

KEEPING FAITH SERIES

A practical Guide to the spiritual care of the dying person

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This is a draft for consultation. If you have any comments please send them to asta.radziunaite@cbcew.org.uk at the General Secretariat of the Catholic Bishops' Conference of England & Wales no later than Friday 26 February 2010

A practical Guide to the spiritual care of the dying person

Contents

INTRODUCTION	4
SECTION 1 - PROVIDING SPIRITUAL CARE	5
1.1. THE LIVERPOOL CARE PATHWAY.....	5
1.2. SPIRITUAL CARE	5
1.3. KEEPING CARE PERSONAL	6
1.4. INDICATORS OF SPIRITUAL PAIN.....	6
1.5. HOW TO HELP	7
1.5.1. <i>Personal Approach</i>	7
1.5.2. <i>Building Trust</i>	7
1.5.3. <i>Communication</i>	7
1.5.4. <i>Anxiety</i>	7
1.5.5. <i>Privacy</i>	8
1.5.6. <i>Dignity</i>	8
1.5.7. <i>Sedation</i>	8
1.5.8. <i>Least Restrictive Option</i>	9
1.5.9. <i>Nutrition and Hydration</i>	9
1.5.10. <i>Asking about Faith</i>	9
1.5.11. <i>Prayer</i>	9
1.5.12. <i>Care for Family and Friends</i>	10
SECTION 2 - ETHICAL ISSUES AT THE END OF LIFE	11
2.1. RESPECTING LIFE AND ACCEPTING DEATH.....	11
2.2. WHAT ETHICAL ISSUES ARISE WHEN APPLYING THE LIVERPOOL CARE PATHWAY?.....	11
2.3. IS IT EVER RIGHT TO WITHDRAW OR WITHHOLD TREATMENT WHICH COULD PROLONG LIFE?.....	11
2.4. IS THERE A DIFFERENCE BETWEEN DECIDING NOT TO HAVE A TREATMENT AND STOPPING A TREATMENT WHICH HAS BEEN STARTED?.....	12
2.5. SHOULD ORAL NUTRITION AND HYDRATION ALWAYS BE OFFERED?.....	12
2.6. IS CLINICALLY ASSISTED NUTRITION AND HYDRATION (CANH) MEDICAL TREATMENT?	12
2.7. IS IT EVER RIGHT TO WITHDRAW CANH?.....	13
2.8. HOW SHOULD DISPUTES ABOUT CANH BE RESOLVED?.....	13
2.9. IS IT EVER RIGHT TO OFFER TREATMENT THAT COULD SHORTEN LIFE?	14
2.10. DOES THE CONCEPT OF 'DOUBLE EFFECT' APPLY TO THE USE OF ANALGESIA (PAIN MEDICINES) AT THE END OF LIFE?.....	15
2.11. IS IT EVER RIGHT TO SEDATE PEOPLE AT THE END OF LIFE?.....	15
SECTION 3 - RESPECTING THE MYSTERY	16
3.1. THE 'SHOCK' OF DEATH.....	16
3.2. THE WHOLE PERSON IN THE PROCESS OF DYING.....	17
3.3. DEATH AND OUR DEEPEST QUESTIONS	17
3.4. MOURNING MY DEATH	18
3.5. THE GIFT OF BEING PRESENT	19
3.6. ON THE MOURNING OF RELATIVES AND FRIENDS	20

A practical Guide to the spiritual care of the dying person

3.7. THE RESOURCES OF RELIGIOUS FAITH	20
3.8. CONCLUSION	21
SECTION 4: FAITH-SPECIFIC NEEDS: CARING FOR THE CATHOLIC PATIENT	22
4.1. SOURCES OF FURTHER INFORMATION REGARDING SPECIFIC FAITHS AND SPIRITUAL CARE OF THE DYING	22
4.2. THE SPECIFIC SPIRITUAL NEEDS OF CATHOLIC PATIENTS	23
4.3. PRAYER	23
4.4. THE SACRAMENTS	24
4.5. WHAT TO DO IF A CATHOLIC PATIENT REQUESTS A CATHOLIC CHAPLAIN	24
4.6. BAPTISM	24
4.7. HOLY COMMUNION	25
4.8. CONFESSION	25
4.9. ANOINTING OF THE SICK	26
4.10. WHAT TO DO IF A CATHOLIC PATIENT DIES	26
4.11. OFFICIAL ROMAN CATHOLIC TEACHING ON ETHICAL ISSUES AT THE END OF LIFE	27
4.12. WHAT DOES THE CATECHISM SAY ABOUT WITHDRAWAL OF TREATMENT?	27
4.13. WHAT DID POPE JOHN PAUL II SAY ABOUT USING ASSISTED MEANS TO PROVIDE FOOD AND FLUIDS?	27
4.14. WHAT DOES THE CATHOLIC CHURCH TEACH ABOUT THE USE OF ANALGESIA AT THE END OF LIFE?	28
4.15. CONCLUDING REFLECTIONS: DEATH FROM A CHRISTIAN PERSPECTIVE	28

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A practical Guide to the spiritual care of the dying person

Introduction

The purpose of this guide is to assist front-line staff to provide good spiritual care at the end of life.

The Liverpool Care Pathway (LCP) is a framework which prompts staff to address the different aspects of patient care which are important in the last days of life. It makes explicit reference to the requirement that spiritual needs are addressed and has highlighted this sensitive but important area of care.

Many staff working with patients approaching the end of their life might feel ill-equipped to respond to such spiritual needs, indeed, they might not always recognise them. While it is good practice to call the chaplain in such situations, this guide will provide some understanding of spiritual need at the end of life, the nature of good spiritual care and how clinical staff can help to provide it. This guide focuses primarily on the care of patients who are expected to die in the near future, however much of the content is relevant to other situations such as sudden death.

The first section of the Guide offers practical pointers to the provision of good spiritual care of anyone, making no assumptions about whether or not either the dying person or the healthcare professional has, or does not have, any particular religious faith.

A second section looks at some of the common ethical questions that may arise at this time, for example withdrawing or withholding medical treatment. Specific issues regarding the ethical use of the LCP are explored briefly as well. A third, more reflective section is designed to assist staff in thinking more deeply about the experience of dying for the person and what it might mean. The process of dying is intensely personal and in some way mysterious. Attending to the spiritual dimension in this way can help to allay our own fears and stimulate more sensitive and attentive care.

Section 4 gives sources of further information regarding the needs of specific faiths and sets out some further detail regarding the care of Catholic patients.

The Guide has been jointly written by healthcare professionals, hospital chaplains and academics who are involved with the Healthcare reference group of the Catholic Bishops Conference of England and Wales.

Section 1 - Providing Spiritual Care

1.1. The Liverpool Care Pathway

The Liverpool Care Pathway defines a clear framework for providing care to patients approaching the end of life. It incorporates the principles of Hospice care, translating them into other care settings, and promotes the development of skills such as those outlined in the Marie Curie Religious and Spiritual Care Competencies for Specialist Palliative Care which have been used successfully in hospices. However any tool is only as good as those who use it and it is important to keep the patient's best interests at the centre of care at all times.

The Liverpool Care Pathway should be understood as a guide rather than a list of instructions and is not intended to replace clinical judgement and professional skill. The purpose of the Pathway is to guide multi-disciplinary teams towards the priorities of care and comfort for a patient when it is clear that they have reached their last days or hours of life. It aims to bring together professional support to address physical, psychological and spiritual needs. It is also important to ensure that patients and their families/visitors are aware that the nature of the care has changed and that the main purpose is now to ensure a comfortable, peaceful and dignified death, as far as possible.

An important aspect of care for many patients approaching the end of their life is that of their faith, their spirituality. Spiritual care is therefore included as one of the domains of care within the LCP framework. For those who have practised a particular faith throughout their life it is important to maintain that link with their worshipping community and draw from their faith the hope and comfort it offers. For those who might not have regularly practised a faith during their life, or possibly might even be indifferent to such matters, it is not uncommon to find that they, or their families, reach out for meaning and spiritual care at such times. Supporting them in their spiritual searching can transform their experience and contribute to what might be described as a "good" death.

1.2. Spiritual Care

Spiritual can have a spectrum of meaning ranging from the explicitly religious to a less defined sense of 'otherness' or 'connectedness' or for some, a personal search for meaning. This is not to suggest that those requiring more formal religious care do not need or want to address the wider questions of meaning. Conversely, at such times many people who might not describe themselves as 'religious' might wish to return to a faith they were brought up with, finding in that hope and comfort. Alternatively they might express none of these and simply want the presence of someone who will be with them in the loneliness of their suffering. To care for the spirit is to attend to all of the above.

A practical Guide to the spiritual care of the dying person

So from the devoutly religious to those searching for meaning or those with no expressed interest in religion or spirituality there is much a healthcare worker can do to help support a dying patient and make these moments as valuable as possible.

1.3. Keeping Care Personal

Any admission to hospital can have a depersonalising effect on a patient, leaving them feeling somewhat anonymous as events and suffering overtake them. In day-to-day practice it is usually nursing staff who are presented with the signs of spiritual distress, so the ability to identify this need is essential in order to support the patient as meaningfully as possible. Such distress might be seen in several ways:

1.4. Indicators of Spiritual Pain

- Patients asking “Why is this happening to me?”
- A fear of falling asleep and not awaking
- Anger at God
- Crying out to God
- Doubting one’s faith
- Feeling lost
- A sense of abandonment
- Asking for spiritual help
- Questioning the purpose of suffering
- Physical pain can be a sign of spiritual distress
- Asking to see the chaplain

At first glance it might seem that providing for a person’s spiritual needs can be a complex matter. However, in reality it is very often in the small things that nursing staff are able to provide spiritual care.

A practical Guide to the spiritual care of the dying person

1.5. How to Help

1.5.1. Personal Approach

Use the patient's name as they like to be addressed. This keeps care personal when a patient might be feeling increasingly anonymous. The patient might have impaired hearing or not understand what is happening to them. This will mean having to take more time to make oneself understood and to understand.

1.5.2. Building Trust

Building trust with a patient can help them express deeper needs. For example, asking a patient if something is worrying them and waiting for a reply. Some people find it easier to confide in a stranger and to feel heard at such times can be very affirming. This has particular importance if caring for a patient with dementia who might need continuous reassurance.

1.5.3. Communication

Talking to the patient should also be continued after they pass into unconsciousness. It is often said that hearing is a sense which may continue even once the patient is unconscious. It is also a good reminder to everyone involved in a dying patient's care that their human value does not diminish with their ability to communicate.

Maintaining open communication with family and visitors is very helpful in assisting staff to gain a fuller picture of the patient and better understand their needs. Family and friends are more likely to be able to interpret what the patient requires and to understand their mood and feelings. It is also worth noting that family and friends might not always be aware of how the LCP is used or what end-of-life care entails. Open communication and explanation can help to reassure them and include them in the planning and providing care.

1.5.4. Anxiety

Visitors who feel events are overtaking them also might display heightened anxiety which, in turn, can exacerbate the mental/spiritual state of the patient. Ensuring visitors are kept apprised of any appropriate information can help mitigate this.

A practical Guide to the spiritual care of the dying person

1.5.5. Privacy

Private space with friends and family becomes increasingly important during this time. Availability of a side room should be a priority so that families can have time alone with their loved one. Being able to grieve, to cry, to sit silently together are made more difficult in a public space, not to mention the distress this can cause other patients and visitors.

1.5.6. Dignity

Maintaining dignity for the dying patient takes on an added significance. Enquiring about a patient's spiritual well-being, how they feel in themselves, ensures more than physical symptoms are being considered. Keeping patients clean and the space around them tidy can add to their own sense of dignity. Taking time to wash and comb a patient's hair, for example, not only helps the patient feel better but also adds a personal dimension. In fact physical touch can be a profound way to support a dying patient. Holding someone's hand may give more reassurance than the wisest of words. Death is not so much a private affair as a social one. We share a common humanity if not always a common faith and warm human contact can help the patient who feels afraid as their life draws to a close.

Patients sometimes ask for particular things in the last days of their life. It is important to be sensitive to such requests. Something that might seem unimportant to an onlooker can be of great importance to the patient. It might be a personal item with deep sentimental value, or a religious item such as a crucifix, a rosary or a prayer book. Holding and touching such items can often be the only prayer a patient has the energy to make. Seeing such items at a patient's bedside is also a further indication of their spiritual and religious needs and should prompt carers to ask questions about them and encourage patients to talk about their beliefs.

1.5.7. Sedation

There are times when medicines required for relief of symptoms may also cause drowsiness or sedation. This is compounded towards the end of life by increasing weakness and fatigue as the patient's condition deteriorates. The patient or their family may find this difficult. No one wants to see a loved one suffer but at the same time sedation may compromise a patient's ability to communicate at what might be important moments.

There are occasions when family or other visitors find it easier if a patient is sedated so that they do not become distressed by seeing them restless or apparently in pain. However it is important to consider the patient's wishes about this. Some individuals prefer to be more alert, accepting that they may have some degree of pain or other symptoms if this means that they can communicate with their family before they

A practical Guide to the spiritual care of the dying person

die. It could also be the case that hearing prayer or scripture or conducting religious ritual may give them great strength and solace in their final days.

1.5.8. Least Restrictive Option

It is important to seek the views of the patient as far as possible. Assume that they have capacity to make personal decisions until proven otherwise. Patients might live longer than expected and trying to give timescales will inevitably be difficult. It is important to keep all realistic options open even when a patient is deteriorating as capacity can vary and a person may wish to exercise choice up until the time of death

1.5.9. Nutrition and Hydration

Family or other next of kin might have particular anxieties about the cessation or withdrawal of nutrition and hydration, considering it to be premature or that they have not been involved in discussions about this issue. It is important that those close to the patient have an opportunity to discuss their concerns with the aim of understanding the realistic choices open to the patient as they are dying.

1.5.10. Asking about Faith

Remembering to ask a patient if they have a religious faith is the most obvious way to see whether there are any specific religious or spiritual needs that need addressing by a chaplain. This information is usually gathered by members of the multi-disciplinary team following which, the chaplain can be contacted if appropriate. It further reassures a patient with a faith that their spiritual and physical needs are central to their care,

1.5.11. Prayer

Some healthcare staff pray with patients. This should not be done with any intention of converting or thrusting one's beliefs onto a patient. But if a patient is known to be a person of prayer, of faith, it could be of immense support to them if staff felt able, at the patient's request, to pray with them or read a passage of Scripture to them

Some people, for various reasons, have ceased to practise their faith, or during the course of a long illness might have "fallen out" with God. This may cause great distress which in turn, may aggravate a patient's mental and physical state. Alternatively it may cause spiritual distress for family and friends. In these circumstances it is often the non-threatening presence of a carer that can help the patient express anger, bitterness, guilt, or other emotions hitherto concealed. Such feelings ought not to be avoided, dismissed

A practical Guide to the spiritual care of the dying person

or glossed over but allowed to flow out. Sometimes the most helpful thing for a carer to do is to hold this anger and frustration as it pours out and in doing so, this shows the patient that in the midst of their suffering they are not completely alone.

1.5.12. Care for Family and Friends

Once the patient has died, the care for their family and friends does not end. It is not unusual for the bereaved to seek spiritual and religious support from the chaplaincy. The sooner a chaplain is involved in a patient's care the greater the chance of building trust with their family and friends. The chaplain can also arrange on-going support in the community or can be available in the hospital should they find this helpful.

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Section 2 - Ethical issues at the end of life

2.1. Respecting life and accepting death

There are two things that need to be kept in mind in end of life care: respecting life and accepting death. Respecting life means that every person must be valued for as long as they live. One implication of this is that **death should never be the aim** of our action or of our inaction. We should never try to bring about death.

On the other hand, accepting death means that we should prepare properly for death. One implication of this is that we should **not deny the reality of the situation** or flee from the inevitable by seeking every possible treatment. A religious person will see both life and death as coming from God.

2.2. What ethical issues arise when applying the Liverpool Care Pathway?

The Liverpool Care Pathway (LCP) provides an approach to care in the last few days of life. It does not sanction euthanasia or suicide and does not mandate any unethical actions. It aims to improve end of life care. It can be used in an ethical way. Nevertheless, the LCP is not a substitute for individual assessment, professional knowledge and skill or for virtue and moral reasoning.

The ethical application of the LCP requires clinical judgement, not least about whether the person is in fact in the last few days of life. **Accurate diagnosis and by implication, prognosis** plays a key part in the ethical judgments surrounding the LCP and the healthcare team should consider the risks of misdiagnosis. It also requires respect for the patient and for those close to them and good communication, including a willingness to listen to hopes and concerns.

Other ethical issues which arise when initiating the LCP relate to **withdrawal of treatment**, especially to withdrawal of clinically assisted nutrition and hydration (CANH), and to the use of medication with **sedative** effects, including analgesia. These are considered below.

2.3. Is it ever right to withdraw or withhold treatment which could prolong life?

It may be. It is never acceptable to withdraw treatment for the purpose of hastening death. However, how one spends one's time on earth is more important than the length of one's life. Though people have a duty to care for their health, they do not have a duty to prolong their life at all costs. So also, healthcare workers do not have a duty to keep people alive at all costs. As death approaches a treatment which may

A practical Guide to the spiritual care of the dying person

briefly prolong life could impose suffering such that the patient considers the treatment to be excessively burdensome.

If treatment could have some limited benefit in terms of prolonging life or symptom relief then it may still be wanted by the patient. Decisions relating even to marginal benefit may be very important to some patients. Hence **good communication** and sensitivity are essential if these decisions are to be made well.

2.4. Is there a difference between deciding not to have a treatment and stopping a treatment which has been started?

There is at least a psychological difference between deciding not to have a treatment and deciding to stop a treatment which has been started. It may feel more difficult emotionally to stop something than deciding not to start it in the first place. However, we cannot always know whether a treatment will work until we have tried it. We should not discourage people from starting treatment simply to avoid anxiety about discontinuing it. Instead, it may be more helpful to discuss beforehand in what circumstances a treatment or intervention would be stopped.

2.5. Should oral nutrition and hydration always be offered?

Food and water should never be withheld from a patient who needs them. Sometimes patients receive inadequate oral nutrition and hydration because of inadequate care and lack of attentiveness to their needs. This is clearly unacceptable. If there are risks because the patient has difficulty swallowing, these should be explained, but it is for the patient to weigh these risks. If the patient is unable to make their own decision due to impairment of the brain then the decision about whether to switch from oral to clinically assisted nutrition and hydration should be made in their best interests realistically weighing up the risks and benefits. This judgement will be influenced by the patient's stage of illness and how close they are to death.

Even though the need for nutrition and hydration will decline in the last few days of life, the human significance of eating and drinking should not be neglected, for it may be part of addressing spiritual need (for example, a drink of tea shared with a son or daughter).

2.6. Is clinically assisted nutrition and hydration (CANH) medical treatment?

It is a mistake to understand 'artificial' or 'clinically assisted' nutrition and hydration (CANH) as medical treatment, if this is interpreted as meaning that it has the same status other medical interventions.

A practical Guide to the spiritual care of the dying person

It is true that CANH bypasses the natural mechanisms of eating and drinking and that it requires clinical monitoring. Some people (whether patients, relatives or healthcare professionals) will see the significance of CANH as a (perhaps unwanted) clinical intervention, primarily in relation to the insertion and maintenance of drips or feeding tubes,.

Nevertheless, the administration of water and food, even when provided by tube is a natural means of preserving life. Feeding someone or quenching their thirst is a common and a fundamental expression of solidarity and care. Hence there are people (patients, relatives and healthcare professionals) who will understand nutrition and hydration, even when clinically assisted, as elements of basic care which should always be provided so long as they are effective.

For this reason, decisions concerning the provision or withdrawal of CANH should be treated with special sensitivity and take into account the patient's needs and his or her wishes and values. A decision to withdraw CANH should never be motivated by the desire to shorten their life.

2.7. Is it ever right to withdraw CANH?

While CANH should generally be provided where this is the best way to address nutritional needs, this may not be indicated **in the last few days of life**. At this stage the nutrition will have little or no effect of prolonging life. If there is doubt about whether clinically assisted hydration may provide some symptom relief or may marginally prolong life, then this is to be weighed against the burdens of the insertion and maintenance of drips or feeding tubes. The burdens will vary depending on the method of CANH and the situation of the patient.

The provision of clinically assisted hydration may also be difficult to combine with other important goals such as the wish to die at home. From experience, many palliative care physicians and many of those GPs who care for dying patients at home regard clinically assisted hydration as generally unhelpful in the last few days of life. However there should not be a blanket rule here but each case should be judged on the basis of the best interest of the particular patient.

2.8. How should disputes about CANH be resolved?

A competent patient has the legal right to refuse medical treatment and CANH is counted as medical treatment for this purpose. However, a dispute may occur when a patient or a relative wishes the healthcare team to provide CANH but the team are unwilling to provide it. In these circumstances it is unhelpful to frame the dispute in terms of the right or power of the doctor to withhold medical treatment

A practical Guide to the spiritual care of the dying person

that he does not think is indicated, and the classification of CANH as medical treatment. This approach does little to alleviate concern and may well inflame a situation. It is important to recognise the psychological and spiritual meaning of food and fluids to the patient or the relatives as they often represent life, comfort and hope. What is needed instead is sensitivity to the concerns of the patient or relative and openness about the reasons for the decision.

The first steps should be an honest assessment of benefits and burdens of different kinds of CANH and the **clear communication** of these. It may well be that the patient or relative overestimates the benefits of CANH for prolongation of life or for symptom relief. It may also be that the healthcare team underestimate the benefits or overestimated the burdens of hydration. If there is a possibility that CANH (and particularly hydration) would provide some marginal benefit and is unlikely to do harm, and if it is relatively easy in the context of care to provide (for example subcutaneous fluids) and is strongly desired by the patient or relative then there would seem no good reason not to give it, at least on a trial basis.

A particular concern might arise if the patient or relative is unwilling to believe he or she is dying, and fears that withdrawing CANH would make the prognosis a self-fulfilling prophecy. This may be a reflection of unwillingness to face reality, but it may also be a genuine concern about misdiagnosis. In response the team should assure themselves of the diagnosis and reassessed the situation. The patient or relative should also be informed of their **right to a second opinion**, and clinically assisted hydration should generally be given while this is sought. The team should not be overly defensive but should admit that misdiagnosis does sometimes happen and it is reasonable for people to wish to be sure about this.

2.9. Is it ever right to offer treatment that could shorten life?

It is never acceptable to offer treatment for the purpose of hastening death. However, many treatments have side effects and it is sometimes reasonable to accept the risk of life being shortened for the sake of some other goal, such as adequate symptom relief. For example, some drugs prescribed to help control the symptoms of common conditions may cause serious or life threatening side effects. Nevertheless, the drug may be justified if it can relieve symptoms effectively and hence improve quality of life. This acceptance of unwanted side effects is sometimes called the **principle of double effect**.

2.10. Does the concept of 'double effect' apply to the use of analgesia (pain medicines) at the end of life?

Analgesia at the end of life has often been cited as an example of 'double effect'. However, we now know that this is misleading. While many patients and even some healthcare workers are under the impression that effective analgesia hastens death, the evidence is that current best practice for **analgesia at the end of life does not generally shorten life**. In practice therefore, the anxiety that analgesia may hasten death leads to a false dilemma. Where this anxiety is present, healthcare workers should be clear that their interventions are unlikely to hasten death and they should communicate this effectively to patients and relatives.

2.11. Is it ever right to sedate people at the end of life?

In some circumstances it may be. Some people face the prospect of pain or other distressing symptoms such as breathlessness at the end of life. One of the key aims of palliative medicine is to alleviate these symptoms so that a person is as comfortable as possible during the last months and days of life. In some cases, the type of medication or dose required for effective symptom relief may lead to a patient becoming drowsy, but this still be justified for relief of suffering. A person should not have to wait for the pain to become unbearable before being offered pain relief.

Undertreatment of pain can cause considerable physical, emotional and spiritual suffering. However, overtreatment or inappropriate treatment can render people unconscious or semi-conscious when this is not necessary for effective symptom relief. This could deprive people of the **opportunity to make a good death**, setting things right as much as they can, making peace, saying their goodbyes. It will rarely be the case that pain cannot be controlled without deep sedation. Nevertheless, it may be that there is a compromise to be made between comfort and lucidity and different people will want to compromise at different levels. Some people will prefer less comfort for more lucidity. For this reason it is important that patients are recognised to have different needs and that, wherever possible, the patient is involved in the development and revision of their care and treatment plans.

Section 3 - Respecting the Mystery

The fact of death is quite different from the reality. The fact is a given; we may try to delay it or deny it, but we cannot avoid it. But when it happens, how it happens and the circumstances in which it happens create a deeply personal moment which belongs to each person alone, and is unrepeatable. Every living thing must die but despite this common reality, it is always *my* death.

We must not minimise the significance of death. If we do, we lose something of the depth of living. It marks us as inescapably finite while at the same time raising for us the question of our existence being more than we can see or know in a purely material world. Although it marks the end of life, death is always implicit throughout our lives.

3.1. The 'shock' of death

Death is not something with which we can grow familiar. Even when it is imminent and expected, it always has the quality of 'shock'.

There is a strange interruption of the flow of time and routine activity of living. That hiatus is the shock of finality, an absoluteness which neither our experience of life nor our imagination have really encountered before. It is the moment when we come to a boarder beyond which we cannot see; the point beyond which we cannot journey. In that moment our life – all life – seems simultaneously smaller and more fragile than we thought and more vast and puzzling that we can imagine.

So much of our thinking and dealing with death is governed by fear as well as compassion. It is not surprising, therefore, that we develop defences for dealing with this moment. Our culture, which so often presents us with the fiction of death in films and television, paradoxically, colludes with our defences. Physically and psychologically it pushes the reality death to the margins.

In the moment of death, in that small space between the on rush of emotion and memory, relief or anger, before we are overtaken by procedures or numbness, lies a moment of stillness. No matter how fleeting, we recognise in that silence something intangible. We have no words to speak about it. For a moment everything seems suspended and touched a quiet solemnity or even reverence. Sometimes this happens at the moment of death itself, sometimes later in remembering. Even in sudden or violent deaths the trace of this still space can still be found. It holds knowledge both familiar and now oddly new: death reveals the

A practical Guide to the spiritual care of the dying person

value of life – a life, a person, whatever their condition or status. It illuminates and brings its own stark truth without ever exhausting the meaning of a life or uncovering all its secrets.

3.2. The whole person in the process of dying

Dying is a complex process because it entails the whole of us, especially our relationships, not just our bodies. Even if we are semi-conscious or apparently unconscious there are still dimensions of our reality which can be active and present though not visible. The best science and the best religious faith come to these mysteries of life and death with a necessary humility. We know enough to know that we know so little and understand only a fragment of the immensity of any life.

Whether we have a religious belief or not, we can recognise that the human person is more than the sum of their physical parts. Indeed, if that is how we consciously or unconsciously treat them, then we distort, instrumentalise and thereby devalue a life.

We don't have an easy way of expressing our sense of the 'more' that a person is. Many religions posit a body and soul and in that way defend against reduction of the human person. Even if this language is difficult, or if we suspect its religious overtones, we can still have a place and a language for the spiritual. In this way we create an opportunity in our thinking and in our acting which allows us to recognise that the human reality is more than that which is just material; it cannot all be measured or known or satisfactorily explained in purely physical terms. A human life and the person who lives it are always more than a bundle of genes and actions. Even the most restricted of lives is lived in transcendence by virtue of being human. This is the core of a genuine humanism.

If we fail to see this and honour it, then we not only fail to respect a person; we do that person violence. There is a hidden violence in so many of our systems, even those of care, because their operational mode is reductionist. If we reduce death to a clinical event and manage it through a series of standard procedures then we do not deal with it well either clinically or humanly.

3.3. Death and our deepest questions

If we only see death as a medical failure then we fail to understand that the real gift of medicine is not just a science but a wisdom: how to live life of which dying is a part. That requires a sense of the wholeness of the person and the wholeness of a life. When it understands this genuine care will have time for the multi-faceted reality of dying. Giving time is the most precious resource of all. In the situation when we know how limited the time we have to have the courage and the generosity of spirit to be most liberal with it.

A practical Guide to the spiritual care of the dying person

In the process of dying everyone – the person dying and his or her carers – will in some way be touched by the most profound questions of life. What does it mean? Is death the way in which our lives end in nothingness or is death a movement into something which is unknown? We need both skill and courage to honour and respect these questions however they arise.

Often, we will not find an answer that is equal to their simplicity and depth, but care of the person who is dying as well as those who share this time with them, is often about the assurance of presence rather than the certainty of argument. Whoever we are -the one who is dying, family, friend, or professional carer - death requires humility of us all.

3.4. Mourning my death

A great deal of very positive work has been done on the process of mourning and how to help those who are bereaved to work through loss. Sometimes, however, we forget that the person who is dying is also mourning. The imminence of death throws up a complex variety of emotions, thoughts and needs. This is why pain management is critical. It can certainly give the person who is dying the time, energy and freedom to deal with the questions and relationships that need to be attended to. The process of dying not only makes death real, it changes my relationships, especially my relationship to myself and my life. I can feel suddenly alone and overwhelmed. I would like to be calm and generous and in control but in so many ways I know that I am not nor cannot be. It is not just my body that may be in pain and confusion but my soul or inner life. It maybe that I choose denial; I may want to assert myself and 'rage against the dying of the light'; I may slip into a passivity born of hopelessness and despair. The process of dying and the imminence of death does not necessarily remove the great primal urge to live.

At some point, if I have the time and the space, I have to learn to say my goodbyes. As well as the goodbyes to people and places there is the goodbyes to self, the self I have been, the self I wanted to be; I must mourn these 'selves' and these 'lives'. There are, too, the faces, experiences, moments that that come upon me unbidden and sometimes painfully, welcomed and unwelcomed. These are the relationships that have made up my life, the threads through which is woven the story of 'me'.

The process of dying can be a time when by choice or force of the moment I can no longer maintain the act or the pretence. Illusions - positive and negative - melt away and I am left with a truth, a reality that I can't control, an experience I can hardly understand. There are the regrets as well as the accomplishments – the small things that mean something only to me. Sometimes, on this threshold of death we can discover a freedom either denied or resisted at other times, to say things that need to be said or to restore the things that have been lost or broken.

A practical Guide to the spiritual care of the dying person

In this unfamiliar place of dying familiar things can comfort me. They have been part of 'my home'; they take on a symbolic quality because they carry memory and feeling. So, too, with the natural rhythm of the seasons. Winter, spring, summer and autumn – how many seasons have I lived? They are the steady, natural *cantus firmus* of my life's improvisations.¹

This precious time of mourning can also be a time of new creativity; a time of reparation in which my life still gives life, especially to those I love and care about – sons, daughters, partners, grandchildren, friends – there is no limit to the relationships that make up a human life. Even my relationship to material things becomes important.

Just as we need time to build a life and inhabit a world, to make our home in it, we also need time and help to leave it. In this moment, we often come to see it and understand it in ways that we could not have done before. That can intensify as well as reconcile. As well as the pain of loss there can also be a sense of gratitude. And so I find myself in this movement of gathering and handing over; holding on and letting go until that point of readiness comes.

3.5. The gift of being present

At some level, the person who is dying is also the person who is mourning. There is no script for how it should go or does go. Understanding is always tentative at best for I neither know who I am in this new relationship, nor do I know what I may become. I may surprise myself either with equanimity or panic. Dying, I am deeply vulnerable precisely because this is *my* experience, one that no one can make for me. When medicine understands this, then it can use all its resources to create the best conditions to support the person. But the most important resource of all is caring presence.

It is not easy to be with a person in this process. Even when we armour ourselves with professional skill the human in us too is vulnerable. But it is the human as well as the professional that is needed.

The skill is not so much in having answers but in being able to listen and, being *attentively* present, and through that seeking to create a relationship of trust and generosity. In this attentive caring I can also create space and time to receive and honour confidences, help carry fears and doubts, and reassure that a life is valued and acknowledged, whatever its outward appearance. At this moment, the most precious gift is not just the professional gift of competent care but the human gift of wanting to care.

The carer also needs personal as well as professional resources to do this.

¹ Cantus firmus – taken from Plain Chant. It is the constant voice or melody that moves underneath all the polyphony and is the basis of it.

3.6. On the mourning of relatives and friends

All that has been said about the experience of dying is equally the case for those who are relatives and friends. Our lives are a delicate tissue of relationships in which our identity is held and formed. This interconnectedness becomes even more significant when the person we know and care about is undergoing the experience of dying.

One of the greatest services that can be offered is accurate and sympathetic information. When we are with someone who is dying there is a double need: the need to know what is happening for them and the need to know for ourselves. This knowledge is critical in helping us frame our moments with them and gauge the most appropriate responses. It is important to know about the physical process of dying but it is just as important to know and have some understanding of the emotional, psychological and spiritual dimension as well. Often the professional carer can help the family carer or the friend carer to be more naturally present, to acknowledge the fear, anger, confusion and pain that they carry as well and cannot show. Often, too, the professional carer can give permission for the most natural responses – the physical touching, the speaking and singing and sharing – that are so consoling to the person dying (even though they may not be ‘conscious’) as well as to the relatives and friends. This creates that other quality of space where it is permissible not to be competent and efficient or in control; where it is possible to be overwhelmed and inarticulate and confused. These responses are not failures; they are the measure of the love and the care we carry and the immensity of the event at which we are present and involved. In the presence of death we all have to learn a new way of being; of not being afraid of passivity and the sense of impotence but of accepting that there comes a point when ‘doing’ comes to an end and just being there is what is needed most; doing our best to understand, to care, to love, to wait and to accept either the pain or relief of letting go.

3.7. The Resources of Religious Faith

Death and the process of dying need all our resources: clinical, professional, human and spiritual. We need to come to this moment without prejudice. Often people who have no religious faith discover that they are open to it in an unexpected way. Equally, persons who have lived with strong conviction may find that this deserts them. This is why community is crucial, whether it is a religious community or the human community of carers that forms just at this moment.

Different religions will approach death and understand it in different ways. All will have a way of placing it in a context of belief and meaning. They all will have a way of narrating it and transposing it into symbol and ritual so that it forms part of a greater story of life and future life. Even if we do not understand that

A practical Guide to the spiritual care of the dying person

belief structure and its symbols or even if we are atheist or agnostic about it, every person has a right to their faith and their community especially at this moment. It is the right of every person that their faith is acknowledged, provided for and treated with respect.

In the same way, even if the person dying has had no explicit faith before this moment, they may decide that now they do want to explore it and draw some consolation and strength from the wisdom of the great communities of faith. Again, good end of life care will understand this and, just as it will wish to make available various medical strategies; it will want to make available spiritual and religious ones as well. In order to do this, it is important that professional carers have some understanding of the religious beliefs and customs of those who are in their care. It is also important that they are able to call upon the expert practitioners of religion to assist them in caring for the person who is dying and for relatives and friends.

3.8. Conclusion

One of the most important and valuable things we can do for a person is to care for them in the final stages of their life. I have suggested that to do this well is never just a matter of clinical knowledge or professional skill though these are valuable. More importantly is the sense and knowledge of a whole life, of the wholeness of a person and their relationships that makes up a life. It is this knowledge that allows us to use all our professional and clinical knowledge well. We also need to have time. In the final stages the pace of the processes – internal as well as physical – cannot be hurried. Time is such a precious gift at any moment, but especially now – time for the person dying, time for the family and friends, time for the carers to care rather than perform procedures. In this time, the freedom to have conversation, to allow silence, and sense our own inarticulacy is also important and real. This time is time to establish new relationships as well as repair, celebrate or cherish old ones.

We can only come to the final stages of our life with humility. Again, the most valuable thing is to be released from expectations – we do not know how we may behave or feel or what we may say. The truly caring environment is one which helps us let go of expectations and helps us find the resources we need to live with the reality we are now asked to face.

Death is the moment of truth for human life and meaning. Whatever we may discover there it may not be nothingness. We may begin to touch some sort of mystery that has been present in our lives from the beginning. It is not the fact of death alone. It can be the mystery of an undeserved love, the generosity of a care which is given not only as a professional skill or requirement but as human gift.

Section 4: Faith-specific needs: Caring for the Catholic Patient

As noted in the introduction, this guide has been written to assist healthcare staff to provide spiritual care to the person who is dying, whether or not they have, or do not have, a religious faith.

Clearly when the dying person is a member of a faith or a community of belief, they may well have specific needs that should be met as far as possible. This resource has been developed within the Roman Catholic community and in this section provides information regarding the specific needs which Catholics may have. This will overlap with the needs of members of other Christian churches, but there may be differences and staff should not assume that what is said here is true of all Christians. So also there will be specific needs of other faiths or communities of belief. This guide does not attempt to speak for other faiths but gives links below to resources for different faith communities where these are available.

In all cases whether the person belongs to a particular faith group or not, staff should be sensitive to the particular individual needs of the patient. What is set out below is simply a guide to help prompt some issues that may be relevant to Catholic patients.

4.1. Sources of Further information regarding specific faiths and spiritual care of the dying

The following are suggested as initial reading for the spiritual care of specific faith groups:

Julia Neuberger CARING FOR DYING PEOPLE OF DIFFERENT FAITHS, Radcliffe Publishing.

Susan Hollins RELIGIONS, CULTURE AND HEALTHCARE: a practical handbook for use in healthcare environments, Radcliffe Publishing.

Caring for Bahai Patients

The Multi-Faith Group for Healthcare Chaplaincy has a pdf of the Bahai guidance:

http://www.mfghc.com/resources/resources_72.htm

Caring for Hindu Patients

Diviash Thakrar, Rasamandala Das and Aziz Sheikh (eds.) CARING FOR HINDU PATIENTS, Radcliffe Publishing

A practical Guide to the spiritual care of the dying person

Caring for Jewish Patients

<http://www.jvisit.org.uk/hospital/index.htm>

Caring for Muslim Patients

Aziz Sheikh and Abdul Rashid Gatrad (eds.) CARING FOR MUSLIM PATIENTS, Radcliffe Publishing.

Caring for Sikh Patients

www.sikhchaplancy.org.uk/Booklet.pdf

4.2. The Specific spiritual needs of Catholic Patients

Although most of this guide is relevant for all dying patients, there will be a good number for whom more specific religious care is important. Religious care should not be seen as isolated from and perhaps less important than generic spiritual care. It is rather that some people will express their spiritual needs through a specific tradition of belief and practice, and respecting these specific forms will be important for addressing their spiritual needs. A central expression of spiritual need within Catholic Christianity is prayer.

4.3. Prayer

Prayer is essential to Catholics and is about communicating with God. For Catholics, prayer is about being able to share one's worries and joys, as well as listening for God's guidance. Catholic patients may wish to talk to a chaplain about how they pray. Chaplains are trained in discerning how to direct someone in their prayer life. If a Catholic patient wishes to pray, they may need privacy and wish to pull screens around their bed. If they are mobile, they may wish to visit the hospital chapel.

Catholics enjoy a diversity of devotions within prayer. Some may wish to pray the Rosary. The Rosary is a string of beads, that guides people through the life of Jesus while repeating specific prayers. Rosary beads have religious significance for Catholics both for prayer and because they are often blessed. Rosary beads are often twined round the hands of a dead Catholic to symbolise their prayer and journey through life and into eternity. In Critical Care Units when patients are seriously ill and unable to hold the Rosary, it may be placed at the head of the bed or under the patient's pillow.

Medals which are worn by Catholics on a chain around their neck, are another symbol of prayer. Medals may bear an image of Jesus, or of Mary the Mother of God (a very common medal of this kind is called

A practical Guide to the spiritual care of the dying person

“The Miraculous Medal”) or of a particular Saint. Like a Rosary, medals will often be placed in the hands or around the neck of a dead Catholic as a sign of their faith and devotion. In Critical Care Units when patients are seriously ill, the medal may be placed at the head of the bed or pinned to the patient’s gown or pillow. Scapulars are similar to medals, but are made of cloth. In Critical Care Units when patients are seriously ill, the scapular may be placed at the head of the bed or pinned to the patient’s gown or pillow.

Before preparing a Catholic patient for a procedure, staff may need to ask the patient to remove their medals or scapulars. Staff should reassure the patient that these will be stored in a safe place.

4.4. The Sacraments

Catholics believe that Jesus instituted the seven ‘sacraments’, in which the dynamic presence of Jesus is experienced through word and action.

The sacraments are divided into: the Sacraments of Christian Initiation: Baptism, Confirmation, Holy Eucharist (also called Mass); then the Sacraments of Healing: Penance (also called Confession) and the Anointing of the Sick; the Sacraments at the Service of Communion and Mission: Holy Orders (or Priesthood) and Matrimony. The sacraments touch all the important moments of a Catholic’s life.

Central to Catholic life is prayer and worship at Sunday Mass where Catholics give thanks to God and offer their lives to Him. They receive the Body and Blood of Christ at Holy Communion in the form of bread and wine that builds them up as the people of God.

4.5. What to do if a Catholic patient requests a Catholic chaplain

There are various reasons why a Catholic patient may request to see a Catholic chaplain. Catholics have a great respect for the sanctity of life from conception to death. Patients and staff may wish to have the support of a chaplain.

4.6. Baptism

If a baby is in danger of death a mother may request that a member of staff contact the chaplain to baptise their child. Baptism is a sacrament which involves the pouring of water over the child, while invoking the Trinity (Father, Son, and Holy Spirit). Catholics believe that this sacrament enables them to share in the life of Jesus Christ and to be members of his Church.

The chaplain may request sterilised water in a small container. The chaplain will need to spend time with the baby’s parents and may request that the baptism is private with screens drawn around the family. In

A practical Guide to the spiritual care of the dying person

an emergency where a chaplain is not available, any baptised adult may carry out the ceremony. When an emergency baptism is performed, the chaplain must be notified.

Sometimes, in danger of death, an adult may request to be baptised. The same procedure needs to be followed as above.

4.7. Holy Communion

For Catholics, the Body and Blood of Jesus Christ is truly present when they receive Holy Communion, usually under the form of a small wafer of bread. A priest, a deacon, or a person known as an Extraordinary Minister of Holy Communion, may administer this.

The chaplain or priest may consult with staff in deciding whether Holy Communion can be given to a patient (who may be feeling sick or fasting before a medical procedure). The chaplain and patient may wish for screens to be drawn around the bed for privacy.

If the patient is very poorly, a small particle of Holy Communion may be administered under the tongue which will not interfere with medical procedures. When Holy Communion is administered to a dying patient, it is called "Viaticum" meaning "food for the journey."

4.8. Confession

A Catholic patient may request to see a priest to celebrate the Sacrament of Penance. In this sacrament, Catholics experience the forgiveness of God by confessing their faults and receiving absolution which leads them to peace and a change of life. This sacrament is also known as Confession or Reconciliation. Only a Catholic priest can hear a Catholic's confession.

Privacy is essential. The priest or patient may request screens to be drawn to ensure privacy. What is said is absolutely confidential.

4.9. Anointing of the Sick

This is a sacrament that Catholics receive when they are seriously ill. They will especially want it before undergoing theatre procedures. This sacrament can only be administered by a Catholic priest. It is also known as the Sacrament of the Sick.

The priest brings specially blessed oil and anoints the patient on their head and hands while saying some special prayers. In this celebration the patient is reminded of the compassion of Jesus for people who are sick. Oil is traditionally associated with strength and healing and is a sign that the patient is being given strength for the journey towards healing and recovery or death.

The Anointing of the Sick is often associated with the Sacrament of Penance (Confession) and the receiving of Holy Communion, especially near to death.

Please note that sometimes requests may be made for the “Last Rites” (also known as Extreme Unction). In the past it was offered as close to the moment of death as possible. This is the reason why so many people do not think of calling a priest sooner, and why the approach of a priest can be unsettling for the sick person. Priests nowadays prefer to see the patient well before this stage. Practice has shifted for many reasons, but it is important to assure the seriously ill person of God’s healing presence, and to try to diminish the fear of death.

Catholics have an expectation that a Catholic priest will be called in the case of an emergency, or if they lapse into unconsciousness. This sacrament is not given to a patient who has died so it is important to call a Catholic priest before death occurs. The priest may wish for screens to be drawn to provide privacy for the patient and the family.

4.10. What to do if a Catholic patient dies

If the Catholic patient has received the Anointing of Sick before dying, it may still be necessary to call the Catholic chaplain when the patient has died. It is always important to ask the family or the next of kin of the deceased patient before doing this. Sometimes, if the death has occurred in the night, the family will be prepared to wait until the morning before the

Catholic chaplain is called. Catholic families may wish the chaplain to lead prayers for the recently deceased person. They may also wish to talk about funeral arrangements.

A practical Guide to the spiritual care of the dying person

Before moving the dead Catholic patient to the mortuary, staff should ask the family or the next of kin if they would like Rosary beads, medals or scapulars to be removed or placed with their loved one.

They may wish to talk to the Catholic chaplain. Before death Catholic patients may wish to talk to a Catholic chaplain about a dilemma in their lives, or worries about their families. It is important that they have access to a member of the Catholic chaplaincy who can understand their needs and concerns.

Please ensure that privacy is maintained whenever a patient is speaking with a priest.

4.11. Official Roman Catholic teaching on ethical issues at the end of life

Section 2 on ethical issues at the end of life addressed questions that are common to all human beings and not only to Catholics. The quotations that follow are not given to provide different conclusions on the ethics of end of life care, but are given to show that these same ethical truths are strongly affirmed by the authoritative sources of the Catholic tradition. They are presented here also so that Catholic staff or patients can be reassured that the Catholic Church does allow withdrawal of treatment and also allows the giving of sedation when these are clinically appropriate.

4.12. What does the Catechism say about withdrawal of treatment?

Catholic teaching about withdrawal of treatment is set out briefly in the Catechism of the Catholic Church (paragraph 2278):

‘Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to their expected outcome can be legitimate: it is the refusal of ‘over-zealous’ treatment. Here one does not will to cause death; one’s inability to impede it is merely accepted. The decision should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected.’

4.13. What did Pope John Paul II say about using assisted means to provide food and fluids?

Pope John Paul II, writing about people who are not dying but who are in a ‘vegetative state’, stated that it is obligatory to provide nutrition and hydration:

A practical Guide to the spiritual care of the dying person

'I should like particularly, to underline how the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering. The obligation to provide "the normal care due to the sick" in such cases includes, in fact, the use of nutrition and hydration.'

4.14. What does the Catholic Church teach about the use of analgesia at the end of life?

Catholic teaching on analgesia is presented in the Vatican *Declaration on Euthanasia*:

'[H]uman and Christian prudence suggest for the majority of sick people the use of medicines capable of alleviating or suppressing pain, even though these may cause as a secondary effect semi-consciousness and reduced lucidity. As for those who are not in a state to express themselves, one can reasonably presume that they wish to take these painkillers, and have them administered according to the doctor's advice.'

'[T]he suppression of pain and consciousness by the use of narcotics... [is] permitted by religion and morality to the doctor and the patient (even at the approach of death and if one foresees that the use of narcotics will shorten life)... In this case, of course, death is in no way intended or sought, even if the risk of it is reasonably taken; the intention is simply to relieve pain effectively, using for this purpose painkillers available to medicine.'

'However, painkillers that cause unconsciousness need special consideration. For a person not only has to be able to satisfy his or her moral duties and family obligations; he or she also has to prepare himself or herself with full consciousness for meeting Christ. Thus Pius XII warns: "It is not right to deprive the dying person of consciousness without a serious reason."'

4.15. Concluding reflections: Death from a Christian perspective

The Christian faith comes to death with a unique understanding and hope. It sees in it a moment of truth when we must come to terms with the reality of our life, its relationships and deeds, but it also finds there an infinite guarantee of love and understanding. This is because the Christian faith sees death as uncovering the fundamental truth of our existence – that every human person is created for God and by God. Here, at the final moment of our life, we come to know this and it is precisely in this moment, the moment when we are most vulnerable, God has placed himself in mercy and love. He has done this through his Son, Jesus Christ, who himself enters into this reality of death – our death – on the Cross. Yet, this

A practical Guide to the spiritual care of the dying person

moment, which could be a moment of such emptiness and despair, is forever changed by Christ's resurrection. Here is the gift of life, and not just life as it was but as it will be; an unimaginable fullness, a fulfilment of all that we are, a sharing in the Divine life of God who is the Love of the Father, Son and Holy Spirit. This is a life of inexhaustible meaning and because it is the life of God Himself who is love, it will be a life made up of all our relations of love. The resurrected life is an embodied life but a life in which matter is itself transformed so that it may bear the fullness of life everlasting.

Every Christian lives in this truth and this hope. In the Catholic Church it is celebrated every day in the Eucharist and in the sacramental life of the community. Understood in this way, no one faces death alone. Christ and his Church – that great community of faith – meet them there. Often in the moment of death and through the process of dying the person and those with him or her will feel the presence and consolation of this community – visible and invisible. Even in their doubt, confusion or despair, in their silence or in their struggle, the community is present. A community not bounded by time, space or mere physical presence, but a community of all those who 'have gone before us marked with the sign of faith', the community of those who already enjoy this fullness of life, the community of the saints.

Without in any way disguising the reality of death and the fragility with which we all come to it, the community of Christian faith lives with a knowledge that 'for us life is changed not ended'. Death opens up to a reality which is as yet only dimly glimpsed, unknown but not emptiness or nothingness. It is here, too, that so many make the words of the Jewish psalm their own, "*Even though I walk through the valley of the shadow of death, I fear no evil. For you are with me; your rod and your staff, they comfort me.*" (Ps.23)

Faith is always more than an intellectual assent to doctrines; it is a living, personal relationship with Christ. In the reality of death that relationship holds more strongly than ever, for Christ has Himself entered into this reality and so, however we may make that final journey and live those last moments, we walk and live in Him. We can never predict nor determine how we shall face the last moments of our life, but we can be sure of Christ and his Church's faithfulness to us whether we are weak or strong, struggling or tranquil, awake or in some other inner space. Again, the Church makes her own the beautiful words of the Jewish Psalm 91, "*He who dwells in the shelter of the Most High and abides in the shade of the Almighty, will say to the Lord, "My refuge and my fortress; my God in whom I trust. For he will deliver you from the snare of the fowler and from the deadly pestilence; he will cover you with his pinions and under his wings you will find rest....."*" In this way the moment of death becomes a moment of faith and God's faithfulness.