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 also kindly accepted invitations to join: the Revd Peter Ball (nominated by Life and Witness); Dr Sue Brisley; the Revd Michael Cruchley; and Professor Malcolm Johnson.* The group's work was aided most helpfully by additional specialist input from Dr Phyllis Mortimer,** the Revd Francis Amenu (Ghanaian Minister for London through the United Reformed Church), Mr John Bunker LLB and the Revd Dr Peter Jupp, and by the secretarial and administrative support supplied by Dr Andrew Bradstock and Ms Wendy Cooper in the Church and Society office. The group would like to thank all who helped in any way with their work, and in particular those who so kindly responded to their appeal in *Reform* for reflections on the conduct of funerals. These responses have been drawn upon particularly in the section on funeral liturgies.

The group thought long and hard about how it could best respond to the wishes of Assembly. Churches were consulted early on to ascertain which areas were of specific concern to them, and the results of this survey helped inform, and provide a framework for, the group's thinking in the early stages. Gradually the group came to a common mind that a pack offering resources, advice and reflections on a range of issues might be of use to churches and ministers, and set about identifying key issues to be covered and preparing draft sections. This document represents the fruit of their labours, and they offer it to the church in the hope that it will inform, stimulate, resource and challenge us all as we minister in the vital areas it covers.

Behind this pack lies a conviction that we are living in rapidly changing times and need constantly to think through our theology and practice in order to stay connected to the communities we serve. Some of the funerals we conduct or attend today are very different from those we experienced even just twenty or thirty years ago. Popular attitudes to issues like euthanasia, the natural or induced death of unborn children, suicide and bereavement have also changed in that time. The advances in areas like organ donation and transplantation, and the artificial preservation of life, present us with questions and situations for which no 'precedents' exist. The emergence of a new and disturbing phenomenon like HIV/AIDS, which has impacted especially on the young, has challenged and reshaped our thinking and practice in many ways. We have tried in this pack to reflect a little on these issues, and while we would hardly claim to be offering the last word in any case, we hope that what we have said will equip us a little better as churches and ministers for each new or unanticipated situation.

The working group would be the last to suggest that this pack means the church has now 'done' end of life issues. Far from it, for they are only too aware how barely they have scratched the surface of such a large area. The Church and Society Committee would like to keep open the possibility of further work being done in this area, and would welcome comments on this pack, suggestions for further topics to be covered, and offers of help from suitably qualified and experienced people. Please write to the Church and Society office if you feel you have any contribution to make.

* Professor Johnson withdrew from the group towards the end of 2001.
** We record with great sadness that Dr Mortimer died shortly before the final production of this pack.

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 have all drawn on our expertise and personal experience to put this resource together, but it is not intended to be exhaustive, nor a 'step-by-step' manual. We have deliberately not made any reference to 'assisted suicide', for example, since euthanasia is at present not legal in this country. Given these qualifications, we hope that what we have produced will be helpful.

The dictionary defines 'dead' as 'no longer alive, not endowed with life; no longer valid, effective, in use or relevant; unresponsive, unaware, insensible.' This is a concept with which many people find they cannot cope. There is a 'taboo' about death which makes it a difficult subject to discuss. Often it is a case of 'Oh, don't say such things!' or 'Don't tempt fate', or it is treated, as Stoppard does in *Rosencrantz and Guildenstern Are Dead*, with light-hearted flippancy.[1] Even epitaphs sometimes make light of it. Death is a difficult area for many of us, and the difficulty lies, not in not knowing what to say or how to say it, but in creating a situation in which people will be willing to discuss the issue at all.

Yet this anxiety about death may not be shared by all generations. Teenagers and students seem happy to discuss death along with other popular topics like sex, politics and religion. The dictionary defines 'death' as 'the *permanent* end of all functions of life.' Perhaps a change in attitude comes with age, when the total finality of death imposes itself on us. In the main, the young have little experience of death among their peers. The elderly - the very old - have no problem either with the idea of death. Most of them have lived far longer than they had ever hoped or wished, and death itself presents a kindly release. Is it just those in 'middle age' who find death, in fact and in theory, difficult to handle?
If so, the unfortunate thing is that this 'middle age' group is becoming ever wider, with the young growing up so early and the elderly living so much longer. It used to encompass the ages 35-50, now it probably extends from 25 to at least 65, if not higher.

And it is people in middle age who most often have to cope with death - that of their parents, grandparents and sometimes even their children. It can be an enormous strain, and the biggest problem can be a lack of openness and honesty between and within the generations. The scattering of families around the country and even the globe, the weakening of age-old family ties, can create further tensions: ministers and general practitioners are now much more likely to receive calls when there is trouble in the family where previously grandparents' or an uncle or aunt's advice would have been sought.

The only absolute certainty in life is that one day we shall all die. So why do we pretend that this is not so? Why does granny's death, at the age of 95, have to be seen as a mistake? Why does someone have to be blamed for it? Members of the medical profession would say that doctors are there to relieve suffering, not to cure or to save life - God does that. And, despite popular misconceptions, doctors do not believe themselves to be equal with God!

In our modern culture the received wisdom is 'promote healthy living and thereby prolong life'. But the process of getting to that longevity can be very selfish and tedious. 'Take this pill', 'don't smoke', 'don't eat this, that or the other', 'subject yourself to agonizing pain in taking ridiculous amounts of exercise'. It reduces the dignity of death, which is a gift of God, and produces miserable, self-orientated lives. A young boy whose father had died in his early forties, when asked if he was distressed by this, replied, 'Of course I am sad and I miss him terribly, but my father had a short, fat life. So many people have long, thin lives.'

Perhaps we are looking at death from the wrong angle. Maybe we should be concentrating more on the importance of life than on the significance of death. If we can handle life successfully, death will not be a problem. As Nicholas Rowe has put it, 'Death is the privilege of human nature, and life without it were not worth our taking'.[2]

One final thought. Should death education be taught in schools as well as health education and sex education? After all, you can have many goes at sex but only one at death. SuB

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[1] Rosencrantz: 'We might as well be dead. Do you think death could possibly be a boat?'
Guildenstern: 'No, no, no . . . . Death is . . . not. Death isn't. You take my meaning. Death is the ultimate negative. Not-being. You can't not-be on a boat.'
Rosencrantz: 'I've frequently not been on boats.' (Hilarious laughter)

[2] Nicholas Rowe, *The Fair Penitent.*

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

Following a bereavement, most people closely affected by it will go through the so-called 'grieving process'. This will include:

- denial and disbelief
- numbness
- developing awareness
- anger
- bargaining
- pining
- disorganisation
- depression
- re-organisation

To complete the process there are four 'tasks of mourning' that have to be done. Much simplified, these are:

- to accept the reality of the death
- to experience the pain
- to adjust to the environment from which the dead person is missing
- to withdraw the emotional energy that went into the relationship with the dead person and re-invest that energy into the future

The phases of the grieving process are only to be seen as a guide to what most people experience. They are not meant to be clear-cut stages. Not everyone will pass through each phase in the same sequence, or at the same pace or with equal ease. Grieving is not orderly and tidy.

Most people eventually reach the end of the process, although this will take anything up to two years. Reaching 'the end' of the process does NOT mean that those who are grieving will ever forget the dead person, or even totally 'get over' the bereavement. The pain may still be there, re-surfacing from time to time, but they learn to live with it. There will come a time when they carry their grief, and it no longer carries them.

Time does not heal;
it makes a half-stitched scar
that can be broken, and you feel
grief as total as in its first hour.
Elizabeth Jennings

How we cope with grief depends on many things, such as

- *The nature of the death* - whether it was sudden, expected, anticipated, untimely, traumatic, violent.

- *The place of death* - if it was in a faraway place, acceptance of the reality will be postponed and the grief prolonged.

- *If there is no body* - an early miscarriage, or someone lost at sea, or in war, or missing but never found, means the acceptance of the reality is hard and may be delayed.

- *The relationship with the dead person* - the more straightforward the relationship, the more straightforward the grief. If there are unacknowledged ambivalent feelings or denied feelings, the grief will be more complex. The more intimate the relationship, the more intense the grief. If the relationship was not public and needed to be hidden, the bereaved person may struggle to cope with feelings that cannot be openly expressed, and so find little support.

- *The age of dead person* - the death of a child may be the hardest of all deaths; it is not in the correct order of things. We expect to outlive our parents; we may expect to outlive a partner; we never expect to outlive our child.

- *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* - the current loss may ‘re-awaken’ previous 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.

A few suggestions …

- Try to avoid platitudes ('You'll get over it', 'It's for the best'). They may make *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.

- Don't be tempted to say 'I know how you feel'. Even if you have suffered exactly the same loss by 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.

- Don't be afraid of anger. This is normal in a bereavement. The anger may be directed at many people: the doctor, the driver of the car if the death occurred in an accident, themselves, the dead person, God… The anger might even be directed at you. Anger is hard to deal with in our culture. We do not like attaching blame. Sometimes anger is about blame - and sometimes justifiably so. But often the bereaved person is simply trying to make sense of what has happened. Try not to react adversely to anger - try to accept it as normal. Like other phases of normal grief, it will pass.

- Don't stay too long if you are visiting for the first time soon after the death. Grieving is exhausting, and the bereaved person may tire easily. Visit regularly but briefly early on, unless specifically asked to stay longer.

- Use the dead person's name. Talk about him/her. This will NOT be a painful reminder: the bereaved person won't have forgotten. Re-living memories is a very necessary part of the grieving process. It may provoke tears but that's OK!

- Make a note of the date of the death (or make sure someone in your church is responsible for doing this) and acknowledge it in some way one year later. Again, this will NOT be a painful reminder. The bereaved person's thoughts will probably be on nothing else. The fact that you remember too will be a great comfort.

- Maintain contact even if you don't feel you are getting very far. The bereaved person may be afraid of getting close to someone again for fear that that person goes away too - they feel that they can't bear any more loss so shrink from care and support. But in fact they will probably be feeling very lonely as well as frightened - so persevere, but keep the boundaries very clear.

- Grieving can take a long time. Be patient and be prepared to keep in touch for some time. Be prepared for good days and bad days. Many bereaved people experience a low point at around six months after the death. Give reassurance that this is normal.

- Most people grieve normally, but watch out for signs that the grief is becoming abnormal - for example, if the bereaved person seems to be 'stuck' at one of the stages of grief. It's helpful if you know someone whom you can refer a bereaved person on to if they need professional help - start with their GP.

- Don't be tempted to say too much about eternal life, heaven etc. A belief in the resurrection cannot take away the pain of grief. Indeed, beware that it doesn't 'get in the way' of the grieving process.

- Don't assume or try to guess what the bereaved person is feeling. ASK how they are feeling - and listen to the answer. Listen, listen and listen again.

- Don't expect the bereaved person to ever get over the death. The will learn to live with it, learn to cope with it, but they will never be the same person again. At times the grief may feel as intense as it did at the beginning. This is normal.

- Caring for a bereaved person is time-consuming and emotionally draining. Make sure you have someone to talk to. Ask for help and advice if you feel you are out of your depth or worried. You needs are important too!

SaB

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.

Death is a word which is often used in our churches: we talk about 'dying to the old and putting on the new,' of 'dying to self', of death being the gateway to full life. The death of Jesus lies at the very 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?

This sheet offers some thoughts as to how a church might approach this subject in a helpful and non-threatening way. The principles outlined here could be appropriate in any situation where someone is facing death, though they may be particularly suitable when working with older people, with whom there is great need and opportunity and with whom the church often has a natural contact. And scope for this contact will increase, if we consider the statistics: in 1971 there were 12 million pensioners, with 2 million over 80; in 2021 it is projected that there will be 19 million pensioners with 5 million over 80.

There are clear indications that we are living in an increasingly ageist society in which many older people are left in need of feeling affirmed and valued. The following are crucial elements in the spiritual well being of people:

1. LOVE: to receive and to give it
2. FAITH/TRUST: someone or something to believe in
3. WORSHIP: something or someone of highest value in our lives
4. HOPE: something to look forward to in this life and beyond
5. PEACE: a sense of security and tranquillity.

As a church our desire is to seek to help people towards an understanding of Christian hope and peace in this world and the next. Elderly people themselves admit, in response to questioning, that areas which prevent them feeling a sense of well being are loneliness, fear of dementia and failing bodies and death itself. In the light of this there is clearly a role for the church to play, in two particular areas:

1. Meeting specific requests
2. Ensuring opportunity for people to address their fears in a safe and supportive environment.

Obviously any discussions about death need to be handled with sensitivity. The last thing we need to do is leave people feeling more fearful than before we began. The main priority is to ensure that conversation takes place in a safe and secure environment. To this end it is often good to work with existing groups, as there may be a supportive base to begin with. Smaller groups (5-20 people) are often better than larger groups.

One non-threatening way of discovering where the people in your church are at in their thinking about death is an anonymous questionnaire. This allows you to see where your future conversations need to be directed. One excellent resource is the questionnaire which Albert Jewell prepared whilst he was Senior Chaplain to the Methodist Homes. Copyright permission has been sought and granted for our use, and a copy of the questionnaire is included in this pack for you to use as you wish. The section on *Death and Dying, the last things* is especially helpful. You may wish to use this section for your own discussions.

We would suggest that discussions take place over at least three sessions: this means that time and space is being given to developing the right environment - one in which people know that they are being led by a person or team which is sensitive and genuine in their listening and response. Worship to support these sessions would, we believe, be of huge benefit.

It is important that those who lead these sessions have a reasonable amount of background knowledge themselves. To this end there is a booklist included in the pack, and those who have compiled the information are also available to you.

PB

SIR HALLEY STEWART PROJECT

This questionnaire will help us to find out about the needs of older people in relation to the Church. Unless otherwise stated, please tick the box next to the category that best describes your opinion.

Part One: About You

1. Are you ☐ Male ☐ Female

2. What is your age?

☐ Under 60 ☐ 70 to 74 ☐ 85 to 89

☐ 60 to 64 ☐ 75 to 79 ☐ 90 or over

☐ 65 to 69 ☐ 80 to 84

3. What is your marital status?

☐ Single ☐ Widowed ☐ Other (please specify) _____

☐ Married Divorced

Part Two: About Church

4. Do you currently attend church?

☐ Yes, at least once a month (Go to Q5a)

☐ Yes, between one and ten times a year (Go to Q5a)

☐ Not regularly, only for weddings, funerals etc (Go to Q7)

☐ No, but I used to (Go to Q5a)

☐ No, I've never gone regularly (Go to Q7)

5a. If at any time in your life you have stopped going to church for at least a year, at what age did you stop? (If never stopped, go to Q6)

☐ Under 20 ☐ 40 to 49 ☐ 70 to 79

☐ 20 to 29 ☐ 50 to 59 ☐ 80 and over

☐ 30 to 39 ☐ 60 to 69

5b. For how long did you stop?

☐ 1 to 5 years ☐ 11 to 15 years ☐ More than 20 years

☐ 6 to 10 years ☐ 16 to 20 years

5c. Why did you stop? (Tick all that apply)

☐ Family responsibilities ☐ Because of illness

- ☐ Left home to study/for a job
- ☐ Moved house
- ☐ Moved into present accommodation
- ☐ Lack of time
- ☐ Death of a spouse
- ☐ Death of someone else close to me
- ☐ Too far to travel
- ☐ Fell out with ministers/leaders
- ☐ Disillusioned with the church
- ☐ Loss of faith
- ☐ No particular reason
- ☐ 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, apart from family/close friends?

- ☐ Local club/group/activity
- ☐ Day/Community Centre
- ☐ Among neighbours
- ☐ Pub
- ☐ Church
- ☐ 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 unchanging
- ☐ Strong, but not as strong as in the past
- ☐ I wish it was stronger
- ☐ I am happy to stay on the fringe
- ☐ Don't know

9. Where do you have the deepest sense of God's closeness? (Tick all that apply)

- ☐ Outdoors, e.g. in the garden or countryside

☐ Whilst listening to music

☐ In church services

☐ With other people

☐ Other reason (please specify) _____

10. How often do you sense God's presence?

☐ Always ☐ Occasionally ☐ Should not expect to

☐ Regularly ☐ Hardly ever ☐ Never

Part Four: About Your Beliefs

11. Do you believe in a God who created the world?

☐ Believe strongly ☐ I'm not sure if I do believe this

☐ Believe most of the time ☐ I definitely don't believe

☐ Believe, but not sure I understand

12. Do you believe in a God of love?

☐ Believe strongly ☐ I'm not sure if I do believe this

☐ Believe most of the time ☐ I definitely don't believe

☐ Believe, but not sure I understand

13. Do you believe that Jesus Christ was more than just a man?

☐ Believe strongly ☐ I'm not sure if I do believe this

☐ Believe most of the time ☐ I definitely don't believe

☐ Believe, but not sure I understand

14. Do you believe that Jesus Christ rose from the dead?

☐ Believe strongly ☐ I'm not sure if I do believe this

☐ Believe most of the time ☐ I definitely don't believe

☐ Believe, but not sure I understand

15. Do you believe that God can influence your life today?

☐ Believe strongly ☐ I'm not sure if I do believe this

☐ Believe most of the time ☐ I definitely don't believe

☐ Believe, but not sure I understand

16a. Do you believe that that Church has a place of relevance in today's society?

☐ Yes ☐ No

16b. Why do you feel this way?

Part Five: Prayer

17a. 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

18. How do you pray? (Tick all that apply)

☐ Alone ☐ Using a prayer book

☐ With others ☐ With a minister

☐ At communion ☐ In my heart following a set Pattern/diary/system

Other (please specify) _____

19. What do you pray about? (Tick all that apply)

☐ Family/friend ☐ Strength for the day

☐ Things to thank God for ☐ Praising and worshipping God

☐ Health/healing of particular people ☐ Other (please specify) _____

☐ Suffering in the wider world

20. Do you ever use the Lord's Prayer when you pray on your own?

☐ Yes ☐ No

21a. As an older person, do you personally feel valued by the Church?

☐ Yes ☐ No

21b. If yes, what makes you feel this way?

21c. If no, what do you feel is the reason for this?

22a. Do you feel that the Church makes good use of older people's spiritual gifts and natural talents?

☐ Yes ☐ No

22b. If yes, are <u>your</u> spiritual gifts and natural talents used?

☐ Yes, regularly ☐ No, but I wish they were

☐ Yes, occasionally ☐ No, but I am happy about it

☐ Yes, they used to be in the past

Part Six: Death, Dying and the Last Things

23a. Do you ever think about death?

23b. If yes, your own or another person's?

23c. What do you think about it?

23d. If no, is this something you would rather not think about?

24a. Does your faith help you when you think about death?

24b. If so, in what ways?

25a. Do you think the church teaches enough about life and death and judgment?

25b. What do you think about these matters?

Part Seven: Getting Help

26. Where do you find spiritual nourishment? (Tick all that apply)

- ☐ Books
- ☐ Hymns/songs
- ☐ Through prayer/meditation
- ☐ Listening to the Daily Service
- ☐ The Bible
- ☐ Church services
- ☐ Other Church groups
- ☐ Through relationships
- ☐ Watching Songs of Praise
- ☐ Other (please specify) _____

27. Do you watch Songs of Praise on BBC1 on Sunday Evening?

- ☐ Yes, regularly
- ☐ Yes, occasionally
- ☐ I used to
- ☐ No, not at all

28. How important is fellowship/meeting with other Christians to you?

- ☐ Very important
- ☐ Quite important
- ☐ Important
- ☐ Not very important
- ☐ Not important at all

29. Does the Church meet any of your non-spiritual needs?

- ☐ Yes, regularly
- ☐ Yes, occasionally
- ☐ No, but I wish it did
- ☐ No, but I am happy about it

30a. Does the Church cater physically for older people adequately?

- ☐ 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 encourage older people more, what would it be?

_____

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 the loss of a planned and anticipated future. They will ask whether there is any point in training or even working, and whether the drugs will work and, if so, for how long.

Anger is an almost inevitable reaction: anger against self, anger against the disease itself, and, especially, anger against the source of the infection, if known.

Examples: The most angry person I ever met was a 16-yesr-old haemophilic lad who had been given infected anti-clotting factor, long before any treatment existed. I have seen some men so angry on discovering their condition that they want to go out and infect as many other people as possible.

Young deaths from other causes share many of the same reactions. There are rare malignancies or congenital conditions in which the young person knows they are dying and will go through similar feelings. However, many young people die as a result of a crime, accidents and suicide, leaving relatives with need for support of all kinds.

Isolation can be an issue for older people with this 'young' illness: older people can feel as if they have behaved in a depraved manner. Sex and drugs are more 'accepted' among the young.

Depression is an almost inevitable consequence of diagnosis. Suicides were quite common in the early days of antibody testing when an early death was almost certain. Little sympathy may be given by those who feel that the illness is the sign of a dissolute lifestyle. Some doctors used tranquillisers and anti-depressants in the early days, but many do not provide this sort of comfort when it may be all that they have to offer. Hence the enormous importance of **spiritual comfort**.

Guilt is a very common reaction: 'I have brought this on myself', 'I knew all about safe sex and the danger from injected drugs but I just took chances'. Another common question is 'Have I infected anyone else?', and, in the case of a woman, 'Have I passed it on to my child?' Feelings of guilt can be most strong in those who make just *one* mistake.

Example: I had a bright delightful student who, at a party, got drunk and was persuaded to share some infected drugs. The next day he came to me in a panic. In three months the test was done – he was positive! He was in despair about the effect on his mother and all the sacrifices she had made for him. His guilt and remorse was heartrending.

Guilt may be a factor in many other 'end of life' situations: smoking, alcohol and even diet are factors in many illnesses and, especially when advice has been ignored, will cause the 'if only I had stopped smoking or cut down drinking' regrets. Some congenital conditions cause early deaths: how do parents feel when it was they who 'took a chance'?

How long have I got? is another often-asked question, as is 'Is the treatment worth all the side effects?' and 'They say the virus is becoming resistant to the present drugs - are there any new ones I can try?' What about the group of patients who seem to stay healthy without any treatment? Every blood test is a source of fear.

There are parallels in many malignant diseases - is there any point in yet another course of chemotherapy? In remission or, hopefully, cure, every scan brings a similar threat of recurrence.

Who makes the decisions about treatment, whatever the illness? What about NHS rationing? Who makes decisions for children?

How about **dependants?** Young people rarely think about life insurance other than to cover a mortgage. Often they want to protect their relatives from knowledge of their illness for as long as possible. Like suicide, an AIDS death may provoke more curiosity than sympathy, and this adds greatly to relatives' grief.

Example: A friend's son was killed in a road accident: he went to sleep in his car and hit a tree. One of the 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 that their relatives are dying 'at home'. There are also terrible problems if a person's culture demands that 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: In 1983 he became one of the first people in this country to be diagnosed with AIDS. He hid his homosexuality from his macho work colleagues where jokes about 'poofters' were common. There was little support in those days, he had no close friends or counselling, and lived with his mother who was still hoping he would 'find a nice girl'. In despair he committed suicide. Rumours of his HIV status leaked out, his workmates panicked and his mother received hate mail.

Give us compassion even when we do not understand. Let us not fear the unknown but let God turn our fear into courage so that we can comfort those in need and give them strength.

Joshua: He was a Ugandan refugee and was eventually joined in this country by Mary his wife and Joyful, their 6-year-old daughter. They settled well and Joyful loved her school. They were all delighted when Mary became pregnant again. Soon after their baby son was born, Joshua developed Pneumocystis pneumonia and a diagnosis of AIDS was made. Joyful was the only one who had escaped the infection. By the time she was 8 years old she was the only one still alive. Relatives in Uganda wanted to take Joyful back there but she has lost father, mother and brother - she said her friends here were all she had left. Until the AIDS diagnosis they were regular church worshippers but then they felt ashamed and did not attend again. No one came to see what had happened.
Help us to be more aware of others' needs and give us the grace to know the right words of comfort. May our churches care for all, whatever race, colour, patterns of worship or differences from ourselves.

Andrew: He is still a very successful businessman. When very young he was on a business trip to Thailand and went with a prostitute. He had a glandular fever like-illness when he returned, soon felt well and thought no more about it. Eventually he found the girl he wanted to marry and decided to have a thorough health check before proposing. He was found to be HIV positive. He did not know what to do and was overwhelmed by guilt and grief. On his way home he did what he had not done since early childhood - he went into a church and prayed.

Give us the conviction that God's forgiveness is limitless. When we look at our own lives we are so aware of the actions and words that we want to undo. Help us to show God's love to those who are in times of great need.

Susan: She went right off the rails in her late teens - left her caring home to sleep on the streets, took drugs including intravenous ones, and was often blind drunk. One day when in a collapsed state she was found by the Salvation Army: they cared for her until she was well enough to be weaned off drugs and alcohol. In the course of the treatment she was found to be HIV positive though, surprisingly, not yet

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 what is the right way to help them and to remember that, even in degradation, they are still God's 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 and another son was born. A visitor from the States accidentally let slip that Bruno had, in fact, had AIDS. Margaret was tested and was positive: her only joy was that the baby and her new husband were both fine. She learnt the amazing way of living – to accept whatever happens - and she plans for a future, not knowing if she will have one, and lives each day to the full. She is happy and serene with no bitterness.

Help us to face up to whatever tragedies come our way, knowing that we are never alone. God shares both our joy and our sorrow, so we should also stand beside those in need of comfort and support.

PM

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.

Suicide is at the extreme end of a continuum of psychological stress, distress and tragedy for individuals, their families and their communities. Death as the result of an automobile or industrial accident, or of a fire, impacts on the wider community in a way that the more normal pattern of dying seldom does. Within the church, we need to be carefully aware of some of these questions so that they may be seriously addressed and not left unanswered.

A recent report, based on findings from the Office for National Statistics, showed that almost one in six British adults aged between 16 and 74 had considered suicide at some point in their lives. This report indicated that suicidal thoughts are more likely among women, younger adults, divorced individuals and lone parents. A report published in 1997 by the Samaritans indicated that 19% of all deaths of young people were suicides, averaging 2 per day. These are tragic statistics, yet it is known that coroners often try to find other ways of defining the incident since they wish to ‘ease’ things for the survivors.

Not all of these deaths are ‘preventable’, because a very high proportion of those committing suicide are very determined, and usually have access to reliable methods of ending their life. (Veterinary surgeons, dentists, farmers, pharmacists, doctors and chemical scientists all appear in the ‘top ten at risk’ list). However, an awareness of the signs of significant stress in people ought to help people in the church recognise the earlier cries for help that too often end in suicide. ‘...depression, if not checked, can spiral out of control with disastrous results...’ (Ben Gill, ‘Coping with Stress’, The Samaritans, 2001) There are good short courses of training that could well be used at appropriate gatherings of church people.

Dealing with the aftermath of someone who has taken his or her own life is often made more difficult by the still held feeling that suicide is sinful. There is acute need for words of comfort, not condemnation, to be spoken to the survivors who are often suffering from shock and perhaps a sense of guilt as well as loss. That family and friends did not observe the signs can lead to a sense of guilt that has to be eased. Most of this work has to be done outside the formal funeral service, but it needs to appear within whatever form of funeral takes place.

The funeral of someone who has taken their own life may be sparsely attended because friends and colleagues do not know how to deal with their own emotions - or it can be a significant occasion attended by many who have little or no experience of a religious service. Simplicity and honesty in use of words recommend themselves as virtues for the leader of the service. Any sense of condemnation should be avoided - even of the circumstances that gave rise to the suicide - lest that sense gets linked in hearers' minds to the person.

MC

(b) FROM CRADLE TO GRAVE: the death of a baby before or shortly after birth

The Funeral

The funeral is primarily for the parent/s, but also present may be siblings, grandparents, other family members, friends, midwife and nurse.

Needs include:

- to hear the baby's full name spoken publicly;
- to be assured that God still loves us - despite and through anger, confusion, loss of faith, questions;
- to be assured that God loves the baby and will take care of her;
- to share what memories there are - acknowledging that these may be few, especially in the case of stillbirth: 'giving thanks for the time that she was held in her mother's womb and in the father's / family's heart'. There may be memories you can tap into - memories of the pregnancy, ultrasound scans, the baby's movements in the womb - but they may of course include the sad memories of learning of the baby's death and the delivery. These need careful and sensitive handling, but should not be totally avoided;
- careful choice of words - not 'loss' but 'death';
- for the parent/s to be involved as much as they wish – choosing poems, readings, music etc, and taking part in the service if they want to by carrying the coffin, speaking, reading...
- for siblings to be involved if this is appropriate - possibly by releasing a balloon afterwards, drawing pictures to put in the coffin, carrying flowers and placing them on the coffin;
- a printed order of service, with a significant symbol on the front - e.g. teddy, special flower, butterfly (or parents' choice);
- the coffin to be treated with dignity and respect;
- assuring that the baby will never be forgotten but will live on, in our memories, and will have a special place in the family;
- some words that point to eternal life - that the baby is a now in the full light of God's presence, a cherished daughter of God. BUT proclamation or belief in the resurrection cannot take away the pain of bereavement. The baby is with God, but the family would much rather that she was with them!
- saying goodbye:

> 'Merciful and Tender God
> we commit Chloe's body to be cremated
> and her spirit to your love.
> As she was cradled in the womb
> cradle her and hold her
> that as we let her go
> we may know that she has gone
> from our loving arms
> into yours for ever.
>
> We do not ask for the power to forget
> but for greater courage to remember.'

General points

- don't imagine that the parents never knew the baby. Many women who have been pregnant will say that they knew their unborn baby very well. Fathers may experience this too, though probably to a lesser extent.

  Yes, they never got a chance to get to know her better - but this does not make them grieve any less. Indeed, it might make their grieving more difficult. Memories help us to grieve. The funeral will become one of those important memories - which is why it is so important to do it well.
- It's quite difficult to find appropriate hymns if you are asked to choose. The parents can be encouraged to choose, or if they can't think of any, they might choose some music to listen to instead. Singing at funerals is notoriously bad anyway - you may end up singing a solo! If you must have a hymn, a funeral is not the place to introduce very much that is unfamiliar - unless specifically requested by the family. However, unfamiliar words can often fit a well-known tune.
- if the baby was blessed or baptised at birth, it can be good to use some of the same words – for example a reading - and explain this.

- possible use of candle(s) - parents can light one to represent their baby's life. ‘Death is not the snuffing out of a candle, but simply its dimming because the dawn has come’.
- and finally … it is very difficult for everyone - 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 bereavement 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 bereaved 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 recognise and treat the parents as being bereaved. It is not helpful if others refer to the parents as having suffered ‘a little upset’ or having ‘lost a pregnancy’ - much better to use the word ‘death’. Sometimes parents are not imagined to have known the baby properly (‘you never really knew him anyway’) and so are not expected or allowed to grieve.
- they need to experience the pain of loss. This may sound harsh, but before healing can happen, the pain must be faced and felt. Others may want to shelter the parents from pain - a natural reaction - but the pain doesn't go away, and will only re-surface later, when it may well feel more intense. There is no way out of the pain of grief, only a way through.
- they may need to express anger - against the midwife, doctor, family, themselves, God. This is often expressed in the question ‘why?’ and with the words ‘if only’.
- they need to have the baby recognised as an individual and person in her own right. This means not being told ‘you can have another’ or ‘never mind, you've got other children’. One human being cannot be replaced by another.
- they need to see that others recognise that their baby deserves respect, particularly after death.
- they need to be offered accommodation in a quiet area - away from the main Delivery Unit or Neonatal Unit, where they can spend time with their baby, overnight if necessary, and with facilities for parents to stay together (e.g. double bed settee).
- they need something to remember their baby by. Memories play an important part in the grieving process. After the death of a baby, such memories may be few. It is important to try to ‘create’ memories - by allowing the parents and others to hold and spend time with their baby, by offering photographs (and not just the Polaroid type as these fade with time), the label from the cot, a lock of hair, hand and foot prints. The parents can be encouraged to keep any cards or letters they receive, and to select a flower or two from the funeral to press and preserve. All these mementoes can be collected together and kept in a special box, or displayed in a special way.
- they need to be encouraged to make their own decisions as much as possible. It is difficult to make any decisions when in the first throes of grief, and the parents may need help and guidance, but others should not be tempted to take over. However well-meaning, this may prolong the parents' denial of the death and prevent them from facing the reality. They need to be involved as much as they want regarding the funeral arrangements. Remember there is no need to rush into arranging the funeral, particularly if the woman is still unwell after the delivery.
- they need someone who will listen, and in the long term, who will listen and listen again.
- they need time: time to spend with their baby; time to reflect on what has happened; time to talk about their experience; time to adjust to their new life without their baby; time before they consider another pregnancy.

In short, they need time to grieve.
Time itself does not heal. It is taking time to grieve that heals.

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 'How are you?' and not just 'How is your wife / partner?'
- Brothers and sisters: they may be grieving too. They should be allowed to see the baby if they want and if their parents want them to, and might like to bring a special toy or flower or draw a picture. If they have not seen the baby, they may want to see a photograph, and depending on their age, will almost always (at some point) want to talk about what has happened. Silence on the subject can be frightening and confusing. Their questions should be answered gently and honestly. We need to take care what words are used. If the mother is referred to as having 'lost' a baby, the surviving child might be afraid that his mother might lose him too. Alternatively, the child might see a 'loss' as only temporary, and that the baby will be found again soon. Don't be afraid of the word 'death'.
- Grandparents: they too need their grief to be acknowledged. They may be grieving doubly - for their son or daughter in their grief, and for their grandchild. They too can be encouraged to see the baby if appropriate. It may also bring back grief of previous bereavements, especially if they themselves experienced long-ago baby death - which may not have had the same recognition.
- Parents of twins: they may well be grieving doubly of course if both babies have died; or they may be grieving for one more than the other, for various reasons. This should not be considered abnormal or unfair. The babies were, after all, individuals, and should be regarded as such.
  Where only one twin dies, the parents may have conflicting feelings and needs, and great anxiety for the surviving baby. Great sensitivity is required. It is not helpful to say 'at least the other one is all right'. This may make the parents feel guilty and ashamed of their grief.
  It may be helpful for both twins to be photographed together if possible.
- Parents of a baby with a disability: the parents may have surges of conflicting and confusing feelings and may need particular help and reassurance.
  The disability may have been detected ante-natally, and so the parents may have already done some anticipatory grieving before the delivery. Although the death may have been expected, they may be surprised at the overwhelming sadness when it finally comes, and will need reassurance that this is normal.
  If the disability was not detected, the parents will be in a state of shock for some time, and should not be rushed into anything.
  It is often better to allow and encourage the parents to see the baby even if there is a visible abnormality - what they imagine is often far worse than the reality. Nursing staff are skilled at dressing babies to hide the worst abnormalities - though the parents may want to see everything, and this can be done sensitively and gently if appropriate.
- Other people who are pregnant: for a bereaved parent, they can feel as if suddenly everyone else is pregnant or has just given birth successfully. People with prams and pregnant women seem to be everywhere; the television seems to show nothing but nappy adverts. This is obviously painful and can be embittering. But this can also be difficult for those other people - especially if they know the bereaved parents well. They can feel guilty about being pregnant, or frightened that something will happen to their pregnancy, or about having a live, healthy baby. This situation might be acute in a church / Sunday school context and demands sensitivity for all concerned.
- A subsequent pregnancy: this is a very anxious time and this must be acknowledged. Hospital staff need to be extra sensitive and fully informed. Regular ultrasound scans may not be necessary medically, but may be very necessary to allay anxiety. Also, another pregnancy and another baby cannot make it 'all alright'. In fact the birth of a healthy baby can re-kindle grief, and the parents need reassurance that this is quite normal, even to be expected.
- Anniversaries: these are bitter-sweet times. It helps parents enormously to receive cards or letters or phone calls; these do not 'remind' the parents - they won't have forgotten - and there's nothing wrong in remembering even if it produces tears.

SaB

(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

Unborn babies before the gestational age of 24 weeks are deemed to be 'unviable' - 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.

It is often also possible to provide mementoes such as photographs, hand and foot prints etc, as for an older baby, and the parents can be encouraged to name the baby.

Disposal of the body

Where there is anything identifiable, this must be treated with respect. Use of the hospital incinerator should be avoided if at all possible, but if this is unavoidable, the parents need to be aware of this, and the incineration should be carried out in a respectful way, and as far as possible be done separately from other hospital waste. The parents need to know that they can ask when the incineration will take place and that any remains will be burnt respectfully and not kept by the hospital.

In the future, it may be that hospitals will have their own 'baby cremator', where anything identifiable and even any products of conception from an early miscarriage can be disposed of with dignity. Any ashes recovered could then be scattered in a dedicated garden within the hospital grounds.

There is no legal requirement for a funeral, but for many parents some rite of passage is necessary. The parents can arrange the funeral themselves; alternatively, many hospitals arrange a committal service once a month at the public crematorium, led by a hospital chaplain. The parents must be informed of the arrangements - that the service will include other babies as well as theirs; that each baby is cremated separately; that every effort is made to recover ashes, though this is not always possible, or at least there may be very little, depending on the gestation and size of the baby.

Specific needs surrounding early miscarriage

- there may be no identifiable body. This can be quite difficult for the parents as this may mean their grief is not recognised or acknowledged; that they did not know the gender; that often they do not know the reason for the death as no tests can be carried out on the baby. There is the question of disposal - as outlined above. Some hospitals consider that there is a moral obligation to provide respectful disposal if any evidence has been found (usually in the laboratory) that conception has taken place.

- 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, may suspect it. If her menstrual period is late, with unusually heaving bleeding and pain, she may wonder if she has been pregnant and has miscarried very early. This can be very distressing; she may feel her grief is totally ‘hidden’ and so unacknowledged, possibly even by her partner.

SaB

(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!

Outside the conurbations, the impact of a death may well be greater.
For instance:

Towards the end of 2001, when an explosion at Port Talbot killed three men - two of them under 25 - the small, close community was left reeling. Within weeks, and not far away, a fire swept through a house, killing three generations of the same family - two of them being under 4 years of age. These small communities were living with real shock.

The exercise of a pastoral ministry in such circumstances has to go far beyond caring for the family of the bereaved. It becomes a community-wide ministry that will be watched and commented on by all and sundry - and will usually gain a media coverage to which many ministers and leaders of funeral services are unused.

Where sudden and 'unnatural' death has occurred, great shock, denial, numbness and anger affect people who appeared to be unconnected to the person who has died. These symptoms often affect some usually balanced people and bring them to the verge of hysteria. Some practical matters ought to be addressed - for instance, to ensure the presence of a trained person who can offer medical support in case of need.
Even so, it is difficult to see how adequate preparation can be given for 'accidental death care'.

It is very important for all of us within the church to be aware of the demands that dealing with such situations make on leaders. The preparation of a funeral or memorial service needs extra space and time and elders and church members should offer strong pastoral support to whoever is handling such difficult services in the name of their church.

The ministry to the wider community will not end with the benediction at the end of the service - it will continue as people 'gossip' the impressions of how the service was handled. It may have proved to be an 'evangelical opportunity' - or a public relations disaster, and the leader will be held to account for a considerable time. Folk memories in close or small communities last a long time!

MC

(e) DEATH IN A ROAD ACCIDENT

Each day 10 people die on Britain's roads and 850 are injured. The price in terms of human loss, grief and care is immeasurable. Road accidents produce many victims: the primary victims are those who die, but the survivors are victims too, and face, in addition to devastating shock and grief, a multitude of practical and legal problems.

An organisation called **RoadPeace** exists to provide emotional and practical support to bereaved and injured road traffic victims. It aims to help victims through the complex and confusing procedures following road death, and also to put those who have known the tragedy of losing a loved one in a road crash in touch with others who have suffered similar experiences. RoadPeace also endeavours to raise awareness of the responsibilities of all road users, and promotes the European Day of Remembrance for Road Crash Victims on the third Sunday of November, with services in many churches and cathedrals.

The RoadPeace Helpline number is 020 8964 1021, and further information may be obtained from: RoadPeace, P.O. Box 2579, London NW10 3PW (tel/fax: 020 8964 9353).

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.

'Tailor-made' services are become increasingly popular, and we need to think hard about the questions 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 being honoured in a much more 'personal' way than might otherwise be the case: but a number of issues need to be born in mind by ministers when the question of officiating at such a service is broached.

Sometimes, for example, bereaved people will indicate that they want to 'celebrate the deceased person's life'. We need to clarify whether they are using the term as a synonym for what would more traditionally be called a funeral, or whether they have something altogether different in mind. We need to be clear what *we* mean by a 'funeral': do we see it as providing an opportunity to 'celebrate a life', or do we want it to do more? If the latter, would we be happy to participate in or officiate at an event which was intended only to be 'celebratory', or would we insist that some deeper 'spiritual' dimension, acknowledging death and reflecting on its meaning, be included? 'Celebrating a life' can, of course, also have humanist connotations – and there will be cases where the bereaved will decidedly *not* be celebrating a life, for example, where a marriage has been difficult or the deceased unfaithful.

A related question to this is, Who is a funeral for? In some cases it will not primarily be for the family, who may be less affected by the death than friends, colleagues or a lover or even mistress. We might need to assess which people have actually been most affected by the death, with whom the deceased person was having the most intense or meaningful relationships at the time of their death. It is necessary to assess who are the people in need following a death, and perhaps in some cases to use terminology like 'the bereaved' rather than 'the family'.

The importance of making the service meaningful and personal cannot be over stressed, and to this end, if the deceased is not known to us personally, every effort must be made to build a picture of them through time spent with families, neighbours and friends as they share their memories. We need to be attentive as facts or recollections are described, and not afraid to ask questions in a sensitive manner. Too many of us can recount stories of funerals where the 'duty minister' did not even know the name by which the deceased was usually known, and of the effect this had on those present. Even in cases where we are called upon to conduct a service at the last minute, and have nothing to go on but a name and an age, it may be possible to ask a friend or relative, in the few minutes before the services starts, if they would be prepared to say some brief words about the person they loved. It is almost always better to acknowledge that we do not know the deceased if that is the case, and give a simple message of Christian hope, than attempt to summarise the deceased's life and work without proper knowledge. And a lot will be forgiven if, despite errors, we show a real concern for those who are grieving.

Bereaved folk should be encouraged to choose hymns, readings and music, including that to be played at the entry and exit of the coffin. If several drafts of the service need to be drawn up and exchanged before all parties are satisfied, it will generally be worth the effort. Some families may have prepared material already, and this should be welcomed and used as a basis for discussion. Others may have little or no experience of funeral services and need guidance and encouragement to offer ideas and suggestions. Friends and relatives should also be encouraged to take part in the service if they want to - even to the point, if they wish, of pushing the button at the crematorium.

Sometimes it may help to have a personal tribute from a friend or relative, and a separate talk from the minister which expresses the faith. In some cases the minister may pick up aspects of the character and life of the person which the personal tribute may not have brought out. During the preparation for the funeral the widow(er), children and other close relatives should be encouraged to recall and share the qualities and aspects of the life of the deceased person which were important to them. People often need encouragement to speak to a minister, as they may not think they can do this or are too emotionally stunned to do so without prompting. If the deceased has children it is important to get feedback from all of them about their departed parent rather than from just the most vocal. This will ensure that a balanced picture is secured and vital memories are not left out. A common concern is that the ideas and thoughts

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 aspects of character including the deceased's less flattering qualities. The latter will require sensitive and 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 from the deceased's faith tradition be considered, and that if there is a surviving partner who is from a 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 ministers find it important and appropriate to emphasis the concept of 'life after death' and encourage bereaved people to see death as not the end. The emphasis here is on death as a 'temporary parting', to be followed, in due course, by a reunion in the next world. Others believe that talk of this kind can hinder the process of 'letting go', and point to the gospel teaching that in losing we gain and in trying to hold on we lose. They prefer to speak of death in terms of radical change and transformation rather than continuity, and of defeating it by meeting it without fear rather than by 'surviving' it.

The importance of sensitivity toward those who are bereaved when planning a funeral service cannot be overemphasised. For many people their only contact with a church is following a bereavement, and if the situation is handled badly they may be lost to the church for good. Many people who have broken with organised religion have done so within the context of a bereavement, sometimes because clergy neglected to offer support, but sometimes as a consequence of things happening in the setting of funeral services in which they were personally involved. Funerals are a great opportunity for the church to reach out to the family and friends of the deceased, to show understanding, compassion, sensitivity and pastoral care, and to share the truth of the gospel.

Church and crematorium

If there is going to be a service at both the church and the crematorium, the traditional practice has been to have the funeral service in the church, with the coffin then taken to the crematorium for a committal service with the family and closer friends. Often the family and friends would then come back to the church, village hall or a nearby house, pub or hotel for refreshments. One major problem with this was that those going to the crematorium often missed seeing those who came just to the funeral service, the latter perhaps being unable to wait, or feeling awkward about waiting, for the second service to finish. An alternative which is becoming increasingly common is to have the 'private' funeral service at the crematorium first. This allows the family and closer friends time for more private grieving, for getting through the emotion of the coffin disappearing behind the curtain, and for collecting themselves (perhaps aided by a good old-fashioned cup of tea!) before a thanksgiving service in the church. The two services could even be on separate days if preferred. There are a number of other advantages with this arrangement.

- the service at the crematorium is more private, and this is particularly helpful where the deceased was a well-known and loved person, who will have many people from the local church and community wanting to come and 'pay their last respects';

- a church service can be a real service of thanksgiving for the life, in a more positive atmosphere, particularly where someone is part of the Christian church and their faith can be celebrated;

- the larger turnout at the church can then be better appreciated by the family and close friends, who can enjoy the support that this gives; and, where the deceased was part of the local church, the warmth of the fellowship can be particularly valuable;

- the lunch, tea or other refreshments can follow immediately after the church service - in an adjoining hall or somewhere nearby - with everyone able to stay on and without the awkward gap as some go off to the crematorium. This might allow more opportunity for people to share their

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;

- the atmosphere at the 'wake' (or whatever one calls it) afterwards can be much more positive following such a thanksgiving service, and be that much more healing and restoring for the bereaved. Funerals can be very therapeutic occasions if handled well, and this arrangement of the church and crematorium can make a huge difference.

AB / JB

8. ATTITUDES TO DEATH IN DIFFERENT ETHNIC COMMUNITIES

(a) THE CONCEPTS OF DEATH, BEREAVEMENT AND FUNERALS WITHIN THE GHANAIAN WORLDVIEW

INTRODUCTION

Death is a universal phenomenon that affects all humans irrespective of their constitution and status in life. The attitude towards it, however, is everywhere ambivalent. In general Ghanaians, and West Africans for that matter, regard death not as the end of life, but as a transition from this present earthly life to another life in the land of the spirits. It is a journey which every human being must make in order to reach the life beyond, and continue to live as an ancestor. The Ghanaian believes that human beings are never annihilated. They only change their earthly mode of existence for another, in fact, better one. The dead, therefore, do not remain in the grave, but become spirits and proceed to the spirit world. In the life after death, there is no cheating, there is no physical pain or deformity, and there are no evil intentions or machinations.

DEATH

As rightly pointed out by Peter Sarpong, in his examination of Ghanaian dirges and activities at funerals, it is clear that death is regarded as the occasion when a deceased person sets out on a journey to the underworld or spirit world to which his ancestors have already gone, a place where he must settle any account he has with those who have gone before him. The journey is arduous and unavoidable. One who sets foot on it, cannot and should not come back, except as a respected ancestor spirit. But if the person had been particularly wicked in his lifetime, or something had gone wrong before the journey or in the course of it, he might not be admitted to the world of spirits. Hence it is considered a sacred duty to give a dying person water to drink to prepare him for the journey, and to put gifts of all sorts into his coffin for use during the journey and on his arrival among his forebears.

There are many, and often complicated, ceremonies connected with death, burials, and other related funerals rites. Death extends the family relationships into infinity, and the ceremonies and rituals performed by the living for the dead emphasize the unbroken family relationship between the living and the dead. Both the living and the dead have a part to play in fulfilling family obligations, and things go well for a family when both sides perform their obligations properly. When this is done properly it is believed the dead, on their part, begin to play a larger and more important role in human society in general and in the life of their families in particular because of their increased powers. Their role is to protect, direct, intervene and guide their families, and also to serve as elders of the family.

On the other hand, the Ghanaian generally also considers death as a kind of unjust, heartless oppressor, a wicked destroyer, a killer and a curse, which frustrates human effort and ruthlessly delights in forcibly taking away one's loved ones, mother, husband, parent or best friend, for whom there can be no real substitute. It brings about complete physical separation and constitutes a great loss not only to the immediate family in which it occurs but also the whole community. In the Ghanaian worldview no death appears to be, in Christian theological terminology, 'natural', and the living are therefore at pains to find out the cause, usually mystical, of every death. An individual's own misbehaviour, for example in the breaking of a taboo, can lead to death. Such a death is said to be brought about by the spiritual agent or being who is thought to have been slighted most by the misconduct. Ancestors are most likely to deal severely with one whose duty it is to organize fitting funeral rites in honour of the dead, but who ignores them, or one who sells an ancestral property without due protocol.

Death often creates ill feelings among people; it may result in suspicions sometimes totally unfounded, frequently creating dread of people whom society, by its own standards, judges to be, in one way or other, the cause of its appearance.

No death is more shameful than a death brought about by such 'unclean diseases' as leprosy, epilepsy, or smallpox, or death at childbirth, death due to suicide or death of one alleged to be a witch or wizard. It is also considered shameful to die childless or without being able to give out your 'last will' or to die as a result of cowardice at war.

When an elderly person knows she is about to die she calls her close relatives and friends and speaks intimately to them. She may tell them how she wishes her estate to be administered; she may reveal a clan secret to them; she may tell them how and when she wishes to be buried or given the last respects

through the funeral rites. The person may reconcile herself to people against whom she bears a grudge or who bear her a grudge, and so forth. It is considered “bad” to die without being able to talk in this way.

FUNERALS

Funerals are great social occasions in Ghana. They generally involve whole communities who gather together at these events to perform appropriate rites, which help to strengthen the bond between the living and the dead. Funerals are regarded as a duty, and no pains may be spared to make them memorable. For they are the last transitional rites, introducing the deceased into the spirit world. One of the signs of a successful life and good death is the way a deceased person’s funeral is celebrated. As affirmed by Kofi Asare Opuku, there is a widespread belief in Africa that, unless the proper rites and ceremonies are performed, the spirit of the dead person may not be able to join the ancestral spirits. Thus, great satisfaction is derived from the performance of these funeral rites.

There are many variations in funeral celebrations as the rites performed are dictated not only by the circumstances of the death, making it a good or bad death, but also by such considerations as age, social position, and status of the deceased. The funeral of a child, for example, is quite different from that of an adult; it is generally characterised by less wailing and the rites and ceremonies are usually brief. An adult, however, receives a more elaborate funeral. The funerals of kings and queens are also significantly different from those of ordinary citizens.

Funeral rites are generally performed in stages but these again vary from society to society. Among the Ewes and Akans of Ghana, for example, there are four stages in their funeral celebrations: preparation of the corpse; pre-burial mourning; burial; and post-burial mourning. For the Ghanaian Christian community the sequence of events would include, a Wake-Keeping Service, Burial Service, Memorial and Thanksgiving Services. The Church is always fully committed in the event of the death of a member. In the case of a widower or widow, the church leadership would consecrate the official mourning cloth meant for his or her use as part of the expected widowhood rites. When a family has been informed of the death of one of its members, the chief and friends are also notified. (Note: For the Christian, this is done through the minister of the church and the elders of the bereaved community). The family then prepares the corpse for burial. The preparation includes bathing the corpse, dressing it and laying it in state. This is strictly a family affair and the public is not invited to witness this initial aspect. There is also no wailing at this stage.

Pre-burial mourning begins when the body has been laid in state. Relatives, friends, colleagues and the general public may then come to mourn the dead and sympathize with the bereaved family. They sing dirges, which praise the deceased and philosophise on life and death generally. Those who attend the funeral, including the relatives, must wear mourning clothes, which may be dark red, brown, maroon or ochre in colour. In the case of a person who dies at a very old age, the relatives may wear white. For a young promising person who dies prematurely as a result of a terrible accident, red mourning clothes are the norm. Only very close relations of a dead person see the ceremony of placing the corpse in the coffin. When the deceased is safely in the coffin, then relatives begin to ‘give’ gifts to the deceased by placing them in the coffin for the journey to the abode of the living dead. These are usually in the form of cloth, money or toilet articles or a very handy item that the deceased liked extremely well in life. For a married person, the last person to put gifts into the coffin is the widow or widower. The deceased person’s children and brother’s children usually provide the coffin. For Christians, however, all forms of pagan practices should be abhorred during death and burials. Accordingly, such items as Bibles, Hymn Books, Membership Certificates, Baptismal Certificates, as well as dresses and property, including jewels and money should not be placed in the coffin.

The moment of burial is one of the most dramatic and critical in the community. There is wailing and shouting and singing as mourners, sympathizers and other participants move towards the cemetery. The burial of Christians is expected to be done in orderly fashion with singing of hymns. However, some relatives of the dead person are not allowed to accompany the corpse to the graveyard. For example, widows and widowers accompany the group of mourners up to a certain point, and then must quickly return home, without turning to look behind. It is believed by Ghanaians that a person whose body is not buried with the correct rites will not be admitted to the abode of the departed ones, and therefore will become a wanderer, living an aimless, haunting existence.

The post –burial mourning includes a public ceremony held about a week after the death, during which people come to express their condolences to the bereaved family. Gifts in cash and kind are then made to the family to help them defray the expenses of the funeral.

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 8th, 15th, 40th and 80th 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, whose responsibility it is, as focal persons, take the lead in arranging and preparing for the days of funeral.

It follows, therefore, from the above discussion that West Africans variously answer the question as to where the dead go. Within the Ghanaian cosmology, in particular, there is the general belief that the dead go on a journey in which they have to cross rivers before arriving at their destination in the abode of their ancestors. Thus death, for the Ghanaian, is the beginning of a permanent ontological departure of the individual from the state of humankind to the state of spirithood. The souls of the dead, the undying part of human beings, however, are believed to return to the Creator who made them. Nevertheless, the final destiny of the individual depends upon the way she has lived her earthly life.

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FA

(b) SOME JAMAICAN RITES OF PASSAGE: REFLECTIONS FOR THE TWENTY-FIRST CENTURY

Some African-Jamaican Rites of Passage

The focus [here] will be on the rites of passage of the African-Jamaican population. It should be noted that the customs outlined are not practised by everyone in all cases. Actual practice may differ from community to community because of social class, rural versus urban contexts, migration, religion (notably in cases where some practices are rejected by some Christians), ethnicity, culture and the process of adaptation of African traditions in the diaspora. Some traditions and practices are also not as common now as they were in the past…

Perhaps the most elaborate rituals are performed in relation to death. When someone dies, the spouse usually wears black or red underwear. This is to repel any advances of the deceased. In some cases these colours are worn by the widow or widower for forty days and forty nights. In other cases, a person of the opposite sex to the surviving spouse sleeps in the matrimonial bed with the widow/widower keeping away the spirit of the deceased. This is known as ‘keeping the bed front’. A young lad asked to ‘keep the bed front’ for an older widow would often be teased mercilessly by his male peers. If it was felt that the spirit of the deceased was still around, the 23rd or 27th Psalm would be repeated and the Bible would sometimes be left open in the room at the respective passage.

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 deceased are put outside and this is said to 'turn him out'. In former days the dead person would have 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.

A wake or a ni'night (ninth night) is held on the night before the funeral. This involves 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 the organization would arrange to go to 'keep company' on one of the nights between the death and the funeral. The members prepare food and drink and take it with them, thus catering for all visitors to the bereaved for that night. Some ni'nights are preceded by a prayer meeting. A number of songs are usually sung at the ni'night, expressing different sentiments including faith in God, and time to bring out the chocolate tea or the white rum. One hymn that is often used is 'While Shepherds Watched their Flocks by Night'. This raises interesting questions. Why sing about the birth of Christ at someone's death? Could it be a belief that death is also a birth for the departed one into a new life - an occasion at which angels and ancestors are present, reminding the bereaved to 'fear not' when mighty dread seizes troubled minds, and hear the angels' songs of joy?

Often salt and sugar (in separate bowls) are placed on a table. The singers dip into the bowls from time to time, placing the salt or sugar on their tongues to 'clear the throat'. In some cases a plate of food is served and put on the side or under the table for the spirits, and libations of rum are poured. When the grave is being dug and the body prepared, white rum is also used. It is often poured as a libation, used to wash the face of the grave-diggers and persons preparing the body, or as a drink before the work begins.

On the day of the funeral the bier is sometimes driven past the house of the deceased and any favourite haunts, for example, a bar in which he used to drink often with friends. The bier is then taken to the church where it lies in state for perhaps an hour before the scheduled start of the funeral service. Babies and small children are usually passed over the bier of a deceased parent or close relative so that the spirit will not molest the child.

During the funeral service, close relatives and friends often sing, pay tributes, read scripture lessons, give a remembrance and generally participate in the service. The worship service would follow the tradition of the host denomination and almost always includes a sermon. In the past, men would take off their hats and bow their heads as a mark of respect for the dead as a funeral procession approached. This is not always done today, although older men still observe this custom. When a spouse or partner dies, the surviving partner tears a new white handkerchief in two, keeps one half and buries the other half with the deceased (usually placed in the hand of the deceased).

At the actual burial site, many hymns are sung and the words of committal are said by the minister. The singing will continue until the grave is completely covered. The final song that signals the time for all mourners to leave often is:

> Sleep on beloved, sleep and take thy rest;
> Lay down thy head upon thy Saviour's breast;
> We love thee well, but Jesus loves you best –
> Good night! Good night! Good night!

Some variations of the above take place depending upon the groups and communities to which the deceased belonged. Masonic Lodges often have rites conducted at the Lodge's meeting hall before the church service and last rites at the graveside after the committal by the minister. Many members of the clergy insist that the Christian committal must be done before the last rites of the Lodge.

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 examples are Dinkimini in Saint Mary and Clarendon (two to eight days after the person's death) and 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 policy should be changed. A member of Unity of Jamaica, who described the group as a 'New Thought' Movement, explained that bodies were not brought into the sanctuary as a way of emphasizing that life is eternal.

> Life is eternal, and when a body is brought into the service, people focus on the body. The body is a garment that you put on while on this earth, and when you die, you shed this garment and make a transition to a new plane. We therefore do not speak of having a funeral, but of celebrating the life of one who has made a transition to a new plane.

Extracted from a paper by the Revd Marjorie Lewis-Cooper first published in Black Theology in Britain, 6, 2001, pp.53-71 and reproduced by kind permission of Sheffield Academic Press.

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 assets include investments and/or property, they will have the power to decide when and how to sell these assets or, in some cases, how and on what terms any investment or property is transformed to one or more beneficiaries as part of (or the whole of) this inheritance. Just selling everything may not be appropriate, and the judgment on what to do needs to be carefully exercised. The choice of executor is therefore critical.

- **the appointment of trustees** of any trust which you may set up in the Will (e.g. for children or grandchildren until they attain a specified age). The trustees may be the same as the executors, but can be different.

- **any specific wishes for burial or cremation**, to guide the executors who have the legal responsibility for deciding on funeral arrangements. It is a common misconception that the next-of-kin have this power. While the details of the funeral wishes may conveniently be included in a separate document - as described below - it is quite useful also to include a simple preference for burial or cremation in the Will. This is one of the first questions that will need to be answered after someone has died, and it is logical to look to the Will for confirmation of the executors and these wishes.

- **the appointment of guardians** for any children who may be under 18 at the time of your death (if appropriate, if the other parent has also then died).

- **gifts of your personal property**, which can often be dealt with by asking the executors to follow a separate list of wishes. This can be kept up to date over the years as the family grow up and different items are acquired, whether their value be in money or purely sentimental terms. The list of wishes may wish to guide the executors on the process by which they divide these chattels. This is an important provision, as the division of the personal things is something which can cause great unhappiness and division within families.

- **any money legacies**, whether the money is to be given outright or to be in some form of trust, for individuals, charities or other organizations. The way in which a gift to a charity is left can lead to a saving of Inheritance Tax or Income Tax.

- **the division of the remainder of your estate**, including alternative provisions if your initial beneficiaries do not survive you, e.g. to your spouse (1), your children (2), or, if any of your children predecease you, their share going to their children (3). Careful thought should be given to the age at which any children inherit the capital, whether 18, 21, 25 or another age, and to any powers that the trustees may need to use the income and capital for them if there is a trust running before they attain that age.

- where a husband and wife have minor children, it is quite sensible to think about the situation **if there were a common accident** and none of your children survived you, when the combined estate might then be divided, for example, as to half each for the husband's and the wife's beneficiaries. Each would then be able to choose which of their family, friends, charities, etc. that they might wish to benefit if that situation arose.

- **any additional powers** that the executors and trustees may need to administer the estate and

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 to protect the money for them. If the beneficiary is likely to be in some form of residential accommodation paid for by the state, this can avoid the money simply going to the state!

If a beneficiary cannot handle money, or is in financial difficulties (and may become bankrupt) there may need to be special provision in the Will so that they have help to ensure that the inheritance is not wasted. This would include a beneficiary with marriage difficulties, to avoid the risk that their inheritance simply goes 'down the drain' in financing a divorce settlement. (This is an increasingly major concern, and many people find enormous relief when they know there is a solution to the fear that their hard earned capital will simply be wasted away.)

Providing security for elderly relatives who are living in your property.

Providing for different beneficiaries where there is a second marriage - e.g. if you want your second spouse to have the income or the use of a property during their lifetime, but ensuring the capital goes to the children of your first marriage (or both marriages) on his or her death.

Saving Inheritance Tax - where a husband and wife have combined assets over the Inheritance Tax threshold (currently £250,000), they may want to attempt to mitigate Inheritance Tax through their Wills. With the huge rise in house prices since the mid-1990s, particularly in the south, an increasing number of people who do not consider themselves to be wealthy are being caught by the Inheritance Tax net. The way in which a Will is drafted can ensure that the family money is better protected for the long-term benefit of the family.

In all of the above special cases, there is particular value in taking proper advice, e.g. from a solicitor. It is worth enquiring about the cost of making a Will, which may not be as high as some fear, as it is one of the most important documents made in your lifetime.

Instructions for next of kin and executors
Less often advocated than the making of a Will is the preparation of a document that may be titled: 'Instructions for my next of kin and executors upon my death'. This document should give your name and address and include such points as:

- where the Will is;
- who needs to be told of the death;
- which undertaker you would wish to be used;
- who is to conduct the funeral service (if one is desired);
- what hymns/readings are requested for that service;
- whether you wish to be buried or cremated;
- where legal documents (house deeds etc.,) and insurance policies are stored;
- who your solicitor is;
- where your bank account(s) is (are) held.

Other things may be included as wished.

This document is not a replacement or substitute for a Will, and holds no legal status - but think of the help it would be for the family member or friend who has to deal with your affairs after your death and who would want to honour your views.

It is not morbid to give thought to a Will or 'Instructions' document: making them enables us to live with one or two fewer touches of anxiety. It is important that we make it as easy as possible for others to cope with our deaths when we hope they will be mourning our passing and missing us…!

JB / MC

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 maintained by machinery.

- The family need to know that brain stem death is irreversible.

- To help the family understand what is happening, they are often invited to be present when the test for brain stem death is being carried out. This is still somewhat controversial, but does seem to help - not in accepting the death, that comes much later - but in understanding that it has happened, especially where the patient is a child or teenager. Families who have showed no sign of emotion previously may begin to show emotions and start to grieve when they witness the brain stem death test - particularly when they see that the patient does not breath spontaneously when temporarily disconnected from the ventilator. This is often the beginning of the dawning of the reality.
- It is important that the family is talked through all this, honestly, gently and at length, both before, during and after the test, and that they receive the care and support they need and deserve.

- The request for organ donation also needs to be done with great sensitivity. If the patient carried a Donor Card, then this should be more straightforward - unless the family do not agree. This can cause upset and distress; the family may feel guilty that they cannot go along with the patient's wishes; there may be disagreement among different members of the family. (This emphasises the need to talk to your family BEFOREHAND if you wish to carry a donor card.)

If the patient did not carry a donor card and had not made her wishes clear, then there may be unease within the family regarding whether they are doing what the patient would want. The family needs time to think all this through and should not be rushed.

- If the patient is a child or teenager, the family may want to be present when the ventilator is disconnected, and when the process of dying is completed. They need to know that if organ donation is going ahead, this will not be possible as disconnection has to be done in the operating theatre. The family may feel guilty that they are not able to be present when the patient ‘dies’. This needs careful handling, with a gentle explanation that in fact death has already occurred, though this may be very difficult for the family to understand.

- The family should be offered the help and support of their minister or the hospital chaplain. Prayers and a blessing can be said which may help the family to ‘let go’. It may also be appropriate to include

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 organs can and cannot be donated. Some families do not want the heart to be removed as they believe this is where the soul is; some do not want the eyes to be removed - they are anxious that the patient might not be able to see in the next world. However bizarre this may seem, their wishes should be respected.

- The transfer to the operating theatre is another time of great emotion: it is often seen as the ‘point of no return’, the family being acutely aware that this is the last time they will see the patient ‘intact’, with the external features of life still apparently present.

- The family must be offered the opportunity of seeing the patient again after removal of the organs. This needs careful preparation - what the patient might look like, any visible signs of surgery, etc.

- The family may want some contact with the recipient. This must be done through the hospital, where procedures will be in place for this. At first, the only information they will receive is the recipient's gender and age - and vice versa. Only if all parties consent will further contact be permitted.

If the organ transplant fails and the recipient dies, the family will need a lot of support - it may be like another bereavement to them.

- There are several issues about funding around organ donation. Medical staff need to be trained and available (usually on an on-call system). Also, Intensive Care beds need to be available for potential donors. There is a conflict here - when facilities are limited, how do you decide whether to give an Intensive Care bed to someone who might survive or to someone who is probably brain-stem dead and a potential organ donor? (The words ‘probably’ and ‘potential’ being the operative ones.)

- The recipient also needs and deserves support. They may feel guilty, even quite upset, at feeling happy about having a transplant which has meant that someone has died. It's a bitter-sweet time. They may appreciate prayers, not only for themselves, but also for the donor family.

And bear in mind that they may never feel the same about the words in communion ‘This is my body … for you’ …

SaB

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 funeral is 'just another funeral' - or shouldn't be. That having been said, there are some situations, for 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, but so, too, might be dealing with a local council over the problem of finding space for the burial of a 'pre-viable' baby (one of less than 24 weeks' gestation). Being involved in the funeral of someone 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 training in 'bereavement support', the better to equip them to support their fellow-members involved in the 'front line' of this activity. Yet some ways in which help can be offered are very straightforward. For example, a church should recognise that 'doing the job properly' when it comes to funeral preparation and counselling bereaved people is very time-consuming, and should therefore be accommodating when a minister has to say 'no' to other appointments, including ones already in the diary. They may also consider initiating or developing the role of 'lay celebrant', with 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 surrounding 'end of life' issues need constantly to ensure both that they are properly looking after their 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. Therefore, the death of any member of that community will leave its mark on us: 'Any man's death diminishes me, because I am involved in Mankind', wrote the poet John Dunne (*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. However, public interest in lesser royals such as Diana Spencer, the 'fairytale princess', in pop stars like 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 various contributing factors, including:

- the discovery that the idol has feet of clay and is not immortal;
- being forced to confront the fact of the finality of death;
- a realization that death is no respecter of age, rank, fame or fortune;
- a need to 'do' something;
- not wanting to be thought 'hard' or 'callous' for not mourning; and
- mass hysteria.

The common denominator in all of these is the lack of recognition of the spiritual element in both life and death, or perhaps an acknowledgement of it but a state of loss as to how to go about appreciating and fulfilling it. The person who feels deeply about another's death, be it a famous person or someone unknown killed in a road accident, has a yearning to do something meaningful. Those of us who have a confessed faith can offer our cares and concerns to God in prayer, but those who know nothing of God, or who deny His presence, have to seek other avenues through which to allay their grief. These days, this usually takes the form of laying flowers at the scene of an accident or outside the gates of the deceased's home, or signing a book of condolence. The very fact of making this gesture gives what the Americans would call 'closure': something that affirms the reality of death and makes a tidy ending, allowing us to move on. Christians know that death is not the end of life but, for us all, it is the end of earthly life, the end of an era.

SuB

13. RESOURCES
- there is a vast amount of material available: this is a small selection.

Books

Abrams, Rebecca; Black, Dora, When Parents Die, Routledge, 1999.
Cassidy, Sheila, Light from the Dark Valley, DLT, 1997; (reflections on the nature and mystery of pain).
Dickenson, Donna; Johnson, Malcolm; and Katz, Jeanne Samson, eds, Death, Dying and Bereavement, The Open University/Sage Publications, 2000.
Duke, Michael Hare, One Foot in Heaven: Growing Older and Living to the Full, SPCK, 2001.
Elmhurst, Paul, ed., Wills and Probate, Which? Books, 2001.
Froggatt, Alison; Shamy, Eileen, Dementia, Christian Council on Ageing, 1998.
Hayton, Althea, Never Out of Mind, Arthur James, 1998; (liturgies and resources to facilitate a service of prayer when a baby dies).
Howse, Kenneth, Religion, Spirituality and Older People, Centre for Policy on Ageing, 1999.
Ironside, Virginia, You'll Get Over It, Penguin, 1997.
Jewell, Albert, Older People and the Church, Methodist Publishing House, 2001.
Jewell, Albert, ed., Age awareness: understanding the spiritual needs of older people, boxed set of ten booklets, Derby: Methodist Homes for the Aged/Christian Council on Ageing, 1998.
Jupp, Peter; Rogers, Tony, ed., Interpreting Death - Christian Theology and Pastoral Practice, Cassell, 1997.
Kirkpatrick, Bill, Going Forth - A Practical and Spiritual Approach to Death and Dying, DLT, 1997.
MacKinlay, Elizabeth, The Spiritual Dimension of Ageing, Jessica Kingsley, 2001.
McCracken, Anne; Semel, Mary, eds., A Broken Heart Still Beats: After Your Child Dies, Hazelden Information and Educational Services, 2000.
McWilliams, Peter, et al, How to Survive the Loss of a Love, Prelude Press, 1993.
Noble, Alex, Sunshine Through Shadows, St Andrew Press, 1999; (words of comfort and hope in the form of parables).
On Dying Well - A Contribution to the Euthanasia Debate, Church of England Board for Social Responsibility, Church House Publishing, second edition 2000.
Parkes, Colin Murray, Bereavement: Studies of Grief in Adult Life, Penguin, 1998.
Spufford, Margaret, Celebration - a story of suffering and joy, Mowbray, 1996.
Whitaker, Agnes, ed., All in the End is Harvest, DLT, 1998; (anthology for those who grieve).

Booklets and packs

Celebrating the Gift of Years - Worship material for the International Year of Older Persons 1999, compiled by Basil Bridge; United Reformed Church.
Euthanasia: a Christian Perspective; Church of Scotland Board of Social Responsibility, 1995.
Nuttall, Derek, The Early Days of Grieving; Beaconsfield Publishers, 1991.
RoadPeace, Prayers and Thoughts for the European Day of Remembrance for Road Crash Victims.
The Samaritans, Coping with Stress - Emergency Rural Stress Campaign 2001; (available to download from web: www.samaritans.org).
Shadows: a Study Pack on Euthanasia; Baptist Union and the Methodist Church, 1995.

Journals

International Journal of Social Welfare
Mortality
Priests and People Volume 7 no 11 The Tablet publishing company

Reports

Appleton, Nigel J W, Respecting the gift of years, London: The United Reformed Church, 1998.
Christian Council on Ageing, Spiritual Perspectives on Ageing
Painbearers (Baptists/Methodist)

Books to use with children

Ahlberg, Allan, My Brother's Ghost, Viking, 2000.
Dominica, Sister Frances, Just My Reflection: Helping parents to do things their way when their child dies, Darton, Longman and Todd, 1997.
Duffy, Wendy, Children and Bereavement, National Society/Church House Publishing, 1995.

Mathias, Beverley; Spiers, Desmond, A Handbook on Death and Bereavement: Helping Children Understand, National Library for the Handicapped Child, 1992.
Turner, Mary, Talking with Children and Young People about Death and Dying, Jessica Kingsley, 1998.
Varley, Susan, Badger's Parting Gifts, HarperCollins (Picture Lions), 1992.

Addresses

British Organ Donor Society
Balsham, Cambridge CB1 6DL
Tel: 01223 893636
www.argonet.co.uk/body

Centre for Policy on Ageing
25-31 Ironmonger Row, London, EC1V 3QP
Tel: 020 7253 1787, Fax: 020 7490 4206
e-mail: cpa@cpa.org.uk
www.cpa.org.uk

Christian Council on Ageing Dementia Group
c/o Alison Johnson
33 The Plain, Brailsford, Ashbourne DE6 3BZ
Tel: 01335 361440
e-mail: alison.johnson@clara.co.uk

Colney Wood (Woodland Burial Parks)
Watton Road, Colney, Norwich NR4 7TY
Tel: 01603 811556, Fax: 01603 811770
e-mail: enquiries@woodlandburialparks.co.uk
www.woodlandburialparks.co.uk

The Levenson Centre for the Study of Ageing, Spirituality and Social Policy
Temple Balsall, Knowle, Solihull, West Midlands, B93 0AN
Tel: 01564 730249, Fax: 01564 778432
e-mail: james.w.woodward@btinternet.com

National AIDS Helpline
Tel: 0800 567123

The National Funerals College
3 Priory Road, Clifton, Bristol BS8 1TX
Tel: 0117 928 9023

RoadPeace
PO Box 2579, London NW10 3PW
Tel/Fax: 020 8838 5102, Helpline: 020 8964 1021
e-mail: info@roadpeace.org
www.roadpeace.org

Stillbirth and Neonatal Death Society (SANDS)
28 Portland Place, London W1B 1LY
Tel: 020 7436 7940, Helpline: 020 7436 5881
www.uk-sands.org

Terrence Higgins Trust
52-54 Grays Inn Road, London WC1X 8JU
Tel: 020 7242 1010, Helpline: 0845 1221 200
www.tht.org.uk

Winston's Wish: Grief Support Programme for Children
The Clara Burgess Centre, Gloucestershire Royal Hospital, Great Western Road, Gloucester GL1 3NN
Tel: 01452 394377, Fax: 01452 395656
e-mail: info@winstonswish.org.uk
www.winstonswish.org.uk