum to pay. I suggested that she put her rent weekly into a Post Office savings account. Mrs Brown then told me how her husband's family, with the exception of one brother and his wife, 'have been terrible to me. They seem to have turned against me and they haven't been near since the funeral. They seem to blame me for it all. They 'phone sometimes, but that's it.' We talked

about this development and of the mother's bereavement; of the fact that she had not been able to break through her own grief to comfort and get close to her son in his last weeks. Mrs Brown said she felt sorry for her mother-in-law, but thought she should show more understanding.

It seemed to me that it had probably been difficult for the mother to break into the little circle formed by her son and his family. She may not have been able to find the words or gestures needed to become part of that unit.

We talked about how Mrs Brown and her husband had grieved together and faced their coming separation and that his mother had not been a part of this. Mrs Brown agreed. 'I don't know how we could have carried on if we hadn't been so close. We talked about everything and I feel him helping me now.' Mrs Brown went on to tell me about a rash on her neck and that she had been very worried about her hair falling out. She had seen her doctor who was very sympathetic and had treated her. The symptoms were already alleviated and she was less anxious.

I felt very concerned about Mrs Brown and brought up the case again at our next group meeting. I was reminded that families often encounter breakdowns in relationships in times of bereavement. The visitor is an agent in helping to bridge these gaps where the family, through stress, is unable to share each other's grief. We discussed the importance of encouraging Mrs Brown to talk about her difficulties and how it helped her to stay with the family problem and encouraged her insight into her mother-in-law's feelings. Mrs Brown's symptoms—a rash and loss of hair—indicated the extreme stress she had experienced and it was indeed fortunate that she had a sympathetic doctor who was able to help her.

The next time I visited, Richard had started his job and was happy to be working. Mrs Brown and the boys had settled into a routine. The boys had their responsibilities and jobs to do in contributing

to the running of the home. Relations between Mrs Brown and her mother-in-law were slowly improving. The Saturday visits to football games had been resumed. Mrs Brown and the boys had started going to Hackney again. Mrs Brown still expressed some anger about her mother-in-law. She had been much comforted by the 'Brixton' brother-in-law and his wife who had 'stayed by' them. She was conscious of the importance of working towards a full return to the close relationship of the whole family and she wanted this, especially for the sake of Richard and John.

I made one more visit. Relationships in the family were improving and a good measure of the former intimacy was being established. Richard, with the help of one of his uncles, had been able to buy an old 'banger'. This was a source of interest to all and was a help with visiting and shopping. John had good reports from school, which seemed to indicate that he was settling well. I kept in touch by telephone for several months and felt confident that Mrs Brown would contact me if she became anxious or upset.

I was able to discuss this case at three of our group meetings. The reassurance and encouragement I received were most helpful.

Discussion

Reporting sessions are important in helping visitors to get things in perspective. The leader will pick up a clue in the reported conversations which the visitor may have missed. He will sometimes advise or help the visitor to discover for herself what to do next. The encouragement and discussion within the group are invaluable. In this way, the visitors share their problems and anxieties and thus maintain a balanced view.

A number of features in the story above were of particular significance to the visitor and merit some discussion here.

First, there is the moving account which Mrs Brown gave of her husband and herself grieving together. Though nothing could diminish the pain of her bereavement, Mrs Brown undoubtedly

found great consolation in the knowledge that together they had shared their deepest thoughts about her husband's approaching death. There were no secrets, no deceit and no 'double-talk'. Mrs Brown was able to recall that 'we were happy together'. Her conversations with the visitor show that because of this closeness, there was a marked absence of self-reproach and feelings of guilt. When a husband and wife have not been able to grieve together, there may be a need for the visitor to help the bereaved to express feelings of regret for the things that were left unsaid.

After Mr Brown's death, the boys and their mother continued in this spirit of mutual trust and understanding. They talked of their loss together; they cried together. In particular, John, the younger son, was enabled fully to share his grief with the others. Sadly, this is not always so. There is a tendency in families to shut out the children from the grief of their elders. A young child grieving alone may encounter serious problems later. If a visitor finds such a situation, she should remind the adults that children grieve too and that they should be allowed to feel themselves to be part of the family in their grieving. She should also consider whether or not professional help is required.

So intense is the grief of a family which has lost a partner and parent that sometimes there will be a lack of understanding, or even a lack of recognition, of the bereavement of the wider family—brothers, sisters and parents of the deceased. Minor irritations, which would normally be quickly forgotten, take on an exaggerated importance. Even with the close family ties which were so obvious in this family, there was a period when Mrs Brown feared lasting damage to her relationship with her in-laws. The visitor had to encourage her to discuss their grief as well as her own.

Relatively unimportant matters can worry and appear to threaten a bereaved person. The business of the rent and the rent-book caused Mrs Brown some real anxiety, even though she had resumed well-paid employment and had been assured

by the housing officer that the transfer of the tenancy was a mere formality. Confusion and forgetfulness are typical in the early stages of bereavement, and the visitor was able to explain that this was so. Similarly, the skin rash and the loss of hair were physical manifestations of distress which the general practitioner was able to deal with.

Turning back to the first visit, it will be noted that when Mrs Brown was crying and in great distress the visitor was silent. There are times when nothing need be said. A sympathetic silence can convey a genuine understanding of the other's suffering far more deeply and sincerely than words.

The visitor was active with this case over six months or more and, although she shared in the deep sadness and problems of the family, she could see that they were making good progress in coming through the bitter experience. Cases are not always so straightforward as is illustrated by the following story told by another visitor.

Mrs Jones

Mr Jones died after a long illness, aged sixty-seven. His widow was sixty-five. There was one daughter, Joan, married and living with her husband and two children about two miles away. As Mrs Jones had no telephone, I made my first arrangement to visit her through her daughter.

In response to my knock, Mrs Jones opened the door and immediately turned away and entered a small living room. I closed the door behind me and followed her and saw her throw herself into an armchair in uncontrollable sobbing. After some minutes she turned to me and said through her tears 'And what can you do for me?' To be challenged in this way after such an alarming initial encounter was daunting enough and I realised that I had already asked myself the same question. However, with some trepidation, I suggested that if we could have a cup of tea we might be able to talk about her distress.

She responded to this idea and as we stood in the kitchen she began to tell me about her grief.

She was quite unable to accept her husband's death. 'We should never have been parted', she said. She went on to say that she couldn't adjust herself to her home without him; she couldn't use their bedroom, neither could she make adequate meals for herself. By the time the tea was made Mrs Jones was more relaxed and we were able to sit comfortably in the sitting room. She talked about her despair and said 'I wish I could go to sleep and not wake up. My daughter has lost her father. It couldn't hurt her any more if I died too. Last night I took one Valium. I could have taken the lot!' I questioned her closely about these thoughts and soon she retracted her remarks about suicide, saying that dying would only give her daughter more trouble. 'I don't want to be a burden to her. I depend on her too much and I know I shouldn't.' This led her to talk about her fears of a mental breakdown. Some years earlier, after a serious and prolonged quarrel with her sister over the care of their widowed father, she had been treated for mental illness. She added 'I am determined that it shall not happen again.' She was grateful for the hospital care she had received and went on to express warm appreciation for all the attention she and her husband had received at various hospitals and at the hospice.

A more positive attitude began to emerge. Mrs Jones explained that she had had a mastectomy some six months earlier but that she had begun swimming again and was determined to keep it up. She was also resuming her activities with an old people's club that she had been helping to run for many years. She then revealed that in a few days' time she was due to go on a week's coach tour. It had originally been booked for her husband and herself but a widowed friend was going with her in his place. 'Of course, she has accepted her loss but I cannot accept mine. She couldn't have loved her husband as I loved John. I am very bitter that he couldn't enjoy his retirement.'

Thus, the conversation came back to her husband. She told me about their life together from the time she was sixteen, their interests and activities. Photographs were brought out and gradually the story returned to Mr Jones's final illness and death. In his last hours he had asked for his son-in-law and not his wife. Here was another cause for anger and jealousy.

We had scarcely begun to deal with the problems and bitterness of her grief, but I felt that during this long and demanding visit Mrs Jones and I were getting to know each other. I said I would call again very soon and Mrs Jones made it clear that another visit would be welcome. I had much to think about and I discussed the case with Dr Parkes and the group as soon as possible. It would certainly be a difficult case.

Mrs Jones went on the coach tour and I made my second visit a few days after her return. The holiday seemed to have been reasonably successful but I found her still very tearful. She was distressed and somewhat resentful that her daughter and family had begun a fortnight's holiday the day she got home from the tour. She was still unable to make meals for herself and said she awoke each morning dreading the day ahead but admitted that she felt better by the time the evening came. She was unable to concentrate on reading, knitting or watching TV. Her neighbours were very concerned for her and invited her in for meals, but she continued to be bitter that either they still had their husbands or that they had accepted their widowhood. I urged her to try just occasionally to return the hospitality by providing a simple meal for a friend or neighbour. The tears came freely as we talked about her husband. It transpired that, although they shared a very happy life, he did not take part in her club work or go swimming with her. 'But he was always there when I came home.' I discussed with her the need to make a life for herself again.

When I arrived for my next visit there was no answer to my knock. 'She's out!' called a voice from the window next door.

The neighbour invited me in. She was considerably older than Mrs Jones who, she said, had been a great trouble to her since Mr Jones died. However, the old lady had had Mrs Jones in to breakfast every morning, had spent many hours with her every day and was greatly distressed by her constant crying. Very early the previous Sunday morning, Mrs Jones had knocked on her door in an hysterical state and begged to be taken in. 'You've been a naughty girl haven't you?' said the old lady, 'Go and get me your tablets and then you can come in.' Mrs Jones spent most of the day in her neighbour's bed. During the day, the old lady put the tablets down the lavatory, much to Mrs Jones's dismay when she found out! She was made to promise to see her GP early next day.

By the time this story had been told, Mrs Jones had arrived home. I had to be very careful not to disclose all that I had been told, but I questioned her closely about how she felt and whether she had seen her GP lately. Yes, she had seen him and he had changed her prescription. On the whole, she seemed much more cheerful and was quite enthusiastic about her club. She did, however, disclose that she depended on her neighbour for her breakfast each day, and I urged her to break the routine as a first step to independence.

I was quite alarmed at the apparent suicide demonstration and immediately reported the facts to Dr Parkes. He felt there was no serious suicide risk but that Mrs Jones was increasing her demands on her neighbour while her daughter was away on holiday.

I made several more visits during the year and was pleased to note her enthusiasm for her weekly swim and the imaginative programmes she was devising for her club members. Although she was still over dependent on her daughter, I really believed she was building a purposeful life for herself again. I made a point of visiting her the day after the first anniversary of her husband's death. We talked about the year that had passed.

She was calm and composed and I was pleased to find that she had begun borrowing books from the public library. I explained that I felt the time had come for my visits to cease, but assured her that I was always ready to call again if needed.

A whole year passed and then, about a month after the second anniversary of Mr Jones's death, Joan telephoned to say that her mother's deep grief had returned. She would not prepare her meals or clean the house. Because of her continual crying she was losing friends. Her constant demand for her daughter's company was causing tension between Joan and her husband. Worst of all, secondaries had been discovered in her spine. 'But don't tell her she has cancer', said Joan.

I went to see Mrs Jones as soon as possible. She had had a telephone installed so I was able to contact her directly. She told me about her illness, the x-rays and the time she had spent in a wheelchair. I was astonished when she told me she had started swimming again. 'But I can't stop crying. I get up every morning feeling the uselessness of another day. I can't be bothered to make a meal for myself. It is pointless, but I still enjoy a meal with others and I still go in next door for breakfast each day.' I was dismayed at this set-back. We talked again about her problems just as we had two years earlier. Through her tears, she described her desolation, anger and self-reproach, as though her husband had only recently died.

Suddenly she said 'I want to see a psychiatrist.' I said I would try to arrange for her to see Dr Parkes. An appointment was made and, accompanied by Joan, she went to see him. She found it very helpful to talk with Dr Parkes but after three consultations she said she wouldn't go to the hospice again. 'It upsets me so much to go there.' Various antidepressants were prescribed but there was very little change. Meanwhile, Dr Parkes advised me to continue my visits, to try to give Mrs Jones encouragement and assurance and to suggest some simple targets for her to strive for: for example, to plan and make a

meal for herself on certain days of the week; to invite a friend in for a particular day; *not* to telephone or see Joan on one pre-arranged day each week.

My visits continued for another three months. The last time I saw Mrs Jones was just before Christmas. She reminisced about Christmasses past. She was tearful but relaxed. Yet still she was saying 'I can't believe he has gone. I get so forgetful. I can't make myself do anything.' Though nearly three years had passed since her husband died, Mrs Jones was still going through the early stages of bereavement. Remembering the events of our first meeting I had to ask myself: What have I done for her?

Early in the new year Mrs Jones's condition deteriorated rapidly. She was admitted to hospital where she died, inconsolable to the end.

Discussion

There is really no way in which a visitor can determine how much he has contributed to a person's progress through grief, and cases cannot be classified into successes and failures. Naturally, after sharing the sorrow and grief of the bereaved, it is encouraging to observe them moving forward to a hopeful future. It is inevitable, too, that one should experience some dismay, as in the foregoing case, where the widow endured three years of deep sorrow with no lasting relief. Sometimes, a bereaved person may choose to terminate the contact when the visitor believes there is still much to be done. The visitor should not be too disappointed or feel rebuffed at a premature or abrupt ending to a case.

Bill

Bill's girl-friend Sue died aged seventeen after a long and painful illness. He gave up his job to be with her constantly during the last few weeks of her life. Shattered and broken-hearted by her death, he broke with his family, slept rough and drank

heavily. He had been seen, according to his mother, in a pub on the Dover road, and it was through a message left for him there that he eventually contacted the visitor by telephone.

He seemed very anxious to talk and a meeting was arranged. He arrived for the meeting, 24 hours late, with broken teeth and damaged knuckles acquired in a fight the night before. He appreciated the concern which the hospice showed for him and was glad to talk and talk about his love for Sue, his unbearable anguish and his many problems. After about three hours, Bill had agreed to get in touch with his family and to make an appointment with a dentist. A few days later he was visited in his home. His mother showed deep understanding. But for Bill, the eldest of a large family all living at home, it was obviously going to be very difficult to settle. After this visit, the visitor, believing that family tensions might become unendurable, asked the social worker at the hospice if she could make some enquiries about hostel accommodation for Bill. Another visit was made a week later. By this time Bill had got himself a good job which he was due to start in a few days. However, it was sadly clear that he was determined to work out his anger on his family. He had decided, too, that he wanted no further contact with the visitor.

Discussion

It was very hard to accept this refusal of help when it was so plain that there would be so much sadness and turmoil in this home, but in the face of this obduracy there was no alternative. As in all cases, mother and son were assured that contact could be renewed at any time. Visitors frequently find the grief and anguish of bereaved young men embittered by the well-meaning remarks of friends who say 'Never mind! You're young. You'll meet someone else one day.' That is how Bill came by his damaged hand!

Giving help and advice

It is possible that the bereaved person, having found in the visitor someone who is sympathetic, understanding and willing to share in the problems and distress of bereavement, may look to the visitor for practical help and advice. The needs are two-fold. First, those concerned with business and the adjustments of day-to-day living and, secondly, the problems of coping with grief, loneliness and facing the future with 'more than half one's life gone'.

Practical help

The practical problems are obviously best handled by relatives, close friends or good neighbours, but the visitor should be prepared to play a part should the need arise. Though in all probability not a trained social worker, he should nevertheless be acquainted with the sources of help and should encourage the bereaved person to approach and make use of them. Such agencies are:

the general practitioner and his primary care team
local authority welfare departments
local office of the DHSS
Citizens' Advice Bureau (particularly helpful with problems about wills and insurance)
local office for rent and rate rebates
customer service departments of the Gas Board and Electricity Board

For these last two bodies, an initial contact by letter usually brings a representative to the house and this has more satisfactory results than a visit to the showrooms. The following example will illustrate. Not more than six weeks after bereavement, a

widow suddenly found herself confronted with a bill for £100 for electricity. Following the procedure described above, she was visited by a representative of the LEB who explained that £20 would be accepted on account. In due course, substantial relief was granted under the arrangements existing at the time. Thus, one anxiety was allayed.

The bereaved should be encouraged to make contacts for themselves: only in rare circumstances should the visitor decide to make an initial approach. Experience shows that the bereaved find strength and a sense of achievement in having successfully solved step by step the many problems that beset them.

Specialised help—welfare, financial and sometimes educational —can be sought through professional associations, trade unions, the welfare departments of the civil service and many large firms. For the widows of men who have served in the armed forces, the British Legion and service benevolent funds are always sympathetic to special needs and can make grants accordingly.

It is useful to know of schemes for finding employment for pensioners. Quite often elderly widowers feel they would like part-time employment to occupy their lonely hours and to provide them with much needed companionship. Some London boroughs, in conjunction with Age Concern, have set up employment offices for this specific purpose.

Sometimes the disposal of the deceased's clothing may present problems. A widow might say 'I can't open that wardrobe. All his clothes are there.' She must be urged to enlist the help of a close friend or relative to tackle the very distressing but necessary task of clearing these things. This is not to say that there must be complete removal of all belongings. A comfortable old hat on the hall-stand or an apron hanging on the kitchen door can be as much a happy reminder as a photograph.

'I must move.' 'This house is too big for me now.' 'I can't bear to go on living here now.' 'I'm so lonely, I must find a place near my daughter.' These are remarks one hears so often from bereaved persons and the visitor must try to discuss the problem fully. Except in instances of extreme urgency, the visitor should advise against a hasty move. A change of home and surroundings, though it may ultimately be necessary for financial and other considerations, can cause serious emotional problems if made too soon. It has been said that a complete change of environment and residence could be another form of bereavement. Changing the furniture and rooms around, a good spring-clean, or perhaps a limited redecoration plan can help. 'I think he would like what I have done with this room.' 'We had planned to redecorate this room together.' 'She would be amused that I had managed to make a cake for myself.' Such remarks indicate pride in independent achievement and are signs of real progress.

Help with loneliness

Acute loneliness can cause serious difficulties for the bereaved. For the first few visits, the visitor will almost certainly be welcomed as a counsellor and friend, but sooner or later it has to be understood that visits can only continue for a limited period. A clinging relationship has to be avoided. The bereaved must be encouraged to make the most of their own friendships and to be assured that invitations to other people's homes are offered sincerely and not out of pity. Unfortunately, it sometimes happens that a couple have lived exclusively for each other and bereavement brings an almost intolerable loneliness. In these instances, the visitor will find it necessary to make a greater number of visits but should endeavour to call in the help of other organisations. Considerable help can be obtained from CRUSE, particularly for the younger widow. For the more elderly, contact can be made with visitors from Age Concern which, in some places, operates a befriending service.

The help available from local churches varies from place to

place, but some churches of all denominations have groups of lay people who organise visiting schemes. Their functions are quite different from those of bereavement visitors who have to judge when to call in such services. The Methodist Church and the Salvation Army hold regular meetings called 'Bright Hours' which have considerable appeal for some lonely people.

In times of bereavement, people who have had no particular religious attachment frequently get in touch with the clergy, and a visitor encountering a problem of loneliness might find it useful to make a contact with the clergy and request further visits. Health visitors can also be approached, and it has been known for them to have arranged for elderly people to be visited by younger families. There is no easy solution to the problem of acute loneliness. Much depends on the visitor's knowledge of the neighbourhood. The whole purpose of the help given, the contacts made, and the friendships encouraged, is to enable the bereaved to build up for themselves a life which, though different from the one which has gone, is increasingly satisfying and worthwhile.

The effect upon the visitor

Before undertaking bereavement visiting it is essential to think carefully about your own views and attitudes towards dying and bereavement—to look at how you have dealt with loss in your own life, and to read about the subject. Even with this preparation, it is still natural to feel some apprehension when embarking on a visit. One fears one's own inadequacy. In most cases, these fears are forgotten as the visitor becomes involved in the visit. The anxieties and problems of the bereaved person take over the visitor's personal emotions.

Visitors are frequently asked about the number of bereaved people they can cope with at any given time. There is no single answer. The success of a scheme of volunteers making bereavement visits depends upon the flexibility of the organisation and the certainty that there will never be pressure to deal with more than each person feels able to manage. A widower with an alcohol problem and young children may need frequent and time-consuming visits, and the visitor may need to be easily available to support such a family. During the early times, heavy demands—on time and on emotions—may be made upon the visitor. Most visitors would only feel able to deal with one such family at a time.

However, many people will only need one or two visits and an occasional contact by telephone, and in time one's visiting list will have people at varying stages. After a while, most visitors get to know their limitations.

It may happen that the visitor has known the deceased and his family, but for most visitors the meeting with the 'key person'

will be the first contact. The assessment card and contact with the social workers, and ward and outpatient staff, may give some insight into the family and any possible problems. Initially, the important things are the feelings of the bereaved, their views of the deceased and the relationship as they felt it to be. The visitor's role in the early stages is usually that of a listener. She needs to come to terms with the fact that there will be no one answer, no one action that will get rid of the pain. The event of death cannot be reversed. Grief is a painful and necessary part of mourning. Visitors must understand and be prepared for this, and know that it can be painful for them too.

Emotional over-involvement must be avoided. Inevitably, there are some families or individuals with whom it is easy to identify —the widowed mother with children the same age as one's own, for example. It is here that the sharing of problems in a regular group meeting is so valuable: to put into words the difficulties encountered, to answer questions and to pool resources help to keep things in perspective. An experienced leader of the team is indispensable in helping the visitor to keep a balanced view of her case.

Anxiety about possible suicide is one of the worrying aspects of bereavement visiting. Such fears put considerable stress and responsibility upon the visitor, and there must always be expert help to call upon. These instances are comparatively rare in our experience, but anyone involved in this work needs to have thought about sources of help available. It is difficult for a visitor to overcome the natural diffidence of asking, 'Has it been so bad that you have thought of killing yourself?', when the bereaved shows signs of panic or severe anxiety, or if there is any cause to believe that she has suicide in mind. Anyone in a state of extreme anxiety and panic would have thought of it anyway, and would be relieved to have the opportunity to talk about it. Whether or not a real suicide risk is revealed, the discussion will give the visitor a clearer view and it is not usually difficult to decide what to do.

At first sight this work might seem depressing. There can be sadness, anxiety, frustration and times when there seems to be no progress. What then is the satisfaction for the visitor? It comes from seeing a bereaved person who has been turned inward by shock and grief, gradually emerge and adapt to a new role in life. Let us end with the example of an elderly woman, widowed for the second time. She had reacted with emotional violence to her husband's pain and death. Her married daughter was much concerned, the grandchildren very upset by their own grief and that of their grandmother. She needed to talk at great length, to weep, and to search for some kind of meaning. She gradually regained some interest in life: helping with the children so that her daughter could return to work; making new friends in the neighbourhood. She still welcomes occasional telephone calls from her visitor but no longer has need of support outside the family.

The Pilgrim Club at St Christopher's Hospice

On the first Monday of every month, the Pilgrim Club meets in the Pilgrim Room at St Christopher's Hospice. It is a club for the bereaved relatives of former patients and hospice staff. It is attended by doctors, nurses, social workers, bereavement visitors and administrative staff, particularly those who meet the patients and their relatives. Members can buy drinks at a licensed bar manned by hospice staff.

The bereaved are told about the club by the ward staff or by the social workers. Bereavement visitors may suggest a visit to the club if they feel that the widow, widower, son or daughter would draw comfort from this kind of contact with the hospice. Others who have not been visited at home are invited by a telephone call from the social workers' office.

For the first attendance, it is helpful if an arrangement is made so that the bereaved person knows that there will be someone to greet him and introduce him to others. It may even be wise to arrange to meet in the foyer. It can be a daunting prospect to walk into a crowded and noisy room full of strangers. The bereaved may bring a friend or relative with them.

They are always especially pleased to meet members of the staff, and sometimes a nurse or doctor is able to resolve some anxiety for them. One widow was very concerned about a strange sound that came from her husband at the time of death and wanted to know 'Was it the air coming out of him or was

he in terrible pain?' The nurse, in this case, spent a long time in reassuring the widow that it was not a moan of pain. The widow was very relieved and glad to have this fear cleared from her mind.

The evenings can be purely social occasions but they have other purposes too. One widower with children found that for six to eight months it was the only social engagement he could manage. He came to relax and chat over a drink or two, although occasionally he would discuss his difficulties. An enquiry, 'How are you getting on?' will sometimes start a long talk about the problem and pains the bereaved person is having.

From time to time, someone is met whose need for a home visit only manifests itself some time after the bereavement. One such widower was seen outside the hospice on a club night unable to bring himself to come in alone. He was lonely and very tearful. We were able to arrange for him to be visited at home. In another instance, a bereaved daughter and her aged and deaf father were encountered in the club. The daughter was deeply distressed and embarrassed by her tears until she found that people accepted her grief and showed understanding. In this case, too, visits were arranged, in the course of which it was discovered that the father was not being allowed to show his grief in the presence of his daughter. Two visitors became involved at this point.

A great deal of encouragement and reassurance goes on. The bereaved exchange accounts of their own experiences during the illness and death of their loved ones. They discuss some of the strange things that have happened since their loss.

One widow told of how she decided to trim a hedge in her garden—a job which her husband would have done—when she felt that he was there, standing quite near her and teasing her! She looked up at him and smiled and got on with the job.

Amidst great hilarity and admiration, a widower and his twenty-five year old son, who were making their first shopping forays and cooking experiments, had to report to many friends at the club the results of their Christmas cooking.

An inspiring occasion is recalled when a widow told a group that when she and her husband found that he had only a few months to live they decided they would visit their only daughter in Australia, as already arranged, but would bring the date forward. They had a wonderful time, and when they got home the husband came to St Christopher's almost immediately, and his wife spent seven hours a day with him to the end.

The Pilgrim Club meetings are, in the main, jolly, friendly evenings. The threads of pain which run under the surface could well pass unnoticed. For the bereavement visitors the meetings are most helpful. They enable them to keep in touch with the bereaved when the need to visit them at home is passed. It is also an evening of hard work for the hospice staff and the bereavement visitors. The number of club attendances varies enormously. Some people will come for only two or three months, while others will come month after month for years, but usually a member will attend more or less regularly for about six to eight months. However, it should be said that the club only caters for a minority of those reached by the bereavement service. Many people by nature and temperament are not attracted by social gatherings at this or any other time.

Because of travelling and other difficulties experienced by the elderly in trying to attend functions held in the evenings, arrangements have been made recently to provide an alternative afternoon gathering. A small group of up to twelve widows and widowers led by one of the social workers has been meeting at the hospice on one afternoon each week. This facility has been warmly welcomed by the group and it is likely that other groups will be formed later on.

Suggestions for reading

Bereavement: studies of grief in adult life
by Colin Murray Parkes. Pelican.

Dying, by John Hinton. Pelican.

Death and the family, by Lily Pincus. Random.

A grief observed, by C S Lewis. Faber *and* Bantam.

Grief and how to live with it, by Sarah M Morris.
George Allen and Unwin.

In the springtime of the year, by Susan Hill. Dutton *and* Penguin.

Begin again: a book for women alone, by Margaret Torrie.
J M Dent and Sons *and* Aldine Paperback.

A child's parent dies: studies in childhood bereavement,
by Erna Furman. Yale University Press.

What to do after a death, leaflet available from local Social Security offices.

The loss of your baby, booklet available from the Health Education Council.

Some useful addresses

CRUSE National Organisation for Widows and their Children
126 Sheen Road, Richmond, Surrey TW9 1UR
Telephone: 01-940 4818 and 9047

Provides counselling and advisory service and opportunities for social contact; runs training courses for those working with the bereaved; undertakes research; assists in providing holidays.

Society of Compassionate Friends
25 Kingsdown Parade, Bristol BS6 5UE
Telephone: 0272 47316

Support is given to newly bereaved parents by parents who have undergone the same experience, through meetings, visits, letters and telephone calls; supplies speakers; gives information where possible; library service lends books on bereavement.

The Foundation for the Study of Infant Deaths
5th floor, 4 Grosvenor Place, London SW1X 7HD
Telephone: 01-235 1721 and 245 9421 (day)
01-748 7768 (evening)

Offers support and information service to bereaved parents; contact arranged with nearest parents' group; disseminates information to medical and nursing enquiries.

Age Concern
Bernard Sunley House, 60 Pitcairn Road, Mitcham, Surrey CR4 3LL
Telephone: 01-640 5431

Pioneers new services for the elderly; grants are allocated to groups for the appointment of development staff and to start off new projects; a team of field officers provides guidance in setting up services and training courses for staff and volunteers; provides a forum for communication between statutory and voluntary bodies concerned with the elderly; research unit; insurance schemes; exhibitions.

Forms for confidential notes

The forms shown here are those in use at St Christopher's Hospice at the time of production of the book. They have been modified several times since the bereavement service began, and alterations will continue to be made from time to time as experience and future requirements may determine. Form A is completed by the ward or home care staff and form B by the visitors. In any bereavement service, all notes and records must be treated with the same confidentiality as medical notes. Similarly, all discussion at the monthly group meetings must be strictly confidential within the group.

Form A

CONFIDENTIAL Case Note

Name of Patient (Surname first in capitals)	Age:	Number:
	Date of Admission:	Date of Death:

Surname of Key Person: First Name:

Address:

Telephone:

Relationship to Patient: O.P. Yes/No

Do you think key person would object to follow up? Yes/No/Not known

Staff Member(s) most closely involved:

Other Family Members in need of help:

Comments (include details of help already being given):

FSP Signed:

P.T.O.

Questionnaire: (Ring one item in each section. Leave blank if not known.)

CONFIDENTIAL

..... Tick here if key person not well enough known to enable these questions to be answered.

A

Children under 14 at home

0 None
1 One
2 Two
3 Three
4 Four
5 Five or more

B

Social Class
****Occupation of principal wage earner of key person's family**

1 Professional and Executive
2 Semi-professional
3 Office and clerical
4 Skilled manual
5 Semi-skilled manual
6 Unskilled manual

**If in doubt, guess.

C

Anticipated Employment of KP outside home

0 Works full time
1 Works part time
3 Retired
4 Housewife only
5 Unemployed

D

Clinging or Pining

1 Never
2 Seldom
3 Moderate
4 Frequent
5 Constant
6 Constant intense

E

Anger

1 None (or normal)
2 Mild irritation
3 Moderate – occasional outbursts
4 Severe – spoiling relationships
5 Extreme – always bitter

F

Self Reproach

1 None
2 Mild-vague and general
3 Moderate – some clear self reproach
4 Severe – preoccupied self blame
5 Extreme – major problem

G

Relationship Now

0 Close intimate relationship with another
2 Warm supportive family permitting expression of feeling
3 Family supportive but live at distance
4 Doubtful
5 None of these

H

How will Key Person cope?*

1 **Well:** Normal grief and recovery without special help.
2 **Fair:** probably get by without special help.
3 **Doubtful:** may need special help.
4 **Badly:** requires special help.
5 **Very badly:** requires urgent help.

*All scoring 4-5 on H will be followed up.

Form B

CONFIDENTIAL NOTES (complete before first visit)

Key Person..... Other Names.....

Address..... Telephone No.....

..... Risk Code.....

Name of deceased.....(age)

Relationship to KP.....

Hospice case number..... Admitted.....

Date of death..... Ward.....

FAMILY Children (list all names, ages and locations)

Other living relatives (list all who are likely to help or be supported by Key Person)

Comments on family, friends and others

Dwelling
(Note type, who else lives there, space, any problems)

Occupation of Key Person (now and future)

Money (don't probe) Any problems

Form B

CONFIDENTIAL NOTES First Visit Sheet

Name of KP..... Visitor.....

Date of visit.....

Place of visit: Home/St Christopher's/other (state where)

.....

Means of contact: letter/phone/prior arrangement/visitor just called without prior contact

KP's attitude to visit: welcomed/strongly welcomed/accepted/ accepted reluctantly/refused
If reluctant or refused, what happened?

.....

.....

Need for visit: very great/great/moderate/some/none/ probably harmful

---

Ring round only one word in each set.

KP a Appearance — well groomed/casual but tidy/untidy/ dirty and unkempt

b Activity — slow/retarded/normal/some restlessness and jumpiness/casual restlessness

c Tearfulness — continuous tears/frequent/some/ suppressed/no sign

*d Very sad/sad/variable sadness/neutral/happy/elated

*e Agitated or in panic/severe anxiety/some anxiety/ neutral/calm/extremely calm

f Suicidal risk — immediate/likely/remote/unlikely/none

g Very angry about many things/angry over few things/ minor irritability or anger/no evidence of anger/ denies anger or irritability

If angry, give details.....

.....

h Preoccupied with intense guilt/marked guilt or self-reproach/some minor self-reproach/no evidence/denied

If self-reproachful, give details.....

.....

.....

i Pining — strong/continuing to talk about loss/ some need to talk about loss/little talk about loss/no reference made/says doesn't wish to speak or think about it

*If 'very sad' or 'agitated' response, a question: 'Has it been so bad that you thought of killing yourself?'

.....

.....

PROBLEMS (Ring round all that apply)

Does KP see self as having any of the following problems?

Lack of contact with others

Crying	excess crying/inability to cry
Eating	too much/too little
Sleeping	badly
Smoking	too much
Drinking	too much alcohol
Drugs	too many drugs or medicines
Illness	actual physical illness/fear of physical illness
Fear	of madness or 'breakdown'/suicide/ haunting memories
Job	getting a job/coping with a job
Money	coping with money/insufficient money
Accommodation	getting accommodation/keeping existing home/managing housework
Death	seeking to explain or understand the death/doubts concerning after death
God	doubts concerning the goodness of God/ doubts concerning the existence of God
Belief	other spiritual or religious problems/ doubts concerning own goodness or worth/ doubts about goodness or worth of others
Relationships	difficulty in maintaining relationships with family/difficulty in maintaining relationships with friends/difficulty in coping with children's grief/difficulty in explaining death to children/difficulty in controlling children's behaviour
Other problems	.....
	.....
	.....

HELP GIVEN (Ring round all that apply)

1 None

2 Talk about problems without advising

3 Visitor gave advice

4 Visitor gave direct help

5 Referred to St Christopher's staff (chaplain/social worker/psychiatrist)/Pilgrim Club/volunteer organiser/ nurse/other

6 Referred to others (not St Christopher's) GP/clergy/ church worker/social worker/housing department/ psychiatrist/social security/social services/lawyer/ Citizens' Advice Bureau/Samaritans/CRUSE/schoolteacher/ police/others

PROBABLE FUTURE HELP organised through St Christopher's (underline one or more)

1 Visiting by yourself, suggested frequency.....

2 Befriending (close or frequent contact by other person) state reason

.....

.....

3 Pilgrim Club

4 Volunteer work (suggested type).....

.....

5 Psychiatric (give reason).....

.....

.....

6 Watching brief (check to see that help given by others is adequate or that KP does not need further help)

7 Other.....

.....

8 None needed (explain why).....

.....

.....

FURTHER NOTES

Record here any information not covered by previous questions. Give correct quotations wherever possible to illustrate what the KP said about any of the problems discussed. After the second visit re-read the notes of the first and indicate in pencil any changes that have occurred or fresh problems which have emerged. Also, write notes for the file on each further visit. See that your notes refer to any change. If you wish to do so, you may complete another form for each visit, but this is not obligatory.

Index

Bereavement Visiting
edited by Geoffrey Dyne

Preface by Colin Murray Parkes MD FRCPsych

The account of the St Christopher's Hospice Bereavement Service, by the volunteer visitors, describes one of the important services developed by the hospice in the care of the dying and the continued care of the bereaved. It will be a guide to others who are doing, or would like to embark upon, similar work with bereaved people.

OTHER TITLES FROM THE KING'S FUND

The King's Fund Directory of Organisations for Patients and Disabled People
'A wealth of information on voluntary groups which offer a direct personal service . . . More than 300 organisations are listed . . .'

Health and Social Services Journal

When I Went Home—a study of patients discharged from hospital
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Nursing Times

Asian Patients in Hospital and at Home
By Alix Henley
'. . . the most useful book I have come across in five years.'

Archives of Diseases in Childhood

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