

The BRI inquiry into paediatric cardiac surgery in Bristol (1984-1995)

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1. This statement is intended to provide background information to the Inquiry regarding Issue I.
2. I was first employed in Bristol as personal assistant to the previous Chief Executive, Dr John Roylance, and Office Manager of the Chief Executive's office. Part of my role had included monitoring and overseeing complaints, and dealing with replies to complaints which were sent out in the Chief Executive's name.
3. Following the Wilson Report on the handling of complaints in the NHS there were new procedures and guidelines issued by the Department of Health in February 1996 which were to be implemented on 1 April 1996. I was designated by the Trust as Patient Support Manager from February 1996 and continued in my role as Office Manager of the Chief Executive's office. My aim in that role was to ensure that the Trust was recording complaints from 1 April 1996 in accordance with the new procedures and guidance which had been issued. In some ways this was a refinement of what I had already been doing. At a later stage my title changed to Complaints Manager.
4. One of the things I observed as Complaints Manager was that about 8 out of 10 complaints which proceeded to independent review involved issues around bereavement. It was through this that I developed an interest in the bereavement services that we were providing. By about 1997 I was talking to people in the Trust

about how we could improve bereavement services, with a view to reducing complaints and the numbers of the most intractable ones that were proceeding to independent reviews.

5. Unfortunately, for about a year, from October 1997 through to September 1998, I was off work with a long-term illness. During that period Sue Sealey was seconded to handle complaints for the Trust. When I returned to work I had the option of returning to my role as Complaints Manager or taking on a newly developed role in clinical governance supporting the new Medical Director, Dr Nick Bishop, and the Trust's Nursing Director, Lindsay Scott. I opted for the new role in clinical governance, as Clinical Governance Support Manager.
6. I would say that about half my time is spent on administrative matters supporting the committees which oversee clinical governance issues. These are the Clinical Governance Committee, the Clinical Risk Management Committee and the Quality and Consumer Committee. My role is to support the Director of Nursing and the Medical Director in preparing papers and agendas for those meetings, which are sub-committees of the Clinical Governance Committee of the Board. I take minutes at the committee meetings and follow up the action taken. I make sure that records are updated so that there is a proper audit trail of what has been done and when.
7. The remainder of my job has involved a special project on bereavement services across the Trust. In essence I was asked to find out what the practice was across the Trust, to identify areas for improvement, and then to report to the Quality and Consumer Committee. In about April 1999 I started going out and about in the Trust to meet with heads of nursing and others who are involved in and/or have an interest in bereavement, to see what was going on in terms of policies, procedures and resources. I visited the majority of Clinical Directorates, essentially those which are hospital based specialties, (such as children's, surgery) as opposed to specialty services (such as radiology). I have found that the policies, procedures and resources are quite diverse and varied throughout the Trust. There are many good things being done and there are many good ideas being put forward for improvements. The result of my research was the report I drafted for the Quality and Consumer Committee dated May 1999, attached as **Annex 1**.

8. Following consideration of the report by the Committee, I was asked to proceed to set up a working group to produce policies and guidelines to take effect across the whole Trust. The working group involved a range of people across the Trust with knowledge and experience of bereavement services. The first meeting was on 15 June 1999 and we plan to meet monthly for the time being. The plan is that we will produce a Trust-wide policy document and guidelines, which will cover matters, such as how to break bad news, packing up patients' possessions, last offices and other matters, such as making arrangements for viewing bodies, the practical facilities available in the various hospitals for families, and other matters.
9. We will probably work towards producing a resources pack to be used in directorates and wards, which will include the policy and guidelines, but also documents which are being used already in some parts of the Trust, such as the Directory of Faith Communities in Bristol. This document was prepared by the Chaplaincy. I am currently involved in updating an in-house leaflet entitled "A Guide to the Days Ahead", which was originally drafted by James Brennan, Clinical Psychologist with a particular interest in bereavement services, with the assistance of funding provided by the Special Trustees to the UBHT. The leaflet provides practical advice and also addresses some of the emotional aspects of grieving. The revised and updated edition is about to be reissued (copy attached at **Annex 2**). The resources pack will also contain an updated guide to bereavement services in the voluntary sector, listing contact details of local and national organisations.
10. One of the other aspects of good practice in some parts of the Trust which we will probably adapt across the whole Trust, will be at the time of the patient's death to prepare a card to be written and addressed by the principal nurse who has cared for the patient to be put into a diary or bringing-forward system to be sent to the family at a later date, yet to be agreed as to what would be the most optimal time for this. That card will re-offer support, advice, and contact from the ward staff, and provide national telephone numbers for support organisations.
11. Having noted the diversity of practice across the Trust, the working group has already recognised that there are some areas of the Trust where it will be necessary

to provide for variations to the standard policy or to write a slightly different policy for each of the areas, such as the Children's Hospital which has to meet the particular needs of children and their families, Bristol General Hospital which has to meet the needs of elderly patients and their families, and community services, which are different again.

12. I anticipate that once the working group has dealt with policy and guidelines and prepared the resources pack, then we will also consider the presentation of this material across the Trust, to be backed up by training. As part of my investigation of what happens in the Trust I have attended the training courses arranged by the Children's Hospital and also the annual seminar on bereavement which takes place at Barrow Hospital. Both of these courses seem to me to be very good, although they are attended on a voluntary basis and are not very well attended considering the numbers of people employed in the Trust. It is likely that our recommendation will be that training in bereavement services should be mandatory. It is likely to be based around the resources packs that the working group will prepare. Our emphasis is likely to be on staff being knowledgeable and confident about what they are doing in relation to bereavement services, rather than suggesting that they spend a great deal more of their time on such matters. The aim will be to ensure that the services we provide as a Trust are of high quality.
13. Having consulted with people across the Trust and set up a working group which is now moving forward with recommendations, the other part of my research includes consulting with bereaved families, to obtain their feedback and insights into the bereavement services that they have received from the Trust. I am arranging this through Diane Kennington, the Patient Affairs Officer at the BRI, who has kindly agreed to raise the possibility of my contacting families with them, to identify a few families who would not mind my seeking their advice and guidance.
14. As best I can estimate at the moment, it is hoped that the working group will be able to produce a draft bereavement pack in the next couple of months, which will then be reviewed by the Director of Nursing, Lindsay Scott, for her approval before being issued throughout the Trust in conjunction, we hope, with an appropriate training programme.

15. Once we have achieved this stage, it is likely that the bereavement working group will then meet on an annual basis in order to review practice, developments, to exchange ideas, and to make any changes or improvements which seem to be appropriate, so that the bereavement services will continue to develop and improve.

SIGNED : *Marjorie Ball.*
MARJORIE BALL

DATED : *11 August 1999*

ANNEX 1

BEREAVEMENT PROJECT
ON BEHALF OF
QUALITY AND CONSUMER COMMITTEE

INTRODUCTION

When a death occurs, it affects not only the immediate partner/parents, but the whole family unit. Research has shown that what happens at the time of death rules how the rest of the bereavement goes, and if not handled sympathetically, and the requisite amount of support given, the implications are far-reaching. Grief reaction can lead to difficult behaviour at school in children, disruption within families, illness, absence from work with its attendant financial implications for the family and the organisation for which they work, and often the requirement for psychiatric intervention. It can lead to complaints, which take an enormous amount of time and effort to resolve, often culminating in an independent review panel. If a severe grief reaction is suffered, it can affect the rest of that person's life.

"Although death is a common experience, the loss of a significant person is a traumatic and unique experience for those left behind. The bereaved are affected in every aspect of their lives; physical, emotional, spiritual and socio-cultural. The belief that 'grief work' is essential to recovery from major bereavement is well documented. Bereavement has been shown to be associated with increased mortality and morbidity, and support can influence the course of bereavement after the death. There is evidence to suggest that appropriate intervention reduces the risk of long term morbidity. Thus, bereavement support becomes an issue of health promotion."

(Royal College of Nursing (1993) RCN Palliative Nursing Group and Hospice Nurse Managers' Forum – *Standards of Care: Palliative Nursing* p. 11. Edmundsbury Press.

From this, it is self evident that what happens at the time of a death is critical. It does not necessarily call for more time to be invested by staff, but it does need that time to be used to the best advantage, with clear guidance for staff, awareness of existing resources in the form of support groups and spiritual help, and training to enable staff to deal with issues around bereavement with confidence.

PRACTICE, POLICIES AND PROCEDURES

Practice

Current practice can be variable, but it was felt that on the whole staff did a good job under difficult circumstances. Some areas made extensive use of the Trust Booklet 'A Guide to the Days Ahead', giving useful information to relatives, but it is not clear whether the existence of this booklet is widely known, and whether it is given (or can be given) to relatives routinely throughout the Trust.

It was widely felt that clear guidance (in the form of a policy), easily and quickly available to staff, would give them the confidence to deal sympathetically with bereaved relatives. If staff didn't know what to do next, their confusion added to the distress of relatives.

Policies

There are several policies (or guidelines) existing throughout UBHT, e.g:-

- Protocol following a death (BCH)
- Bereavement Procedure (in the form of a flow chart) - (St Michael's)
- Guidelines for Transportation of Deceased Persons (St Michael's)
- Procedure for removal of foetuses from Ward 78 – 79 (“ ”)
- Procedure for Last Offices (St Michael's)
- Draft Bereavement Policy – Ward 61 (BOC)
- Draft Bereavement Policy – BCH

The above are examples of what is available, rather than a definitive list.

Resources Available

- Chaplains
- Diane Kenington
- James Brennan, BOC
- Ann Dent (for consultation)
- Bereavement Services in the Voluntary Sector in Bristol (support groups)
- The Rainbow Centre (for children)
- Cruse
- Directory of Contacts with Faith Communities in Bristol
- A Guide to the Days Ahead – and other booklets
- Cot Death – a Workbook for Professionals

Existing Training

In 1997 Michelle Twist began study days around last offices, and these developed into a paediatric bereavement study day. Three workshops had taken place, two in 1998 and one in January 1999.

New study day 13 May targeting non-nursing staff. Will be followed by another day a week later.

Once yearly 2 day seminar led by James Brennan (organised by Sue Fyffe-Williams). This year 29/30 June at Barrow Hospital.

MDB to attend both of above.

In house bereavement course at St Michael's, every six months.

Unfortunately, although training courses are arranged, not very many people book on to them, and sometimes they have to be cancelled for lack of support.

Examples of Good Practice

- Arrangements for proper disposal, service and record in book of remembrance for stillbirths/miscarriages at St Michael's
- Sympathetic decoration etc. of viewing room at St Michael's
- Registrar to attend St Michael's three times a week. Visits by crematoria staff to inform staff re: form filling etc.
- St Michael's bereavement group, providing support for its members dealing with this issue. Has resulted in new protocols and procedures, and a flow chart for dealing immediately when a bereavement occurs
- Directory of Contacts with Faith Communities
- Relatives' room in Cardiac Services
- 'Stillbirth' room in CDS for parents to spend time with baby
- Guidelines for the care of families following the sudden death of their baby – BCH A&E

Ideas and Suggestions

- Mobile screens to put round beds (curtains often inadequate)
- Ideally – side room for dying patient and relatives, and also after death so that bustle of ward does not impinge, and relatives can feel free to grieve
- Guidelines on packing of possessions of deceased – what to include, what to leave out, ensure they do belong to that patient
- More sensitive container for deceased's effects, e.g. firm carrier bag or box with carrying handle
- Card sent to relatives 6 weeks after death, giving details of support organisations
- Support for staff – counselling
- Handout for relatives of patients who die on a Friday, (thus causing delay in procedures) – what they can and can't do in the meantime
- Training of **nursing and medical** staff in breaking of bad news, necessity for post mortem etc.
- Risk assessment as in BOC to identify which relatives are at risk of significant grief reaction
- Improvements to Viewing Room BRI
- Bereavement co-ordinator to be resource for staff and relatives, also to handle training throughout the Trust. Also by using risk assessment, to identify the minority of relatives who will require support, and refer them to necessary part of voluntary sector
- Cross Trust networking (avoid individual 'dabbling')
- Improvements to corridor at St Michael's – approach to viewing room
- Interested and dedicated person to deal with bereavement issues
- Small plaque in St Michael's garden for parents to leave flowers in memory of babies
- Crematorium to handle foetal remains as per adults
- Training of nursing and junior medical staff, raising awareness of what to do immediately following a death – plasticised step by step hand-out
- Information to be kept up-dated

- Training of nursing and junior medical staff to include bereavement training. HCA training already includes this
- Links with Community as first step between hospital and community support
- 'Bereavement Services in the Voluntary Sector in Bristol' – should this be available to bereaved relatives as a matter of course?
- Include 'disclaimer' in BCH handout to parents, explaining inability to recommend a funeral director
- Guidelines at BCH on how to handle religious/cultural issues
- Include healthcare professions in training
- Ensure notification of deaths immediately

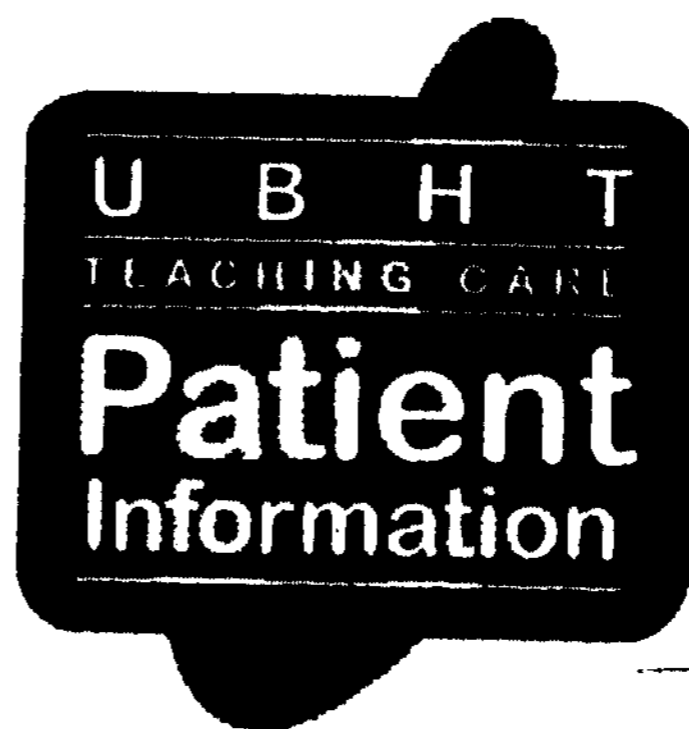
What I would like to see come out of this study

- a) Produce standardised Trust policy/guidelines re; bereavement, but with departmental differences as necessary.
- b) Standardise advice – produce easily accessible hand-out for staff on what to do immediately when a patient dies, to give them confidence in dealing with the situation.
- c) Raise awareness generally of bereavement, and the importance of dealing well with this at an early stage to avoid problems arising later on. Also of booklets and handouts which are already available within the Trust.
- d) Improve training to nurses, junior doctors, receptionists and porters relating to bereavement issues. ?Training to be part of induction, or separate half-day soon after commencing
Training also to be routine, rather than a matter of choice.
- e) Improvements to viewing room - although it is probable that the site of the Viewing Room may move over to the King Edward Building in about five years, with 1200 deaths a year that would be 6,000 sets of relatives to use the current facility in the meantime. Any improvements would therefore be well worth while.
- f) Set up cross-Trust working party to meet annually or half-yearly to discuss initiatives, ideas and to keep all areas up-dated with what is going on. To consist of representative/s from each directorate, and training.
- g) Improve method of packing patient's belongings.
- h) Ensure medical records/PAS systems allow for immediate notification of a death to out-patients, physio, etc where patient may have had future appointment.
- i) Clear designation of quiet areas, where relatives can go for bad news to be broken, or just to cry. All to be clear which these are.

Marjorie Ball
May 1999

ANNEX 2

Draft
14.07.99

A vertical graphic element consisting of a series of thin, parallel vertical lines that form a narrow column. It is positioned behind the central text box, extending from the top of the box down to the bottom of the page.

**A guide to the
days ahead**

What you should do now

Following the death of your relative you should telephone the Patient Affairs Officer **the next working day after 10am.**

Bristol Royal Infirmary

Contact: Diane Kenington
Tel: 0117 - 928 2289

Bristol General Hospital

Contact: Marion Holland
Tel: 0117 - 928 6127

Oncology Centre

Contact: Sue Johnson
Tel: 0117 - 928 2509

Step 1. Death Certificate

see page 3

Step 2. Register Office

see page 3

Step 3. Arranging a funeral

see pages 6 - 9

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A guide to the days ahead

You have recently suffered a great shock in hearing about the death of someone close to you. This booklet is designed to help you cope with practical steps you will need to take over the next few days. This booklet also looks at the emotional adjustment that you will have to face over the coming months, as well as the sources of help and support available to you.

Contents	page
Introduction	2
Steps you will need to take	3
Registering the death	3
How to get to the Registrar	4
If a Post-mortem is required	5
Arranging a funeral	6
Emotional aspects of grief	11
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The do's and don'ts of grief	18
Sources of further help and support	20

Introduction

You have very recently lost someone close to you, though this fact may still seem very unreal. You may be feeling numb with shock, or perhaps already you have begun grieving. Either situation is quite normal. The most important first step is for you to think about who you should contact to support you or even be with you over the next few days.

Find Support

In the first few days after a death it is often the responsibility of the person who is most distressed to make the necessary practical arrangements. It is therefore wise to have a friend or relative to help you with these arrangements.

The guidelines listed below are designed to help you and your friend or relative cope with the practical steps you will need to take.

The staff of The United Bristol Healthcare Trust are committed to doing all that they can to help you through the painful experience you are presently facing. Our sincere condolences go out to you.

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Steps you will need to take

Registering the death at the Registrar's Office

By the time you read this booklet you should have obtained a copy of the Death Certificate (Medical Certificate of Cause of Death). The Death Certificate is an important legal document, showing the cause of death, which has to be signed by the doctor who was responsible for the deceased when they died. Please carefully read both sides of the detachable slip on the Death Certificate.

The next step you will need to take will be to take the Death Certificate to the office of the Registrar for Births and Deaths which is at Quakers Friars, Broadmead, Bristol (telephone 0117 - 929 2461) so that the Registrar can legally record the death. The death should preferably be registered in the district where the death took place and should be done within five days of the death. However, in special cases it is possible to register the death outside the district.

When you go to the Registrar you should take the following forms:

- the Death Certificate, unless the Coroner is involved;
- the deceased person's medical card if they had one;
- any War Pension order book for the deceased person.

The Registrar will give you a Green Form (Certificate for Burial or Cremation) which allows the body to be released for burial or cremation (see page 8). The Registrar will also give you a White Form (Certificate of Registration of Death) which is for the Department of Social Security. Read the information on the back of this leaflet and, if any of it applies to you, fill it in and send or give it to your local Social Security office.

How to get to the Registrar

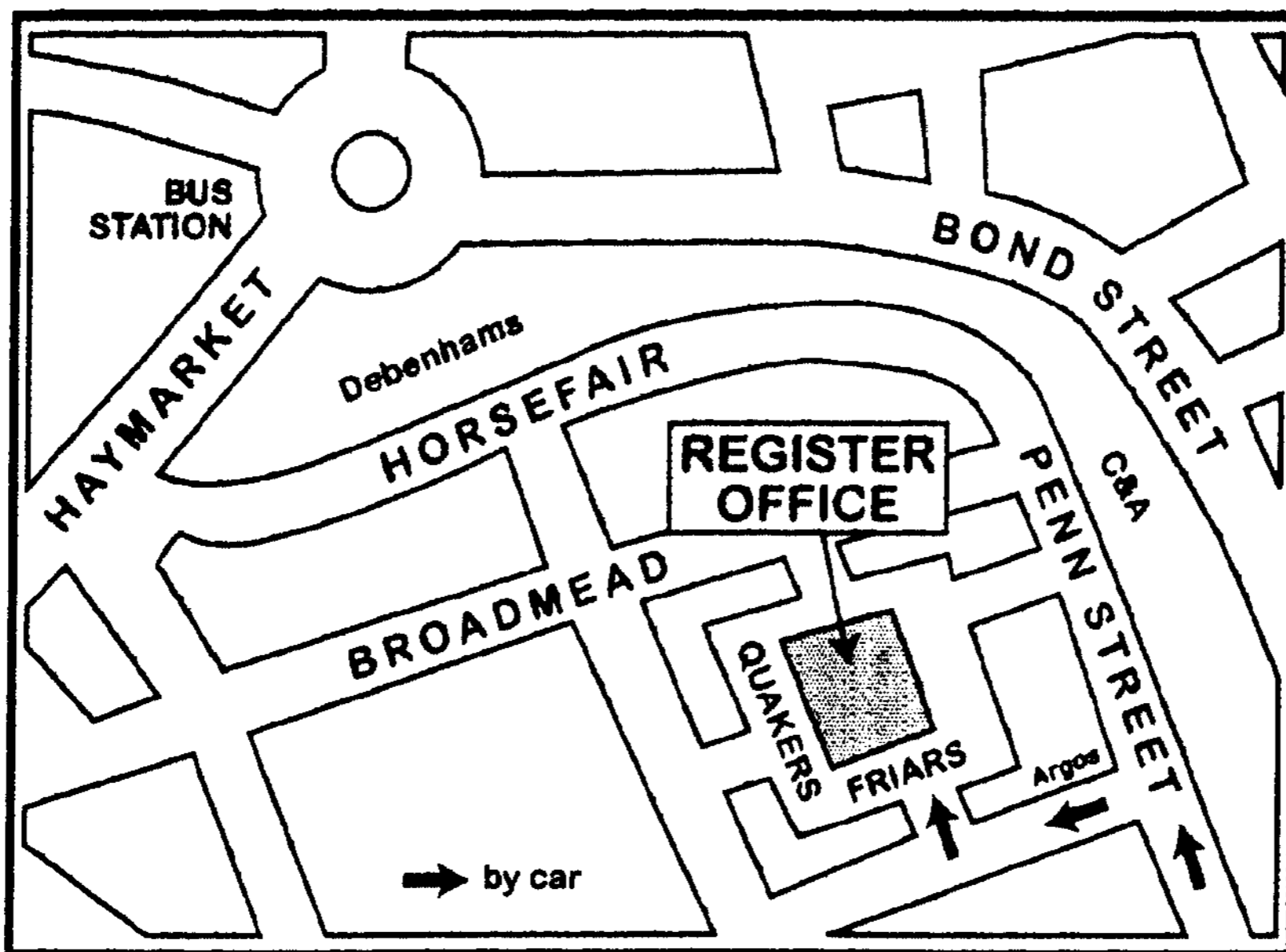
The Register Office
Quakers Friars
Bristol BS1 3AR
Telephone 0117 - 929 2461

The Registrar's office (known as the Register Office) is in the main Broadmead Shopping Centre. The map below shows you how to find it. It is important to register the death as soon as possible.

Opening times Monday to Friday 9am to 4pm
 Wednesday 10am to 4pm

By car Enter only from Broad Weir.

By bus A large number of buses can take you to Broadmead Shopping Centre. From there, follow the map below to find the Register Office.



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Arranging a funeral

When to begin?

Do not make final funeral arrangements until you know that the death does not have to be reported to the Coroner (see above), since this may affect the date on which the funeral is held.

Find out if there is a Will, since this may contain requests about funeral arrangements.

Finding a funeral director

Most funerals are arranged by a funeral director, so you will need to choose which funeral director to use.

The Patient Affairs Officer at the Bristol Royal Infirmary (0117 - 928 2289) can give you a list of local funeral directors and it is wise to obtain at least two written estimates. Funeral directors who are members of the National Association of Funeral Directors (NAFD), or the Society of Allied and Independent Funeral Directors (SAIF) must give you price lists when you contact them and these prices will not be exceeded without permission.

A basic simple funeral does not cover the costs of things like the church or crematorium fees, flowers or notices in the local paper. However, the funeral director will be able to advise you about these.

The Funeral Director will need:

- the Certificate of Burial or Cremation (Green form), which the Registrar will have given you;

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- or the Order for Burial (form 101), which the Coroner will have given to the funeral director;
- or the Certificate for Cremation (form E), which the coroner will have given to the funeral director.

If you are not happy about the service you receive from the funeral director, your complaint can be dealt with by:

NAFD
57 Doughty Street
London WC1N 2NE

OR

SAIF
212 Eversholt Street
London NW1 1BD.

Decide on a burial or cremation

It is up to the executor of the Will or the nearest relative to decide whether the body is to be cremated or buried. Check whether the deceased left any indication of their wishes.

Arranging the funeral service

If there is to be a service or ceremony, contact the appropriate person to conduct it. This may be a minister of the dead person's religion though the funeral director may be able to advise you of other people who can conduct the funeral service. Choose the place of the funeral and decide on a time.

Once a time and place have been agreed, decide who may be able to help you in inviting others to the funeral. Decide if you wish to have flowers for the funeral, or perhaps donations to a named charity.

Burials

If there is to be a burial, find out if the dead person had already reserved grave space in a churchyard or cemetery, by checking the will and looking through their papers. The Church of England have set fees for burial and a funeral service. In addition to the fees for the minister, there are also extra fees for an organist, choir, church heating and the erection of a headstone.

Most cemeteries are non-denominational so you can have the service or ceremony which is appropriate to the faith (if any) of the deceased.

Cremation

If there is to be a cremation, the cause of death must be definitely known. You will need all four of the following forms which are taken care of by the funeral director or crematorium:

- an Application Form (Form A) signed by the next-of-kin or executor;
- two cremation certificates (Forms B and C) each signed by a different doctor. These are paid for out of the funeral costs. If the death is referred to the Coroner, these two certificates are not needed. Instead, the Coroner will give the funeral director or you Form E which is a Certificate for Cremation;
- a certificate (Form F) signed by the medical referee at the crematorium. The medical referee has the power to refuse cremation and either decide that a post-mortem (see above) is required or refer the matter to the Coroner.

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Paying for the funeral

Refer to the Social Security booklet (D49), called 'What to do after a death' (pages 25-31), for information about paying for the funeral. Sometimes it is possible to obtain a certain amount of money from the dead person's estate in order to pay for funeral costs.

Some employers provide occupational pension schemes that pay a lump sum to help with funeral costs.

Professional bodies and trade unions sometimes have schemes to help with these expenses. The Co-operative Funeral Directors make no charge for a basic funeral for children under the age of ten.

Financial help

If you are on Income Support, Family Credit or Housing Benefit, you may be able to claim financial help from the Social Fund, which is part of Social Security. The Social Fund will help towards the cost of a simple funeral, provided it takes place in the United Kingdom. In order to obtain help from the Social Fund you must apply within three months of the date of the funeral. You can obtain an application form (Form SF200) from the Registrar's Office, or from your local Social Security Office (your local Social Services Department, Welfare Rights Unit, or Citizens Advice Bureau can assist you in completing this form). Finally, you will need estimates from two funeral directors in order to apply to the Social Fund.

When no relative can be traced

In some circumstances the Environmental Health Department may arrange the funeral service of someone who dies in hospital if the dead person's relatives cannot be traced or cannot afford to pay for it. However, they may claim on the dead person's estate to pay for the funeral.

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*“Only the unloved and unloving escape
grief. It is the price we all have to pay,
eventually, for the love that makes our lives
worth the living.*

*Whether it be the loss of parent, of spouse,
of child or brother or sister or friend, the
pain lies in wait for us. And when it comes,
it has to be experienced before it can be
erased”.*

Claire Raynor

Emotional aspects of grief

The death of a loved one is an experience that we are all forced to face at some time in our lives. Death is a part of life's cycle and to mourn deeply for someone we have loved is an entirely normal experience.

However, people find it uncomfortable to talk about death and in many ways we are even discouraged from thinking about it. This can make it difficult for us to turn to others for support, even though what we most need is someone with whom to talk and express our feelings.

Each of us experiences grief in our own particular way and no two people are entirely alike. People from different cultural backgrounds will have different ways of mourning and different ways of supporting each other. On the other hand, there are several experiences in grief which appear to be common to everyone, and this section will describe some of these experiences in order to help you through the whole process.

There is a need to mourn

The reason that every culture has some form of funeral ritual is that the ritual itself provides a focus for our grief. At the funeral, if we have not begun already, we have the opportunity to mourn openly for our loved one, and say goodbye.

Mourning is essential. We must experience whatever feelings emerge within us and try to express them out loud, preferably to someone else. It is necessarily a painful process that we have to go through, and there are no short cuts. It is rather like having a piece of work to do. It may take many months, or even years, to feel like your old self again, so give yourself lots of time to complete the work of grief.

What can I expect to feel?

While no two people experience grief in the same way, the feelings described below are a sample of the many that can occur. It is rare to move smoothly from one stage to the next, or even experience all the feelings below. Rather, you may have set-backs and sometimes feel as if you are having to start your grief all over again. Don't be disheartened by this. As long as you are allowing yourself to feel whatever you feel, you are doing the work of grief.

Shock

To feel shocked at the news of the death of a loved one is a natural reaction. You may be feeling numb and unable to believe that it's true. Some people are unable to feel very much for some time; some become quiet and withdrawn, while others quickly become agitated and anxious. Whatever you are feeling try to bring it to the surface and express it. Don't try to put on a brave face in order to protect yourself or others from embarrassment.

Expressing your grief

Grief raises many emotions and it is important to allow yourself to feel whatever you feel. In the early months of grief you will probably feel moments of sharp intense grief interspersed with a more constant sense of dull loss. You may be feeling very lost in the world without your loved one and simple daily chores may involve painful recollections of tasks previously done together. Going to bed at night or waking in the morning may feel particularly lonely and upsetting. People sometimes have difficulty falling asleep though, because grief is such an exhausting variety of emotions, many people feel very tired a lot of the time.

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Anxiety

It is quite common for people to feel anxiety (the same as fear) in the early stages of grief when they are having to face an unclear and unknown future. If you notice that you have persistent physical sensations of anxiety (such as a pounding heart-beat, muscle tension, increased perspiration and breathing) or if you find that you worry a lot, it may be helpful to learn how to relax. Learning to relax is a useful skill which many people can teach you these days. If your anxiety symptoms persist, contact your GP and ask to be referred to someone who will be able to help you with your anxiety.

Anger

Life can feel very unjust when someone we love dies. So it is natural to feel some anger in grief. For some people, however, feeling angry is the only way they know how to grieve. You may be feeling angry at the unfairness of the fact that your loved one is dead. Or you may be feeling that medical services could have done more or should have reacted differently. If you have concerns about the service you have received, ask a member of staff for the Trust leaflet 'Suggestions and Complaints'.

Mostly we feel anger about the death itself and our feeling of helplessness. A part of you may be feeling some anger towards the person who has died (for example, "How could they leave me like this?" or "Why didn't they look after themselves properly when they were alive?") though you may feel more awkward about sharing these feelings. Again, try to talk about them with someone you trust and who is a good listener. Avoid bottling up your feelings as they will only catch up with you later.

Guilt

Another universal feeling in grief is guilt, which is simply anger turned in on oneself. You may be feeling that there was more that you could have done, that you could have reacted more quickly to signs that the person was in distress. You may have been, or felt yourself to have been, responsible for your loved one who has died and now that they are gone you blame yourself for not having taken better care of them. It is worth remembering that for every action we take in life there are always many other actions we could have taken - we usually end up simply taking the action which seems to be the right one at the time.

If you have been caring for the deceased for a long time before they died, your feelings of loss may be complicated by some milder feelings of relief (that both you and the deceased are released from a long painful illness, for example.) This is quite understandable and does not make you a bad person for feeling it. It is helpful if you can talk through these feelings with someone else so that you can let go of your guilt.

If the death was more sudden it may have left you feeling guilty about things left unsaid. There is often a great deal of unfinished emotional 'business'. Perhaps you did not say how much you cared; or you did not say you were sorry about things you may have said or done in the past; or perhaps you did not say "thank you" for the happiness that he or she brought you; and maybe you did not say goodbye. Perhaps it is worth remembering the good things that you were able to give them when they were alive; if you think of what they would be feeling about you right now, if you had died and they had lived, you may have a clearer idea of what you actually meant to them.

Again, it is important to express these painful thoughts and feelings in both tears and words since it is only through expressing our grief that we are able to get through it effectively.

Depression

Acute anxiety and anger often gradually give way to more constant feelings of depression and apathy (a feeling that you don't want to do anything). This happens as you finally come to realise at a deeper level that your loved one will never return. The fight and anger against this realisation and the feeling that somehow "none of this is real" dissolves into a well of despair.

Unfortunately, these feelings of hopelessness often coincide with a time when all the immediate friends and family who were available for support at the funeral seem to be scarce. Our friends are often embarrassed at not knowing what to say to us and, sometimes without realising it themselves, they stay away.

Similarly, people often worry that they may become a burden on others and consequently avoid contacting the very people who they would find it easy to talk to. Try to remember that if a friend had turned to you for support in their grief, there is a good chance you would feel honoured that you had been asked to help them.

If you are feeling particularly low, you may wish to contact one of the bereavement counselling organisations at the back of this booklet, or to contact your GP.

Taking care of yourself

The work of grief is very exhausting and places great physical demands on the body, as well as the more obvious emotional ones. You may feel physically exhausted and tired a lot of the time and consequently, you may have more colds and flu than normal. If any symptom persists, be sure to tell your doctor.

Try to look after yourself. Eat well and regularly, even if you are not particularly hungry. Get plenty of rest, and sleep if you can. If you do have sleep problems, speak to someone who can help; your doctor may be able to refer you to someone who can train you to naturally relax and therefore sleep more easily.

Give yourself lots of time. Don't rush back to work if you are not feeling up to it, but keep your workplace informed. If necessary, obtain a letter from your doctor to give to your boss in order to protect your job. Try to plan things in the future to work towards and look forward to, but don't make any major life decisions, such as moving house. So often decisions made in grief are regretted later on. Try to involve friends and family members in your planning and listen to their views as well as your own. Many people find that a gentle routine is helpful.

Recovery

Grief is such a universal human experience that to talk of 'recovery' is perhaps inaccurate. However, time really is a great healer when it comes to grief. When you are newly bereaved, it is hard to imagine that eventually you will find a way to live without your loved one. It may be hard to imagine that you will ever be able to laugh or

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enjoy yourself again. But somehow, with time, you will be able to take up the threads of your life and begin to weave a new future. It may be a different future from what you expected but it will not necessarily be any less positive than the past; there will almost certainly be good things waiting for you in the future.

There may be many new hurdles to face, things to learn and challenges to meet. In facing these challenges, friends and relatives are an important means of support. Therefore, do your best to maintain your contact with people who have been important to you in the past.

Overcoming grief is not a smooth process. There are many ups and downs. Pangs of grief can sometimes occur years after a death, when you thought you had recovered from it. This is to be expected since you will never forget the person you have lost; their life, however long or brief it was, will have changed the course of your own forever. You may find it comforting to realise that, even though someone dear to you has died, their influence on you and others lives on. The person you are today is probably very different from what you would have been like had you never known the deceased person. In some ways therefore, you were influenced by them and so through you, they live on.

In time you may find you have not thought about your grief for a few minutes, and later this may stretch to hours at a time. At first you may feel guilty that you are not actively grieving, particularly if you have managed to enjoy yourself for a change. Gradually you will feel more comfortable about enjoying the company of other people and new relationships. But, whatever happens, you need not fear that you will ever forget what your loved one meant to you.

The dos and don'ts of grief

Do express your feelings as much as possible.

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Do talk through what has happened and what you are feeling with someone you trust (your family, a close friend or an appropriate support group).

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Do contact one of the voluntary or hospital organisations listed in this booklet if you would like someone to talk to. They are there to help you.

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Do take good care of yourself; get lots of rest, eat well and give yourself lots of time to grieve.

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Do begin to make longer term plans for the future so that you always have something to look forward to but remember: don't rush into any big life changes.

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Do choose a funeral director you like and trust.

Do contact your doctor if you feel unwell or would like the doctor to refer you to someone to talk to.

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Do keep in touch with friends and family. Remember that most people feel honoured to be asked to help. However, many people feel awkward and embarrassed about offering their help, so it may be left up to you to ask for it, even though this may be difficult for you.

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Don't hide your feelings; try to bring out into the open whatever you are feeling. This is central to the work of grief.

Don't rush into having the funeral right away unless it is the practice of your culture and don't be persuaded to have an expensive funeral unless you really want it.

Don't make any major life changes while you are still grieving. Give yourself lots of time to think about changes you may wish to make and discuss these plans with others.

Don't neglect yourself. Try to eat well and get plenty of rest. Don't enter into any financial or legal arrangement unless you fully understand it.

Don't hurry yourself to overcome your grief. There is no fixed time that it takes to get over bereavement.

Don't let others rush you into anything before you are ready. But remember that sometimes you may not know whether you are ready for something unless you give it a try.

Don't turn to drugs, smoking or alcohol to stop yourself feeling the pain of grief.

Sources of further help and support

For further information on the practical aspects of death, refer to the Social Security booklet (D49), entitled 'What to do after a death'. It is a useful source of more detailed information.

Many people manage to get through their grief with the help of their friends and family, and without any professional help. However, sometimes it can be helpful to talk through your feelings with someone who is caring and interested but not directly involved with your life.

Sometimes it is only clear that one needs professional help some weeks or months after a bereavement. If you are worried that you are having problems with your grief, you might find it reassuring to talk to one of the following:

Your GP

Your doctor is responsible for co-ordinating your overall physical and emotional health. Although GPs are usually very busy and unable to offer you a lot of time, he or she may be able to decide what sort of help, if any, you require. The GP, for example, may be able to refer you to a specialist bereavement counsellor, or they may encourage you to contact one of the excellent voluntary groups in or near Bristol.

Inner City Mental Health Team

The Inner City Mental Health Team has trained staff who can offer support to people from Asian or Afro-Caribbean backgrounds. Telephone 0117 - 955 6098.

Voluntary Bereavement Services

- **National Association of Bereavement Services**
If you live outside Bristol, the NABS will put you in touch with a counselling service which is local to your area.
0171 - 247 1080
- **Cruse - Bereavement Care**
(A national bereavement volunteer counselling service with branches in Bristol and Bath and other centres).
Bristol: 0117 - 926 4045
Bath: 01225 - 465878
Or telephone Cruse Head Office for the local contact: 0181 - 940 4818
- **Age Concern**
(A national organisation for older people)
Bristol: 0117 - 922 5353
Bath: 01225 - 466135
- **The League of Compassionate Friends**
(for those who have lost a child)
0117 - 953 9639
- **The Cot Death Research and Support for Bereaved Parents**
24 hours helpline: 0171 - 2351721
- **Sands (Stillbirth and Neonatal Death Society)**
07970 - 930513
- **Miscarriage Association**
01924 - 200799

- **Bristol Lesbian and Gay Switchboard**
0117 - 942 0842
- **Samaritans**
Linkline 0345 - 909090

Hospital Bereavement Support - Hospital Chaplains

The chaplains are available to talk with you whether you are a believer in any faith or none. If they are unable to help you they will try to find a person who can or will put you in touch with a person of your own faith.

- **Anglican (C of E) Chaplains**
Bristol Royal Infirmary, Bristol Oncology Centre,
Bristol Eye Hospital and Bristol General Hospital:
0117 - 928 2136 or bleep 2649

St. Michael's Hospital
and Bristol Children's Hospital:
0117 - 928 5323 or bleep 2558
- **Roman Catholic Chaplain**
radio page via switchboard
- **Free Church Chaplain**
0117 - 928 2136

To contact by bleep or radio page ring the BRI switchboard on 0117 - 923 0000 and ask for the relevant number to be bleeped or paged.

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**Hospital bereavement support -
Bristol Royal Infirmary Social Work Department**

Hospital Social Workers can often assist in organising social care support for vulnerable relatives. Information about other organisations can also be provided.

The main Social Work Office at
the Bristol Royal Infirmary:
0117 - 928 2735

Other hospital services

If you would like to speak to someone in another area of the Health Service, please telephone the Bristol Royal Infirmary's switchboard **0117 - 923 0000** and ask for the department by name. The department concerned may ask you to contact your GP first so that he or she can send a referral letter.

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This booklet was written by
James Brennan
Consultant Clinical Psychologist in the
Bristol Oncology Centre

United Bristol Healthcare NHS Trust
June 1999

GENINFO/DEATHGUI/Jun99