# *A Practical Guide to*
# The Spiritual Care of the Dying Person

This publication has been written by a working group commissioned by the Bishops' Conference of England and Wales to assist healthcare staff in the provision of spiritual care. Contributors include Dr Catherine Gleeson, Consultant in Palliative Medicine, St Catherine's Hospice, Crawley; Dr David Jones, Professor of Bioethics at St Mary's University College Twickenham; Fr Paul Mason, Chaplain at Guy's and St Thomas' NHS Foundation Trust; and Rev Dr James Hanvey SJ. The authors are particularly grateful to all those, including many NHS nursing and other staff, who commented on an earlier draft of this Guide.

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## The Keeping Faith series

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# Contents

# Introduction

Illness is a time when, regardless of one's religious belief or lack of it, questions of a spiritual nature rise to the surface. This is especially the case when someone is approaching the end of their life. The purpose of this guide is to assist front-line staff in identifying spiritual need in their patients and to feel confident in their ability to provide it.

Traditionally the work of spiritual and religious care in a hospital has been the domain of the chaplain and the chaplaincy team. This still holds true, and the presence of a chaplain and the team to provide such care should be routinely included in holistic multi-disciplinary care. But providing spiritual care is not the exclusive domain of chaplains or chaplaincy teams. In some way, everyone who is involved in the care of a patient has something to give. But 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.

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 we only focus on the illness, consciously or unconsciously, 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 and belief systems see it in terms of material and spiritual dimensions. Although they are intricately related in the human person, one cannot be reduced to the other. 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 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 harm. Often there is a hidden and unconscious 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 only through a series of standard procedures then we do not deal with it well either clinically or humanly.

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 advice on how to provide good spiritual care, making no assumptions about whether or not the dying person or the healthcare professional has a particular religious faith. The second section looks at some of the common ethical questions that might arise at this time, for example, withdrawing or withholding medical treatment. And the third offers a reflection on the experience of dying, its personal and mysterious dimension and offers with a view to stimulating a more sensitive and attentive approach to the subject.

The Guide originates within a Catholic Christian perspective, but it is not addressed exclusively to Catholics either as patients or healthcare providers. Its aim is simply to bring the resources of this perspective – experience, practice, ethical and theological reflection - to end of life care. It tries to keep the whole person in view, in their spiritual, physical and psychological reality and it respects that there are many different ways and traditions, religious and non-religious, in which these aspects find expression in a person's life and care.

# 1 Providing spiritual care

Spirituality can be interpreted in a range of ways according to an individual's beliefs. Some people equate it with explicitly religious values, others see it as a personal search for meaning, seeking to find a purpose to their life and the part that suffering plays in that search. 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. This is true for both family and visitors as well as the patient. Alternatively they might express none of these and simply want the presence of someone who will be with them in their loneliness or suffering. To care for the spirit is to attend to all of the above. 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.

Care for those who are dying is also referred to as 'Palliative Care'. Palliative care encompasses care of patients with advanced, progressive illness, including end of life care, and bereavement support for their family and carers. It focuses on relief of pain and other symptoms, emotional, spiritual and practical support for patients and those close to them. Palliative care may be provided at the same time as other medical treatment such as chemotherapy or radiotherapy or may be the main source of care and support when cure of the patient is no longer possible. Its objective is to relieve suffering and provide patients with the best possible quality of life.

There are a number of pathways in use in hospitals, care homes and other settings to enable medical and nursing staff to provide palliative care for dying patients. Central to such pathways is the inclusion of spiritual care which can range from the hands-on day-to-day care of the patient to calling the chaplain for religious and sacramental care.

But any such pathway is only as good as those who use it and so it is important to remember that at the centre of all our efforts is a person whose best interests we are there to serve. If we are to achieve this aim, it is essential to avoid the temptation to see a pathway as a list of instructions to be routinely followed. It should be a prompt to attentive care which encompasses regular clinical assessment and considered decisions made together with the patient or acting in their best interests.

This section initially outlines some of the ways that spiritual distress may manifest so that healthcare staff remain alert to the cues that patients offer. This is followed by suggestions for ways that staff can help to alleviate or address spiritual care of patients and their families. At times, this may raise ethical questions for patients or staff. Some of these questions that arise more commonly are specifically addressed in section 2.

## 1.1. Indicators of spiritual distress

*Remember that we each experience pain, suffering, loss, regret in a very personal way. No two people are the same and so our needs and the way that we express them will be different.*

Serious illness can have a disorientating and depersonalising effect on a patient, leaving them feeling vulnerable or powerless as events and suffering overtake them. In hospitals or other care settings it is often nursing staff or carers who are presented with the signs of spiritual distress and so the ability to recognise this is essential in order to support the patient as meaningfully as possible.

Spiritual distress may manifest in a variety of ways. Some patients are very articulate about the origin of their feelings while others may be unaware or sceptical about the potential emotional or spiritual dimension to their experience of illness. It is important to remember that relatives and friends will also be affected by what is happening and are likely to be suffering in their own way. They may also exhibit signs of spiritual distress and therefore need support too.

The following indicators are clustered into physical, emotional and questioning groups. In reality, an individual may present a combination of these together or over a period of time. While it is important to consider whether there may be treatable psychological illness such as underlying depression, the key is to consider spirituality as a contributing factor to any patient's overall well being. It is often the continued sense of despair, searching or restlessness of spirit emanating from the patient that is the most potent clue to spiritual distress.

### Physical

- Persistent physical pain or other symptoms that do not seem to have a sustained response to drugs or other treatments when this might be anticipated
- Persistent agitation or restlessness despite addressing potential physical causes. This is often very difficult for relatives to see and may cause anxiety for them which in turn, contributes to the patient's agitation
- Repeated questioning about the cause or progression of their underlying illness or unrealistic searching for treatments in a way that suggests the patient is struggling to come to terms with the reality of their deteriorating health
- A fear of falling asleep and not awaking or alternatively, waking up in the early hours and unable to settle again to sleep

### Emotional

- Anxiety which may be ill defined or change focus as the professed cause of anxiety is addressed
- Seeking constant reassurance. It is often difficult to reassure the patient for any length of time unless the underlying spiritual need is addressed
- Unresolved or previously unexpressed grief, anger, loss, family dispute or separation
- Anger at healthcare staff, self, 'the system', family or friends
- Persistent tearfulness, loss of confidence
- A sense of abandonment

- Feeling lost and alone
- Apathy or lack of motivation
- Wanting to die

## Questioning

- Searching for answers ‘Why is this happening to me?’ ‘Did I do something to bring this on myself?’
- Questioning the purpose of suffering
- Questions suggesting a sense of injustice eg ‘what have I done to deserve this?’
- Self blame or guilt for previous actions
- Seeking resolution eg for previous actions, or a desire to heal broken relationships

## Questions of faith

- Crying out to God
- Doubting one’s faith
- Asking for spiritual help
- Asking to see the chaplain (or absolute refusal for fear of what that might represent)
- A need to forgive or be forgiven

At first glance it might seem that providing for a person’s spiritual needs can be a complex matter. In reality, staff and carers are able to provide spiritual support by attending to the small things that matter to a patient. The following section emphasises some important aspects of communication in these situations with some suggestions for ways to address spiritual distress and who to approach for help.

## 1.2. Communication

### 1.2.1. Sensitive and clear communication is at the heart of good patient care

*Ensure that patients and their families are offered regular opportunities to talk to staff about their changing situation and concerns.*

The events and pace of change during serious illness and deteriorating health can feel overwhelming for patients and their families. Clear communication and information at each step can help patients to understand how their illness is affecting them and what can be done to help. It is also important to offer enough information so that patients can maintain some sense of control over choices and decisions that are open to them and are able to make plans for themselves or their family.

Family and those close to the patient may find it difficult to know how to discuss the implications of the patient's condition or potentially distressing topics. They are likely to welcome the opportunity to ask questions about the illness, what to expect and perhaps, how to respond to questions that the patient is asking them. As long as the patient is happy for information about their illness to be shared, discussion of these issues may enable relatives to understand the dying process as they accompany their loved one. It is important to explain 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 this is possible. They should be encouraged to continue talking together as family and friends as openly as they feel able to, as this is likely to provide mutual comfort and support.

### 1.2.2. Communication with the dying person

*Can he still hear me?*

Many people find it comforting to continue talking to the patient after they pass into unconsciousness as it maintains the human relationship and for some, it may be a precious time of healing or exchange of private emotions. It is often said that hearing is a sense which may continue even once the patient is unconscious and therefore relatives should be encouraged to do this if they wish. It is also a good reminder to everyone involved in a dying patient's care that an individual's human value does not diminish with their inability to communicate and that we should maintain sensitive and respectful communication.

## 1.3. How to help

### 1.3.1 Keeping care personal

*Use the patient's name as they like to be addressed.*

Addressing a patient by their preferred name fosters a more personal relationship. It is not uncommon for someone to be called by a name that is not the one registered in their notes and may contribute to them feeling increasingly anonymous. Many patients may not understand what is happening to them but this may be made even more difficult if they have impaired hearing, cognitive impairment or do not speak the same first language as their carers. It may take more time and energy to make themself understood and to understand, time and energy that they may not have. Attention to their personal needs makes communication and care easier and more effective.

### 1.3.2. Building trust

*Make time for the patient.*

Building trust with a patient can help them express deeper needs. For example, asking a patient if something is worrying them and taking time to receive a reply conveys genuine interest in their concerns. Some people find it easier to confide in a stranger and to feel heard at such times can be very affirming. Others may take some time to trust another person with their concerns and anxieties. Using open questions can encourage communication. By contrast, if we give the impression of being too busy or needing to be somewhere else then communication is impeded. It is helpful to take a little time to find out about the patient's care and concerns so that discussion is tailored to their needs. This in turn, maintains trust and the patient feels valued.

Caring for patients with cognitive impairment or dementia requires additional patience and skill as they are likely to need repeated explanation and reassurance. Close family or carers may be able to offer advice about the best way to support them and indeed, it may be best to support the family so that they can reassure their relative in familiar ways.

### 1.3.3. Asking about spirituality

*Create the opportunity to talk about spirituality.*

Many people do not know how to start talking about spirituality or spiritual distress. This may be because they see it as synonymous with faith based beliefs or rituals and may feel unfamiliar or uncomfortable with this personally. Alternatively it may be due to hesitation to broach a personal topic, fear of being disrespectful or upsetting someone, or a lack of shared language to express spirituality. If however we see spirituality as the ‘essence’ of someone, their values, sense of self and self worth, then we can begin by getting to know them as a person.

Some suggestions for opening questions might be:

- Tell me a bit about yourself?
- How are you in yourself?
- How has this illness affected you or your family?
- Are their particular things that are on your mind at the moment?
- Is there anything or anyone that you find helpful in times of trouble?
- Is there anything that makes it more difficult to cope with (the pain, to sleep) at the moment?

### 1.3.4. Exploring priorities and choice

*Always seek to enable a patient to express their preferences.*

It is important to seek the views of the patient and involve them in decisions about their care as far as possible. Patients may have already made their wishes known about treatment and care but it is helpful to offer them the opportunity to revisit these. It is not uncommon for priorities to change as their health deteriorates. For example, they may have previously wanted to die at home but recognise that this is no longer realistic. Such changes may be associated with feelings of sadness, guilt, loss and contribute to spiritual distress.

Patients might live for a shorter or longer period than expected and trying to give timescales will inevitably be difficult. However, for many patients, it is helpful to have some idea about the likely course of their illness to enable them to sort out their affairs, plan their funeral or prioritise those that they want to see. Endings are a very important part of spiritual wholeness.

Assume that individuals have capacity to make personal decisions until proven otherwise. 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.

### 1.3.5. Privacy

*Offer a private room for the patient.*

Private space creates a better environment for sensitive consultations or conversations. It also becomes increasingly important to have the chance to offer privacy with friends and family during this time. Availability of a single 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 is made more difficult in a public space, not to mention the distress this can cause other patients and visitors. However,this may not be right for some patients who might regard a single room as isolation or signifying a need to exclude them from other patients. In this situation or when a single room is not possible then a quiet space for family and visitors can be a great help.

### 1.3.6. Dignity

*Think beyond the patient's illness.*

Maintaining dignity for the dying patient takes on an added significance. Enquiring about how they feel in themselves ensures that more than physical symptoms are being considered. Keeping patients clean and the space around them tidy can add to their own sense of dignity. Mouth-care is also important, to ensure that their mouth feels moistened and more comfortable. Personal care, for example, taking time to wash and comb a patient's hair not only helps the patient feel better but also restores a sense of their 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 or their relatives sometimes ask for particular things to be done or incorporated into care during the last days of the patient's 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 may be the only prayer that 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.

### 1.3.7. Medication for distressing symptoms

*Be clear about the relative benefit and need for sedative medication.*

There are times when medicines required for relief of symptoms such as pain or agitation may also cause drowsiness or sedation. Towards the end of life this is compounded by increasing weakness and fatigue as the patient's condition deteriorates. The patient or their family may find this difficult to understand and will want the best for the person that they love. No one wants to see another person suffer but at the same time sedative medication may compromise a patient's ability to communicate at what might be important moments. This may raise ethical questions for some and is explored further in Section 2.

There are occasions when family or other visitors become distressed by seeing the dying person restless or apparently in pain. They may ask that the patient is sedated so that everyone's distress is alleviated. However it is important to consider the patient's wishes about this and to ensure that their needs and wishes are not obscured by those of others. 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 family or are more aware of their presence before they die. They may also wish to be able to hear prayer or scripture or to participate in religious ritual which may give them great strength and solace in their final days.

The principles of palliative care underpin much of the care that is described in this section. However it may be helpful to ask for specialist palliative care support in circumstances where the patient has complex symptoms or it is difficult to get the right balance between the benefit and side effects of medication for symptom relief. Specialist palliave care advice is available in hospitals, care homes, hospices and for patients at home.

### 1.3.8. Nutrition and hydration

*Provide this as basic care where possible.*

Family or carers might have particular anxieties about the cessation or withdrawal of nutrition and hydration. They may consider it to be premature, perhaps believing that there are other treatment options that have not been explored or that they should be involved in discussions about this issue. It is important that those close to the patient have the opportunity to discuss their concerns so that the realistic choices open to the dying patient are understood. This topic is explored further in Section 2.

## 1.3.9. Asking about faith

*Ask the patients/family if they have any particular religious beliefs.*

Remembering to ask a patient or their family if they have a religious faith is the most obvious way to see whether there are any specific religious or spiritual needs that could be addressed by a chaplain. This information is usually gathered by members of the multi-disciplinary team and can then be passed on to the chaplain. This further reassures a patient with a religious faith that their spiritual as well as physical needs are central to their care.

On the other hand, some people might have ceased to practise their faith, or during the course of a long illness might have "fallen out" with God. This may cause distress which in turn, may aggravate a patient's mental and physical state. A desire to return to one's faith or to make peace with God might be the most significant thing at this point in someone's life. Listen closely to what a patient says and be sensitive to cues which might prompt offering the attendance of a chaplain.

For Catholic Christians the final days and moments of life might be about preparing to meet God and to be alert to the religious/sacramental care provided by the priest. Avoiding the older term "Last Rites" and referring to "anointing of the sick" might also provoke less anxiety.

## 1.3.10. Holy Communion

*Consider offering the sacrament of communion.*

For Christian patients being able to receive Holy Communion from the chaplain can be deeply significant. Where this is not possible, perhaps because of oral or swallowing difficulties or due to feeding tubes, a patient and their family can be reassured that the very desire to receive constitutes a "Spiritual Communion".

## 1.3.11. Inform the chaplaincy team

*Involve the chaplaincy team as soon as possible.*

Ensuring that a member of the chaplaincy team is involved early in the patient's admission to hospital will enable provision of ongoing care and support of the patient and their family at this difficult time. Chaplaincy teams increasingly represent a number of different faith groups enabling them to respond to patients' needs as appropriately and effectively as possible. Chaplaincy is more than a last-minute resource for religious ritual. The chaplain or lay chaplain /team can help support patients, families and staff as the patient approaches the end of their life.

## 1.3.12. Prayer

*Patients may sometimes ask staff to pray with them.*

Praying with patients can be a sensitive area but so long as this is approached properly there is no reason to avoid it. The should be no 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 or family's request, to pray with them or read a passage of Scripture to them. If staff feel unsure of how to act in such circumstances they should discuss this matter with the chaplain rather than assume it is a "no-go" area. There can be a preoccupation with offending patients in this regard and so their unspoken need might go unmet.

## 1.3.13. Organ donation

*Families might need support from the chaplain if they are not sure about whether their faith permits organ donation.*

Organ donation is acceptable in the Catholic faith but individuals may not be aware of this, particular if there is confusion about whether consent to donation had been agreed or the deceased had expressed no wishes on the subject when alive. The chaplain can put a family's mind at rest on this matter and also simply be with them as they discuss this with the organ donation team.

## 1.3.14. Care for family and friends

*Offer on-going spiritual care.*

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 chaplain can also arrange on-going support in the community, ensuring pastoral visits are made through the parish so that bereaved families and friends feel less isolated in their loss. Some parishes also run bereavement support groups over the longer term. Alternatively, the chaplaincy team is always available at the hospital for ongoing care should people find this helpful.

# 2 Ethical issues in care toward 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 or to hasten 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.

## 2.2. What ethical issues may arise in care of those nearing death?

Ethical issues may arise in relation to the care of those nearing death. In all medical care, the most important ethical requirement is respect for the patient. Respecting the patient implies respecting the good of the patient's life, however long or short this may be. It also implies that the patient should be involved in discussion and decisions about their care and treatment. Wherever possible these decisions should be in keeping with the patient's wishes, values and beliefs. Where they are known, it is helpful to record these within the general care plan or as part of an advanced care plan. Treatment or care decisions should not be made on behalf of a competent patient without their consent.

By virtue of their relationship to the patient, it is also important to include close family or carers in significant discussions and decisions, unless the patient does not wish to involve them. This is particularly important if the patient is no longer competent to make their own decisions. There are occasions when there may be differing views or conflict between the patient and family, creating ethical dilemma about how to meet their respective wishes. Clinical staff have a professional responsibility to consider the patient as their primary concern and may need to find other ways to support the family, possibly through spiritual or counselling care.

As a patient is nearing death, they are increasingly unlikely to respond to many medical interventions. It is therefore important to ensure that treatment decisions, including decisions to withdraw treatment are based on accurate diagnosis of the cause of deterioration and regular re-assessment as it is unethical to burden a patient with treatment that is futile. In this situation, the priorities of care shift towards maintaining good symptom relief and providing palliative care.

Other ethical issues which may arise in care towards the end of life relate to the use of clinically assisted nutrition and hydration (CANH), and to the use of medication with sedative effects, including analgesia.

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

It may be. Though people have a duty to care for their health, they do not have a duty to prolong their life endlessly. Death, after all is inevitable. So also, healthcare workers do not have a duty to keep people alive in all circumstances. As death approaches a treatment which may briefly prolong life could impose suffering such that the patient considers the treatment to be excessively burdensome.

On the other hand it is never acceptable to withdraw treatment for the purpose of hastening death.

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. What does the Catholic Church teach about withdrawal of treatment?

The Catholic Church acknowledges that treatment may reasonably be withdrawn if this treatment is excessively burdensome in relation to its expected benefits. The *Catechism of the Catholic Church* makes clear that decisions about withdrawal of treatment should generally be made by the patient or, if he or she is not able to, then by someone with the legal power to act on his or her behalf.

*"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 decisions should be made by the patient if he is competent or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected."*

*(Catechism paragraph 2278)*

## 2.5. 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, and is good clinical practice, to discuss beforehand in what circumstances a treatment or intervention would be stopped.

## 2.6. Should oral nutrition and hydration always be offered?

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 many people offering or sharing food and drink is a sign of care and affection.

All patients are entitled to food and drink of adequate quantity and quality and to the help they need in order to eat and drink. 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. The decision about whether to switch from oral to clinically assisted nutrition and hydration (i.e. tube feeding), should be made by 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.

## 2.7. Is clinically assisted nutrition and hydration (CANH) a form of medical treatment?

Clinically assisted nutrition and hydration (CANH), sometimes called 'artificial nutrition and hydration' or 'nutrition and hydration by artificial means', refers to providing food and fluids by tube. It does not refer to help given to people to eat or drink orally, for example spoon feeding. It is a mistake to understand CANH as medical treatment if this is interpreted as meaning that it has the same human and ethical status as other medical interventions.

It is true that CANH bypasses the natural mechanisms of eating and drinking and that it requires clinical monitoring. Some people will see the significance of CANH as a 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 fundamental expression of solidarity and care. Hence nutrition and hydration, even when clinically assisted, should be understood as elements of care which should be provided so long as they are needed and effective.

## 2.8. What does the Catholic Church teach in regard to CANH?

Pope John Paul II clearly stated that the Catholic Church regards nutrition and hydration as a natural means of preserving life, even when these are provided by "artificial means".

*"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."*

*(John Paul II Address on "Life-sustaining treatments and the vegetative state" 20 March 2004)*

## 2.9. Is it ever right to withdraw CANH?

Clinically assisted nutrition and hydration should generally be provided where this is the best way to address nutritional needs. However, it may cease to be indicated in the last days of life when nutrition will have little or no effect in sustaining life or earlier than this in some conditions, such as dementia, where steady weight loss despite CANH is recognised as part of the late stages of the illness.

In general, there should not be a blanket rule in favour or against CANH. Instead, each case should be judged on the basis of the needs of the particular patient, with nutrition and hydration assessed separately. The burdens and benefits will vary depending on the method of CANH and on the situation of the patient.

Decisions concerning the provision or withdrawal of CANH should be treated with special sensitivity and should 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 someone's life.

## 2.10. How should disputes about CANH be resolved?

In the United Kingdom, a competent patient has the legal right to refuse medical treatment and CANH is counted as medical treatment for this purpose. This may cause difficulties of conscience for a healthcare worker in cases where a patient is not dying but is dependent on CANH to address his or her nutritional needs. Nevertheless, if a competent patient has refused CANH and cannot be persuaded that this would be beneficial then the healthcare professional is not guilty of neglect for any harm that follows from not providing it. This is because the law in effect removes this aspect of the person's care from the doctor's professional responsibility.

A dispute may also occur when a patient or a relative wishes the healthcare team to provide CANH but the team do not think that it would effective. 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, hope and the avoidance of suffering. In these circumstances it is unhelpful to frame the dispute in terms of the right or power of doctors to withhold medical treatment that they do 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. What is needed instead is sensitivity to the concerns of the patient or relative and openness about, and willingness to discuss 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. The patient or relative may overestimate the benefits of CANH for prolongation of life or for symptom relief. It is also possible that the healthcare team may underestimate the benefits or overestimate the burdens of hydration. If it is likely 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 this (for example subcutaneous fluids) and is strongly desired by the patient then CANH should be considered, at least for a trial period to assess the relative benefits.

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, as diagnosis of imminent death may be problematic. The team should assure themselves of the diagnosis and reassess the situation. The patient or relative may also wish to pursue a second opinion and the team should be open to this as misdiagnosis does sometimes happen. In this situation, clinically assisted hydration should generally be given while re-assessment takes place.

## 2.11. 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. This acceptance of unwanted side effects is sometimes called the principle of double effect.

Analgesia towards 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 the use of analgesia towards the end of life does not shorten life if it is prescribed and used appropriately and according to current best practice. In reality 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.

If there is concern about how to achieve a balance between relief of symptoms and potential side effects, Palliative Care services provide advice about effective and safe use of analgesia and other medication for symptom relief.

## 2.12. Is it ever right to sedate people towards the end of life?

Under-treatment of pain or distress 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.

An important element in care for the dying is to ensure that people have the space to make sense of their lives and prepare for their death. This is especially true if, as Christians believe, death is not only the end of this life but is also a moment of judgement and the transition to everlasting life or to everlasting exclusion from life. From a Christian perspective the approach of death is a time of heightened spiritual need.

Palliative care seeks to relieve symptoms of distressing pain by the use of medication, including sedatives. In some circumstances sedation may be appropriate for the relief of intractable and distressing symptoms that cannot be relieved by any other means. Nevertheless, good practice in palliative care is to introduce sedation only where necessary, increasing the dose gradually so that the level of sedation is only that which is needed for symptom relief. This will very rarely be immediate deep sedation.

Wherever possible, the patient should be involved in their care and treatment plans so that they can influence the level of sedative effect that is desirable for relief of their symptoms.

## 2.13. What does the Catholic Church teach about the use of analgesia and sedatives towards the end of life?

Catholic teaching on analgesia is presented in the Vatican Declaration on Euthanasia. This permits the use of analgesia even if this would shorten life (though in fact the evidence suggests that life is not shortened when the analgesia is given appropriately). Nor does the Catholic Church forbid sedative drugs that produce unconsciousness. However, the use of sedation requires "serious reason" because of the need to spiritually prepare for death.

*"Human 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.*

*The 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.'"*

*(Congregation for the Doctrine of the Faith: Declaration on Euthanasia 1980)*

# 3 Respecting the mystery of dying

There are many ways to think about death and there are many ways to treat it as an event. These can be medical, psychological, philosophical and religious. In this section the approach includes some of these but it seeks to explore something of the reality and meaning of death from the perspective of 'mystery'. In seeing it this way, we don't make it obscure, we begin to recognise that it is an event which discloses more about us, our relationships and our history than can be captured in any one category. It opens us to something of the depth of being human.

It also puts us into a different relationship with what is happening. So often we are asked professionally to be objective, to stand outside the immediate process or event, so that our judgement remains clear and detached from any emotional pressure or contamination. Of course, there is wisdom in this, but when we come to understand the process of dying in terms of 'mystery' we realise that we can't stand outside it as if it was some sort of logical or physical problem to be solved. Without any loss to professional judgement or competence, in seeing death and dying in terms of mystery we understand that we are, in some way, part of the whole event. 'Mystery' is not something that lets us stand aloof; whether we are involved in caring or in supporting by our presence, this is an event which touches us. Indeed, at its heart is the changing nature of all our relationships. 'Mystery' gives us a much more complete context for exploring the many different aspects of the reality of care needed at this moment of a person's life. It allows us to begin to explore something of its spiritual nature.

Mystery does not mean that we stop thinking, reflecting, acting and trying to understand the experience we are participating in. It means that it is something which is so charged with meaning that we can never exhaust it. Amid all the other ways of thinking, training, acting, and in the midst of all the decisions that have to be taken, often under pressure, 'mystery' holds open a space to let something greater and deeper come in. It allows us to take time to consider the significance of this moment for the person, for the carers, for us all. It reminds us, that we must not minimise the significance of death. If we do, we lose something of the depth of living.

## 3.1. The 'shock' of death

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.

Death is not something with which we can grow familiar. Even when it is imminent and expected, when the reality occurs it 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 border 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 than 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, also, paradoxically, colludes with our defences. Physically and psychologically it pushes the reality of death to the margins.

Present in the moment of death, in that small space between the onrush 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 by 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 may be found. It holds knowledge both familiar and now oddly new: death reveals the 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. 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 to the full of which dying is a part. That requires a sense of the wholeness of the person and the wholeness of a life. When genuine care understands this, it has time for the multifaceted reality of dying. Giving time is the most precious resource of all. When we know how limited is the time we have, we need the courage and the generosity of spirit to be most liberal with it.

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 of 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.

## 3.3. 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 their 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. Symptom control 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 may be that I choose denial; I may want to assert myself and ‘rage, rage against the dying of the light’[1]; I may slip into a passivity born of hopelessness and despair. The process of dying and the imminence of death do 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 goodbye 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 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’. I also have to re-negotiate my relationship with my body; to understand it anew, its demands, limitations and its grace in this unique moment. Whatever my attitude has been to my body in the past, I know that now it can no longer be ignored or taken for granted.

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[1] Dylan Thomas, “Do Not Go Gently into that Good Night.”

[2] *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.

The process of dying can be a time when, by choice or force of the moment, I can no longer maintain an act or 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.

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 improvisation[2].

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 support 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.

## 3.4. The gift of being present

There is no script for how dying 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 undertake 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 of dying. Even when we armour ourselves with professional skill, the human in us remains vulnerable. But it is precisely the human as well as the professional gifts that are needed. The skill is not so much in having answers but in being able to listen and be 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 needs personal as well as professional resources to do this.

## 3.5. On the mourning of relatives and friends

All that has been said about the experience of dying is equally applicable to 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.

Respect for the body of the person who has died is vitally important for all concerned. It is not just one of the last things we can do for someone who has died, it becomes a simple act which sums up all our values whether we are relatives, friends or carers. In the reverence and care of the body, it does not matter if we have a faith or not, we simply perform a deeply human and humane act. It is part of the natural liturgy of human life which confers a dignity not only on the person who has died but on us all.

## 3.6. 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 differing 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 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 not just in the moment of death but especially in the time before it. Nor, for many religious faiths is death the end, either for the person who has died, or for the relationship they have with their family, friends or community. Often there are the liturgies of remembering, celebrating and praying that continue, particularly when there is an understanding of life and community beyond death itself. 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 particular 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 their relatives and friends.

## 3.7. 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 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 of 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 of trust in God's faithfulness.

## 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. To do this well is never just a matter of clinical knowledge or professional skill though these are valuable. More important is the sense and knowledge of a whole life, of the wholeness of a person and their relationships that make 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 – 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 the pace of the processes – internal as well as physical – cannot be hurried. Time is such a precious gift, and silence, and a sense our own inarticulacy is also important and real. This time is time to establish new relationships as well as to 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 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 will 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.

# Appendix

## Sources of further information regarding specific faiths and spiritual care of the dying

This guide does not attempt to speak for other faiths but gives links below to resources for different faith communities where these are available. The following are suggested as initial reading for the spiritual care of specific faith groups:

### Caring for the Catholic Patient

http://www.catholicchurch.org.uk/catholic_church/the_bishops_work/catholics_in_healthcare/resources

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

Julia Neuberger, CARING FOR DYING PEOPLE OF DIFFERENT FAITHS, 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

### 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.sikhchaplaincy.org.uk/Booklet.pdf

For further information about the spiritual care of multi-faith patients contact the Multi-Faith Group for Healthcare Chaplaincy at:
chief.officer@mfghc.com