# **INTRODUCTION**

Believing that the church needed to do some fresh thinking about issues relating to ageing, dying, death and bereavement, General Assembly in 2000 mandated the Church and Society Committee to set up a working group to tackle this task and report back two years later. The Revd Sarah Brewerton was asked to convene the group, and four other members of the church with specialist knowledge and experience

# 1. THE TABOO OF DEATH

This pack offers practical ideas and suggestions as well as thoughts and reflections on death and dying in different circumstances. Each section is complete in itself and can used alone or in conjunction with others. We

2. 'OUT OF THE DEPTHS' BEREAVEMENT AND LOSS: AN INTRODUCTION

*Multiple deaths* - in a family or a community; the grief is more complex and there may be less comfort or support available. The situation may be made worse by the fact that such deaths are often traumatic or violent.

The age and stage of the griever - a child or teenager will have very specific needs, as will someone with learning difficulties.

How previous losses have been coped with - unresolved grief, which will be difficult to cope with.

Religious faith - may or may not help; it can increase guilt or a shaking of faith if the death raises questions, or it can provide comfort. Those without a faith can be more firmly convinced, or may desperately start searching - which makes them vulnerable.

SaB

### 3. BEREAVEMENT SUPPORT: WHAT WE CAN DO

I will weep when you are weeping, when you laugh I'll laugh with you; I will share your joy and sorrow till we've seen this journey through.

you feel better, but the

bereaved person probably won't find them helpful.

Don't be afraid of tears. Crying is the most natural thing in the world after a death, and is a very therapeutic release. *Your* tears will mean a lot to the bereaved person - they show that you are sharing some of the feelings. It's OK to be vulnerable - but not to the point where the bereaved person needs to comfort YOU. Make sure you've got someone else on whom to off-load.

death as they have, you won't automatically share all their feelings. There are as many ways to grieve as there are individuals who grieve. We react to and cope with situations in our own way.

Don't be afraid of silence. A hug and shared tears in the quietness can actually speak volumes.

# 4. PREPARING THE WAY

The aim of this section is to help equip churches to create an environment in which people feel secure and safe about discussing death and the issues around it.

y heart of

the Christian story. Yet whilst this may be language with which we are familiar, how often do we actually address the issues surrounding death itself?

Left home to study/for a job	Too far to travel
Moved house	Fell out with ministers/leaders
Moved into present accommodation	Disillusioned with the church
Lack of time	Loss of faith
Death of a spouse	No particular reason
Death of someone else close to me	Other reason (please specify)
Please go to	Question 6
6. Did the death of your spouse affect your church-going?	
This question does not apply	
Yes, I started attending more	
Yes, I started attending less	
Yes, I stopped going	
No, it made no difference	
Part Three: About Belonging	
7. Where do you find the strongest sense of belonging, apa	art from family/close friends?
Local club/group/activity	Pub
Day/Community Centre	Church
Among neighbours	Other reason (please specify)
8. How would you describe this sense of belonging?	
A strong sense of belonging, which is growing	
A strong sense of belonging, which is unchangi	ng
Strong, but not as strong as in the past	
I wish it was stronger	

Part Five: Prayer	
7a. Do you ever pray? (If no, go to question 21)	
Yes	No
17b. If yes, how often do you pray?	
Daily	Only in Church
Weekly	Two or three times a year
Monthly	Hardly ever

# Part Seven: Getting Help

26. Where do you find spiritual nourishment? (Tick all that a	pply)
Books	Church services
Hymns/songs	Other Church groups
Through prayer/meditation	Through relationships
Listening to the Daily Service	Watching Songs of Praise
The Bible	Other (please specify)
27. Do you watch Songs of Praise on BBC1 on Sunday Even	ning?
Yes, regularly	I used to
Yes, occasionally	No, not at all
28. How important is fellowship/meeting with other Christia	ns to you?
Very important	Not very important
Quite important	Not important at all
Important	
29. Does the Church meet any of your non-spiritual needs?	
Yes, regularly	No, but I wish it did
Yes, occasionally	No, but I am happy about it
30a. Does the Church cater physically for older people adequ	nately?
Yes	No
30b. If no, what one improvement could the Church make to	improve matters?
31. If you could make just one change in your local church to people more, what would it be?	o encourage older

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# 5. LIVING AND DYING WITH HIV/AIDS

Here we offer some information and reflections on HIV/AIDS in Britain today. We hope this may increase our understanding of the situation and help us to help others more effectively.

The majority of people in Britain today with the HIV infection are young, and so a key issue for them is

### Example

most difficult things for his family was his large life insurance. His mother said it was worse than thirty pieces of silver.

How about **refugees?** It can be difficult for people from abroad to accept lifesaving drugs here knowing relatives can only accept their death if the body is returned to the homeland.

**Appearance** is another important issue: there is a characteristic appearance in people dying from AIDS which is very distressing to them and may cause them to shun company and become very lonely.

All people with wasting diseases need more help to make themselves look as attractive as possible it may be a significant factor in their willingness to see friends at the end.

Some doctors have very little knowledge in the field of **symptom relief** and are bad about asking for advice. Because many of the early patients were intelligent and articulate, the support services for people with HIV infection became excellent and there was plenty of money for care. People with other terminal conditions became, very reasonably, envious.

We do not have the palliative care, respite care, social services support and hospice provision that would add dignity and comfort for anyone approaching death. Would that we did!

### SOME CASE HISTORIES

The following are genuine case histories: all that has been changed in each case is the name of the person. They help us to appreciate that HIV can strike a very wide range of people, that there is no stereotypical person living with HIV/AIDS.

### **Charles**

needing triple therapy. She joined the Salvation Army, worked hard and was happy. Then she became ill, the drugs had awful side effects and it was only the support of her new friends that gave her the strength to continue. Susan knows that she is unlikely to have many years of life but she has now made her peace with her family and says her faith means she can face death with confidence and the belief in an everlasting life to come.

Addicts of all kinds are very unappealing, they often appear dangerous as they seek money in any way to feed their addiction. Help us not to pass by when they genuinely ask for help. Give us the insight to know

creatures. His acceptance never fails.

**Margaret**: After marrying an American, Bruno, Margaret went to live in the USA. She did not know that he was bisexual and, when he died of pneumonia, there was a conspiracy of silence so that she did not know it was AIDS related. She was left with two young sons and eventually returned to England. Three years later she met and a year later married a childhood sweetheart. Then came a welcome pregnancy

# **6. SUDDEN OR UNEXPECTED DEATHS**

# (a) Suicide

It is often thought that people are able to cope with death - amongst their families and acquaintances - if that death is anticipated. The fullness of years or the onset of terminal illness gives - at least in theory - time to adjust. Whilst that perception is held to be true for close relatives and for those called upon to lead a subsequent funeral service, it is not at all clear that this is borne out in experience. Many searching questions are raised when death is sudden - whether as the result of accident or suicide. This is particularly so if the person concerned is young or relatively young.

possible use of candle(s) -

- and that includes the person taking the funeral to see a tiny coffin, often carried by the parents, and to witness the distress of the family. You are *not* a failure if you show some emotion. On the contrary, it will show the family that you are touched by this too.

The best way to cope with this is to feel as confident as possible about the content of the service making sure your words are clearly set out for you to follow, that you are clear about any special instructions (when to ask the congregation to sit, stand, etc, which button to press at the crematorium). And make sure you have some time and space for YOU afterwards!

### Grieving

There are as many individual needs in grief and reactions to bereavement as there are individuals who grieve.

We are all different. We react to be reavement and loss in different ways - depending on, amongst other things, our age, social background, culture, the circumstances and cause of the death, and whether or not we have been be reaved before.

For the parents of a stillborn baby, or of a baby who has died soon after birth, there will be specific feelings and needs:

they need to be allowed to grieve. This means that others need to take the bereavement seriously, to

Certain situations will give rise to specific needs:

The father: don't overlook him. He is grieving too (though maybe differently), whether or not he shows it. Let him know that it's OK for men to be upset. It's often the father who has to make the phone calls, and go home to a house empty of people and full of baby clothes. He may feel upset that he didn't experience the physical closeness of the unborn baby as the woman did. He may want people to ask

Brothers and sisters: they may be grieving too. They should be a

# (c) I WILL NOT FORGET YOU.... I HAVE HELD YOU IN THE PALM OF MY HAND: the death of a baby before 24 weeks' gestation

- that is. incapable of

independent life outside the womb. This age of viability determines the cut-off point for termination of pregnancy (although in some cases it is permissible to terminate a pregnancy right up to 40 weeks). In 1992, the age of viability was brought down from 28 weeks, as more and more babies born around that time were being born alive and were surviving. It may be that in the next few years the age of viability will have to be re-considered yet again; babies are now being born alive as early as 22 weeks.

Babies born dead before the age of viability do not have any legal status. (Babies born alive, at any gestational age, have full legal status.) This has implications for disposal of the body. The legal definition of any loss up to and including 24 weeks is a miscarriage, but parents may find this language unhelpful and distressing. A death at 23 weeks is very different in many ways from a death at 7 weeks. In the light of experience the following classifications may be more helpful to parents:

death up to 12 week gestation - early miscarriage death from 12 weeks to 16 weeks - late miscarriage death from 16 weeks to 23 weeks - early stillbirth

However, this too must be handled sensitively: for some parents, if labour and delivery has been experienced and there is an identifiable body - which is possible at any point after 12 weeks - they may prefer this to be seen as an early stillbirth, irrespective of gestational age.

There is no requirement or facilities for registering a non-viable baby, which is often quite difficult for the parents. It may be that in the future, hospitals will find themselves under pressure to provide some form of certification.

If the baby has been blessed, a certificate will be provided for this.

Wesveftet4,ælss-β(ជន)អំយើចចែក្រាមកដៃ២৮/ਇជាមហជប៉ុខនោនuch as photographs, hand and foot prints etc, as for an older babyraquprefer thi4ab/P #M5u(tc)(om)-20(e f)-7TJET8oETBT1 0 0 1 363.79 4th1 0ll4(uc)-3ragETd0 0 1 130.2p10(bo)

the parents may not have even been aware of the pregnancy. A pregnancy test may be positive even while a miscarriage is happening, so they have to come to terms simultaneously with a pregnancy that existed but that is now failing.

an early miscarriage can go undetected, medically speaking, but the parents, particularly the woman,

# (d) DEATH IN A SMALL COMMUNITY

The majority of the population of our island lives in cities and suburbs, where neighbours are often unknown and death can go almost unnoticed. Yet even here, amidst the anonymity sought by many there are small, closely knit groups of people. They may be circles of community related to occupation, to a school or college, even a church!

### 7. RITES AND WRONGS: planning the liturgy

One area which always needs careful and sensitive handling is the liturgy to be used in funeral services. Often bereaved people will opt for a traditional form of service of the kind found in the Book of Services or other denominational manuals, but sometimes churches and ministers find themselves challenged to be more flexible in their approach to the content and structure of funerals.

these raise. High profile examples of such services - like that of Diana, Princess of Wales, which featured an oration by a family member instead of a sermon and popular as well as traditional music may lead bereaved people to want to suggest unconventional items to be included in the service or propose a highly eclectic form of service radically different from more tradition ones. In many respects the growing popularity of individually crafted services is to be welcomed, since they will usually result in the deceased

of one member of the family will dominate the whole thing because they will take the lead and organise everything. If we are able to pick up some important memory from each of the key members of the family each person will feel that their personal memory is included in the service.

There is often great value in recalling memories that cause people to smile or laugh, and laughter can be very therapeutic at a funeral. These memories may take the form of funny events that have occurred, or

careful handling, but many people respond well to a well-rounded picture of the person who has died, including subtle reflections on, for example, obsessions they had and things they did which used to frustrate other people. This is often preferable to presenting a complete paragon of virtue which bears no relationship to reality and which no one recognizes!

Sensitivity is needed when a request is received to conduct the funeral of a person of another faith: for example, there might be a requirement that it be done quickly. It is important that prayers and readings

different tradition his or her wishes are taken into account.

The question of how death itself is addressed in the funeral service is important. Some churches and

memories and give encouraging feedback to the bereaved. People often make a great effort to get to funerals for people who they may have known many years before, who may have done something very important in their early life, or of whom they have some special memory that they would want to share with the bereaved. All these positive memories, which might otherwise be lost, can be very encouraging and sustaining for the bereaved at a difficult time;

8. ATTITUDES TO DEATH IN DIFFERENT	ETHNIC COMMUNITIES
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The funeral comes to an end when it is getting dark, but donations will not cease coming in until after a few weeks. It is usually one week after the celebration of a funeral that the income and expenditure of the funeral are calculated. When there is a debt the successor of the dead person takes the greater part, leaving the remainder to be shared by the rest of the clansmen.

After the public ceremony, there are subsequent periods of mourning, which occur on the 8<sup>th</sup>, 15<sup>th</sup>, 40<sup>th</sup> and 80<sup>th</sup> days and on the first anniversary of the death in varying degrees among the various ethnic groups. The first anniversary is generally held to be important and libations are poured and the anniversary meal is prepared in memory of the ancestors. On that day also, the relatives shed their mourning clothes. Days of funeral are often heralded in many ways, drumming and singing being the commonest. When the day is certain, relatives, friends and others are informed. Then the relatives,

The furniture in the bedroom of the deceased (especially the bed) would be rearranged in the belief that this would prevent the spirit from finding its way. On the ninth day after the death, the belongings of the

been buried within three days after death. Dead bodies would be prepared with spices, wrapped, and block ice placed on top to preserve the body. The body would be kept in the bed in which the person died or put outside in a box. Nowadays, with the development of funeral parlours in close proximity to most communities and the migration of many Jamaicans, burial is often postponed to allow time for relatives living overseas to return to Jamaica to attend the funeral.

feasting, drinking, games, jokes and singing, as friends, relatives and members of the community go to the home of the deceased to cheer up the bereaved. Usually traditional foods are eaten such as fried fish, bammy, hard dough bread, chocolate tea, or whatever the family can provide. Often friends and relatives tactfully contribute in cash or kind to help with the feast. In recent years, especially in Kingston, Jamaica, dances are held in some poor communities with participants paying to attend. In this way the family is able to raise the funds to pay for the funeral, which is usually an expensive affair.

In some cases, where the deceased belonged to a Service Club or similar organization, the members of funeral. The members prepare food and drink and take it with them, thus catering for all visitors to the

Dances, singing and rituals with much more unmistakably African features take place in some communities. Most involve dancing and singing accompanied by drumming and spirit possession. Some

Gerreh in Hanover (forty nights after the death). Others include Kummina in Saint Thomas, brought by Congolese who came to Jamaica after the abolition of slavery as indentured workers (also held for birth, marriage, consecration, baptism and social purposes), and Etu, of Yoruba derivation, one of the few that do not include spirit possession. The pelvic movements in many of these dances attracted the disapproval of European Christian missionaries in previous years.

Other newer religious groups such as the Rastafarians and Unity do not have dead bodies in the sanctuary. An explanation given by a Rastafarian brother was that the body was not regarded as anything more than a carcass, and members would normally make individual arrangements for its disposal. He indicated that debates are currently being held among the Rastafari brethren as to whether or not this

Movement, explained that bodies were not brought into the sanctuary as a way of emphasizing that life is

### 9. MAKING A WILL

Everyone is advised to make a Will. Doing so frees us from concern that our affairs will not be handled as we wish after our death. Many charities give free support to people writing their Will, usually in the hope that they themselves will receive a bequest! Solicitors offer this service, and even where the bequests are not too complicated employing one is advisable. Some people, though, will feel that the simple completion of a form available in many stationers will suffice - and it may, provided that the guide notes are read and acted upon.

### The provisions to include in your Will may include:

the appointment of executors who will be responsible for administering your estate, sorting out the assets and liabilities, paying the legacies and distributing the residue. The choice of executors is important, for whatever the size of the estate may be, they have a lot of responsibility to deal with your assets, even if it is really only some personal things of sentimental value. If your

any trust that arises.

Particular situations/circumstances which may need special attention:

If a child or other beneficiary has a disability or special needs you may provide a special form of trust

### 10. THIS IS MY BODY: issues around organ donation

Requests for organ donation are almost always made following a traumatic and sudden event - cerebral haemorrhage, road traffic accident, etc.

The family involved are often in a state of shock and find themselves having to make difficult decisions when they least feel able to. This needs to be handled very sensitively.

Requests for organ donation can only be made when brain stem death has been established, and the test for this is very precise and carefully regulated. The test is carried out to discover the function or otherwise of cranial nerves which control basic life support systems, e.g. respiration. Two separate brain stem death tests are normally carried out. If the tests reveal that the brain stem has ceased to function, the patient will not able to breath on their own without the help of a ventilator, and although the heart will remain beating for a while, this will cease within hours or days, regardless of the treatment given.

The patient will remain on the ventilator while the family is asked about donation. Their consent must be obtained even if the patient carried a Donor Card. At no time is the family put under any pressure to make a decision either way; the decision rests with them and remains with them, although they will receive support and guidance in making the decision.

### Issues that often arise are:

the patient will look like any other patient in Intensive Care - sometimes better, as there will only be a head injury, which although severe may not show much damage externally, and there will be no other organ trauma. The patient will be warm, have a healthy colour, the heart is beating and the patient appears to be breathing. The patient's body must be kept in good condition if organ donation is to take place, but this can make it hard for the family to understand the severity of their condition.

It is hard to understand that the patient has been declared brain dead, that breathing is only

prayers for the recipients - acknowledging that they are anonymous strangers. This must be done very sensitively; be alert for ambivalent feelings towards organ donation. This is an indication that there needs to be more consultation between medical staff and the family.

The family will be asked which organ

### 11. CARING FOR OURSELVES

Sometimes we can devote so much time and energy to helping people who are dying or coping with bereavement or planning a funeral that we neglect to consider what effect all this activity might be having on us. Coping with death is always a traumatic experience, even for ministers who are called upon to do it regularly, and it is no sign of weakness to acknowledge this and build mechanisms into our timetables (for example, counselling) to help us manage ourselves. Churches also need to acknowledge the strain this work can have on their minister, and find ways to offer her or him support. The church needs to understand what their minister is going through when s/he is called on to meet with a bereaved family or help arrange a funeral service and committal - and indeed, not just the minister but all in the fellowship involved in conducting funerals and working with people who are bereaved or dying.

No f - example many of those considered in this pack, which will be potentially more demanding and exhausting than others. Conducting the funeral of a baby who has died could not be anything other than traumatic.

one known

personally to us will also be difficult, especially if our involvement has meant that we have not the opportunity ourselves to mourn properly, and this fact has not been noticed by anybody else.

Maybe church members ought to be able to enrol for them to support their fellow-

ing the job -consuming,

ones already in the diary. They may al especial responsibility for planning and conducting funerals at the church. This could take some of the pressure off the minister and help share the load. Whatever steps are taken, all involved in pastoral work

own needs and being practically and prayerfully supported by their church.

### 12. 'NO MAN IS AN ISLAND': the impact of deaths of people we do not know

We are all members of a community and, whether we like it or not, we are involved with each other.

diminis

Meditations, XVII). Just as St. Paul likened the Church to the body, with each of us being a separate and different part of that whole, so it is with any community. When a member of it dies naturally, there is pain, but it is localized pain affecting close friends and family; but when even a very small part is forcibly wrenched off, it causes distress to the whole.

Most people are not left untouched by death, be it that of someone very close to them or of a complete stranger whose death they have witnessed or whose life was very much in the public eye.

The emergency services are well aware of the devastating effect that witnessing a violent death or an horrendous road accident may have on their officers. So great is this awareness of the psychological and emotional trauma that may be suffered by those who have first hand experience of such deaths, that officers will be actively encouraged to seek counselling. It is not, therefore, peculiar, or to be seen as an indication of weakness, when ordinary folks are reduced to a state of shock, tearfulness and insomnia when they have been present at such a scene. Both doctors and employers accept this and are willing to help, allowing the person time to come to terms with it. This may well be a very trying time for family and friends, who may find it odd that so much shock and grief is being shown for the death of a complete stranger. Just as much understanding and compassion will be needed as would be expected of them had the victim been a close friend or relative. It is not an easy situation for anyone and much patience is required.

When someone famous dies, many people will mourn their passing. The death of a monarch, widow of a monarch or heir to the throne, has always merited a day of public mourning. With minor royals, for example Princess Margaret, there will be sadness but not the deep mourning as for a king or queen.

George Harrison and Elvis Presley, and in the young victims of senseless brutality like Sarah Payne, Holly Wells and Jessica Chapman, has been aroused to such an extent by the media that the deceased person has been idolized. Does the death of strangers like Diana, Jessica or Holly resurrect the grief that people may have suffered through the death of one of their own at the same age - or the death of someone who would have been that age had they lived? Some have wondered, controversially, whether some of the grief displayed over the death of the two girls from Soham was in part an expression of guilt by parents who felt they had not devoted enough time to, or taken enough notice of, their own children. Certainly the reactions to their deaths were unusually strong, as were those to the attack on the World Trade Center on September 11 2001- a direct attack on America which had considered itself, and succeeded in convincing much of the world that it was, inviolate. These reactions may have sprung from

# 13. RESOURCES

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